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**National Institute for
Health Research**

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Abstract

Facilitating the transition of young people with long-term conditions through health services from childhood to adulthood: the Transition research programme

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Background: As young people with long-term conditions move from childhood to adulthood, their health may deteriorate and their social participation may reduce. 'Transition' is the 'process' that addresses the medical, psychosocial and educational needs of young people during this time. 'Transfer' is the 'event' when medical care moves from children's to adults' services. In a typical NHS Trust serving a population of 270,000, approximately 100 young people with long-term conditions requiring secondary care reach the age of 16 years each year. As transition extends over about 7 years, the number in transition at any time is approximately 700.

Objectives: Purpose – to promote the health and well-being of young people with long-term conditions by generating evidence to enable NHS commissioners and providers to facilitate successful health-care transition. Objectives – (1) to work with young people to determine what is important in their transitional health care, (2) to identify the effective and efficient features of transitional health care and (3) to determine how transitional health care should be commissioned and provided.

Design, settings and participants: Three work packages addressed each objective. *Objective 1.* (i) A young people's advisory group met monthly throughout the programme. (ii) It explored the usefulness of patient-held health information. (iii) A 'Q-sort' study examined how young people approached transitional health care.

Objective 2. (i) We followed, for 3 years, 374 young people with type 1 diabetes mellitus (150 from five sites in England), autism spectrum disorder (118 from four sites in England) or cerebral palsy (106 from 18 sites

in England and Northern Ireland). We assessed whether or not nine proposed beneficial features (PBFs) of transitional health care predicted better outcomes. (ii) We interviewed a subset of 13 young people about their transition. (iii) We undertook a discrete choice experiment and examined the efficiency of illustrative models of transition. *Objective 3.* (i) We interviewed staff and observed meetings in three trusts to identify the facilitators of and barriers to introducing developmentally appropriate health care (DAH). We developed a toolkit to assist the introduction of DAH. (ii) We undertook a literature review, interviews and site visits to identify the facilitators of and barriers to commissioning transitional health care. (iii) We synthesised learning on 'what' and 'how' to commission, drawing on meetings with commissioners.

Main outcome measures: Participation in life situations, mental well-being, satisfaction with services and condition-specific outcomes.

Strengths: This was a longitudinal study with a large sample; the conditions chosen were representative; non-participation and attrition appeared unlikely to introduce bias; the research on commissioning was novel; and a young person's group was involved.

Limitations: There is uncertainty about whether or not the regions and trusts in the longitudinal study were representative; however, we recruited from 27 trusts widely spread over England and Northern Ireland, which varied greatly in the number and variety of the PBFs they offered. The quality of delivery of each PBF was not assessed. Owing to the nature of the data, only exploratory rather than strict economic modelling was undertaken.

Results and conclusions: (1) Commissioners and providers regarded transition as the responsibility of children's services. This is inappropriate, given that transition extends to approximately the age of 24 years. Our findings indicate an important role for commissioners of adults' services to commission transitional health care, in addition to commissioners of children's services with whom responsibility for transitional health care currently lies. (2) DAH is a crucial aspect of transitional health care. Our findings indicate the importance of health services being commissioned to ensure that providers deliver DAH across all health-care services, and that this will be facilitated by commitment from senior provider and commissioner leaders. (3) Good practice led by enthusiasts rarely generalised to other specialties or to adults' services. This indicates the importance of NHS Trusts adopting a trust-wide approach to implementation of transitional health care. (4) Adults' and children's services were often not joined up. This indicates the importance of adults' clinicians, children's clinicians and general practitioners planning transition procedures together. (5) Young people adopted one of four broad interaction styles during transition: 'laid back', 'anxious', 'wanting autonomy' or 'socially oriented'. Identifying a young person's style would help personalise communication with them. (6) Three PBFs of transitional health care were significantly associated with better outcomes: 'parental involvement, suiting parent and young person', 'promotion of a young person's confidence in managing their health' and 'meeting the adult team before transfer'. (7) Maximal service uptake would be achieved by services encouraging appropriate parental involvement with young people to make decisions about their care. A service involving 'appropriate parental involvement' and 'promotion of confidence in managing one's health' may offer good value for money.

Future work: How might the programme's findings be implemented by commissioners and health-care providers? What are the most effective ways for primary health care to assist transition and support young people after transfer?

Study registration: This study is registered as UKCRN 12201, UKCRN 12980, UKCRN 12731 and UKCRN 15160.

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Glossary

We use the World Health Organization's definition of a **young person** as any person between the ages of 10 and 24 years, and of an **adolescent** as any person between the ages of 10 and 19 years.

A **long-term condition** is a condition that cannot currently be cured but can be controlled with medication and/or other therapies. The Chief Medical Officer used this concept in the 2012 report *Our Children Deserve Better – Prevention Pays* [Department of Health and Social Care. *Chief Medical Officer Annual Report 2012: Children And Young People's Health*. London: Department of Health and Social Care; 2013. URL: www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays (accessed 27 March 2019)], as did the Department of Health and Social Care in its *Outcomes Framework for the NHS* [Department of Health and Social Care. *NHS Outcomes Framework 2016 to 2017 At-A-Glance*. London: Department of Health and Social Care; 2017. URL: www.gov.uk/government/publications/nhs-outcomes-framework-2016-to-2017 (accessed August 2017)].

In our original submission to the National Institute for Health Research, we used the term 'complex health needs' to refer to young people with 'a physical, mental or health impairment that has the potential for a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. However, the term 'complex health needs' is used increasingly to describe the relatively small number of young people with very complex needs who require a bespoke package of care constructed for each individual, involving multiple agencies including health, educational and social services. These young people are usually known by name to Clinical Commissioning Groups and local authorities. Shortcomings in the co-ordination of care for this group are discussed specifically in the Care Quality Commission's report *From the Pond into the Sea* (Care Quality Commission. *From the Pond into the Sea. Children's Transition to Adult Health Services*. Newcastle upon Tyne: Care Quality Commission; 2014). The National Institute for Health Research-funded transition research programme was not designed to consider only this very complex group. For this reason, we use the term young people with a 'long-term condition' instead of 'complex health needs' in the title of the programme and throughout this report to refer to the much larger group of young people who are the focus of the transition research programme.

Developmentally appropriate health care A concept now widely accepted in the UK (e.g. by the National Institute for Health and Care Excellence, the Royal College of Paediatrics and Child Health, and the Royal College of Physicians) and internationally (e.g. in the USA and Canada). It recognises young people's changing biopsychosocial developmental needs and the need to empower young people by embedding health education and health promotion within consultations. In operational terms, developmentally appropriate health care focuses on the approach of health-care professionals to, and their engagement with, each young person and their carers alongside the structure of the organisations in which care takes place.

Mental health and well-being The World Health Organization states that mental health is not just the absence of mental disorder. It defines mental health as:

... a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.

Reprinted with permission from the World Health Organization. Promoting Mental Health: Concepts, Emerging Evidence, Practice. Geneva: World Health Organization; 2005. URL: www.who.int/mental_health/evidence/MH_Promotion_Book.pdf (accessed 3 April 2019). p. 10. Copyright 2005

It is a subjective construct. Participation and mental well-being are important components of quality of life and relate well to the concept of 'person-centred planning', which has been strongly supported in the UK by successive governments.

Participation Defined in the *International Classification of Functioning, Disability and Health* as 'involvement in a life situation'. (Reprinted with permission from the World Health Organization. *International Classification of Functioning, Disability and Health: Children and Youth Version: ICF-CY*. Geneva: World Health Organization; 2007. URL: www.who.int/classifications/icf/en/ (accessed April 2019). p. 129. Copyright 2017.) It is an objective construct, even if self-reported.

Proposed beneficial features Defined by us as features of services for transitional health care recommended as good practice and for which there is some evidence of benefit, at least in some conditions (Colver AF, Merrick H, Deverill M, Le Couteur A, Parr J, Pearce MS, *et al.* Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. *BMC Public Health* 2013;**13**:675). At the start of our research, we identified nine features and hypothesised that these 'proposed beneficial features' would be associated with better outcomes.

Age-banded clinic An intermediate clinic setting, such as a young person's clinic or a young adult team. In children's health services, this means that children younger than about 12 years would not be at the clinic. In adults' services, it means that adults older than about 24 years would not be at the clinic.

Appropriate parent involvement Parental involvement in their child's care, but with changing responsibilities. The parent and young person are asked separately if they think that the level of involvement is appropriate. Involvement concerns what happens in the clinic (the parent being present or not and who does the talking) and discussions at home about the young person's health and how to manage it.

Co-ordinated team Some young people need to see a team of people. Those with diabetes mellitus may need to see a doctor, a nurse, a dietitian and a psychologist. Those with cerebral palsy may need to see a doctor, a physiotherapist and an orthopaedic surgeon. The members of these teams need to work together and communicate well together and demonstrate to the young person that this is happening. Co-ordination of appointments on the same day demonstrates this.

Holistic life-skills training Training for education, relationships, finances, employment, housing, social relationships, etc., as well as health maintenance. The young person is asked whether they have had any formal life-skills training offered because of their condition. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed.

Key worker A single person known to the young person whom they could easily contact or go to if there were any problems of co-ordination or misunderstandings that needed to be resolved. The role could cross into education and social services. Although a clinic may have a policy to 'appoint' a key worker, the young person may report that their key worker is someone else whom they feel most comfortable with.

Meet adult team before transfer This could be in a joint clinic where senior paediatric and adult clinicians consult together, or the adult clinician might visit the child clinic to be introduced, or the young person might be taken to the adult clinic by a member of the child team to meet the adult team.

Promotion of health self-efficacy The young person is asked 'Have you received enough help to increase your confidence in managing your condition?'. The clinic has a written policy about how it will encourage the young person to take responsibility for their health and give them information about their condition.

Transition manager for clinical team The individual who co-ordinates transition in a clinical team may not be known to the young person. The manager will facilitate good working relationships between adults' and children's services, ensure that there are appropriate materials available for things such as health education or the transition plan and monitor whether or not the young person has a suitable appointment in adults' services and whether or not the appointment is kept.

Written transition plan This should be created some time before transfer. It should include plans for wider transition, not just the transfer to adults' health services. The young person should have a copy of it and it should be updated.

Transfer The formal event when medical care of a young person is moved from children's services to adults' services.

Transition The purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic physical, neurodevelopmental and medical conditions as they move from child-centred to adult-oriented health-care systems.

List of abbreviations

ASD	autism spectrum disorder	NICE	National Institute for Health and Care Excellence
CCG	Clinical Commissioning Group		
CHAT	Child Health Action Team	NIHR	National Institute for Health Research
CQUIN	Commissioning for Quality and Innovation National Goals	NPT	normalization process theory
DAH	developmentally appropriate health care	PBF	proposed beneficial feature
DCE	discrete choice experiment	PPI	patient and public involvement
EQ-5D-Y	EuroQol 5-Dimensions (Youth)	QALY	quality-adjusted life-year
HADS	Hospital Anxiety and Depression Scale	SD	standard deviation
HbA _{1c}	glycated haemoglobin	UP	United Progression
HRQoL	health-related quality of life	WEMWBS	Warwick–Edinburgh Mental Wellbeing Scale
IQR	interquartile range	WP	work package

Plain English summary

When young people with long-term health conditions, such as diabetes mellitus, cerebral palsy or autism spectrum disorder, move from childhood to adulthood, their health may worsen and their social participation may reduce.

'Transition' is the process that addresses the medical, psychosocial and educational needs of young people during this time. 'Transfer' is the event when health care moves from children's to adults' services.

Our research included young people, families, health-care staff, commissioners who buy health care, and managers who deliver health care. We undertook interviews, administered questionnaires and considered value for money. A young people's advisory group guided us throughout.

Our findings and implications were as follows.

- Commissioners and managers thought that transitional health care was the responsibility of children's services. This is inappropriate, as transition extends well beyond childhood.
- Developmentally appropriate health care underpins good health care for young people, including those in transition. We developed a toolkit to assist its introduction.
- Good practice, led by enthusiasts in one setting, often did not generalise to other specialties or to adults' services. Organisation-wide approaches are needed to establish better transitional health care.
- Shared planning of transition between adult clinicians, child clinicians and general practice is important.
- Young people adopted one of four approaches to transition: 'laid-back', 'anxious', 'wanting to be in control' or 'socially oriented' (i.e. welcoming the involvement of family, friends and health-care staff). Discussing a young person's approach would make communication with them more individual.
- Over 3 years, we collected information from 374 young people with diabetes mellitus, cerebral palsy or autism spectrum disorder. Three features of transitional health care linked to better health outcomes:
 1. Appropriate parent involvement. 'Appropriate' meant that the young person and their parents were happy with how much and the way in which the parents were involved.
 2. Young person helped to be confident about managing their health condition.
 3. Young person meeting the adult team before transferring.
- Economic analysis found that the first two of these features might be good value for money.

Scientific summary

Background

As young people with long-term conditions move from child-centred to adult-oriented health services (transition), their health may deteriorate and their social participation may reduce. Chronic illnesses, such as diabetes mellitus, may be more difficult to control. Conditions such as cerebral palsy give rise to symptoms, such as pain or spasticity, that interfere with daily living, and for which health needs may not be met. Few young adults with autism spectrum disorder (ASD) attain their potential for participation in society.

Despite guidance over the past 10 years from government, the voluntary sector and the National Institute for Health and Care Excellence in 2016 on how to improve transition, it has been difficult to persuade commissioners and providers of health services to specify arrangements for transitional health care because much of the guidance has little evidence to support it.

The number of young people in transition is increasing; many children with long-term conditions that once commonly caused death in childhood now live into adulthood. Every year, in a typical NHS Trust serving a population of 270,000, approximately 100 young people with a long-term condition needing secondary care reach the age of 16 years. As transition takes place over about 7 years, the number in transition at any time in a typical trust is approximately 700.

Objectives

The overall purpose of the research programme was to promote the subjective well-being and health of young people with long-term conditions by generating evidence to enable NHS commissioners and health-care providers to facilitate successful transition.

The programme had three objectives:

1. to work with young people with long-term conditions to determine what is important in their transitional health care
2. to identify the effective and efficient features of transitional health care
3. to determine how transitional health care should be commissioned and provided.

Methods

Three separate work packages (WPs) addressed each of the above objectives.

- Work package 1.1 formed a young people's advisory group, United Progression (UP), which met monthly over the 5-year programme.
- Work package 1.2 explored the usefulness of patient-held health information ('health passports') in a project co-led by UP.
- Work package 1.3 explored the importance young people attached to different elements of transitional health care by undertaking a Q-sort study.
- Work package 2.1 assessed whether or not nine proposed beneficial features (PBFs) of transitional health care contributed to improved outcomes for young people with type 1 diabetes mellitus, cerebral palsy, or ASD and an associated mental health problem. We conducted a prospective study of 374 young people,

who were visited four times, 1 year apart, by research assistants. Outcomes covered participation, well-being, satisfaction with services and condition-specific measures. Young people with diabetes mellitus were recruited from five NHS Trusts in north, south-west and south-east England and Greater London. Those with ASD were recruited from four NHS Trusts in north and south-west England. Those with cerebral palsy were recruited from one NHS Trust in south-east England and two regional population registers in north England and Northern Ireland (covering 17 trusts).

- Work package 2.2 investigated how young people with long-term conditions experienced transition by undertaking in-depth interviews with 13 young people, their families and health professionals.
- Work package 2.3 examined the relative efficiency of illustrative models of transition. It involved a discrete choice experiment, estimating NHS costs, assessing health-related quality of life and modelling cost-effectiveness. This used a Markov model that compared a transition service with a PBF with a service containing no such feature. The model simulated outcomes for a hypothetical cohort of 14-year-olds over a 10-year time horizon, with discounting at 3.5% per annum.
- Work package 3.1 identified the factors enabling or inhibiting the introduction of developmentally appropriate health care (DAH) by undertaking an ethnographic study in three NHS Trusts. We then compiled a toolkit to assist the introduction of DAH.
- Work package 3.2 identified the factors that enabled or inhibited commissioning for effective transition. It involved a literature review, in-depth interviews and site visits.
- Work package 3.3 synthesised learning from the programme on 'what' and 'how' to commission, drawing on meetings with commissioners.

Results

Work package 1.1: involving the UP group

UP was involved in most WPs and a wide range of activities, such as advising the research team, developing video materials, disseminating results to other young person groups and co-leading a workshop at the final conference.

We forged other patient and public involvement links that included shared project work with the Council for Disabled Children, the Association of Young People's Health and The Health Foundation. Parents, young people and the voluntary sector were represented on the External Advisory Board.

Work package 1.2: health passport work

UP found a lack of conceptual clarity about what a 'health passport' was.

In its survey, UP found that many young people thought that a health passport was a good idea, but that, even if they owned one, they rarely used it.

Work package 1.3: Q-sort study

The Q-sort study identified four interaction styles that young people adopted when approaching transition: 'laid back', 'anxious', 'autonomy seeking' and 'socially oriented'.

Discussing preferences about transition with young people should help clinicians and young people develop personalised planning.

Work package 2.1: longitudinal study (quantitative)

Services provided the nine PBFs very variably. Fewer than half stated that they provided an 'age-banded clinic', 'written transition plan', 'transition manager for clinical team', 'protocol for promotion of young person's confidence in managing their health condition ('health self-efficacy') and 'holistic life-skills training'.

There was a striking mismatch between the features that a service said it provided and the features young people reported that they had experienced. For example, across the three conditions, agreement was 30% for 'written transition plan' and 49% for 'key worker'. Agreement was better at 77% for 'appropriate parent involvement', 77% for 'age-banded clinic' and 80% for 'promotion of health self-efficacy'.

The well-being scores for each condition group remained similar over time. For those with diabetes mellitus or cerebral palsy, their average well-being was similar to that of the general population; those with ASD reported significantly lower well-being. Average satisfaction with services was reasonable at baseline; it remained steady for those with type 1 diabetes mellitus but worsened for those with cerebral palsy or ASD. For participation in life activities, there were significant differences between the three conditions, with young people with type 1 diabetes mellitus in a more independent phase than those with cerebral palsy or ASD. All made progress over time.

Average condition-specific outcomes worsened over the course of the study for those with type 1 diabetes mellitus or cerebral palsy. For those with ASD, average condition-specific outcomes remained the same between baseline and the final visit.

The features of services for transitional health care associated with better outcomes were 'appropriate parent involvement', 'promotion of health self-efficacy' and 'meeting the adult team before transfer'.

'Having a key worker' was inconsistently associated with better outcomes. Features with no evidence of association with better outcomes were 'transition plan', 'age-banded clinic', 'co-ordinated team', 'being part of a service with a transition manager for clinical team' and 'having access to holistic life-skills training'.

Work package 2.2: longitudinal study (qualitative)

Transition and transfer of health care were disorientating and disrupting for young people and their families, in part because hard-earned knowledge about how best to navigate the children's health-care system was lost. Health professionals are in a position to help young people and families adjust to and mitigate these disruptions through actions such as being clear in discussions and documents about processes, explaining how procedures in adults' and children's health care differ and arranging meetings with members of the adult team before transfer.

Although it is important to support young people to become responsible for their health care, family members remain important in this process. Such involvement is normal, not dysfunctional. Family members can be helped to modify their roles so that there is partnership and sharing of care with their son or daughter.

Work package 2.3: discrete choice experiment and economics analysis

Preference for current care was strong, and even stronger for those who had not transferred to an adults' service. Having clinics that welcomed parental involvement was the second most important attribute chosen.

Young people valued clinics in which information was passed on to the right person, parental involvement was welcomed, staff allowed young people to make decisions about their care and the same staff were seen at each appointment. Young people valued seeing the same staff at each appointment more than having a key worker.

In modelling health care, we found the following:

- Differences in health-related quality of life between health conditions, as measured by the EuroQol 5-Dimensions (Youth) (EQ-5D-Y). For those with type 1 diabetes mellitus, the median utility score was 0.94 (0 = worst possible health, 1 = best health) and the sumscore was 5.2 (lower score = better health); the corresponding scores for ASD were 0.76 and 7 and for cerebral palsy were 0.70 and 7. There was a trend towards lower scores after transfer.

- The median annual NHS cost of appointments, medication and investigations for an individual with type 1 diabetes mellitus was £7003, with cerebral palsy was £2934 and with ASD was £2350.
- The cost-effectiveness results suggested that provision of 'having a key worker' and 'promotion of health self-efficacy' represented better value for money. 'Having a written transition plan' and 'having a transition manager for clinical team' represented poorer value for money.
- Implementing features of transitional health care is unlikely to reduce NHS costs over a 10-year time horizon. Therefore, a judgement is needed regarding whether or not the development of a service with, for example, 'appropriate parental involvement', 'promotion of health self-efficacy' and 'meeting the adult team before transfer' would be worth the cost, given that they may increase engagement with services and prevent deterioration in health in the long term.

Work package 3.1: barriers to and facilitators of the introduction of developmentally appropriate health care

Despite different understandings of DAH in the literature, and across clinical and managerial staff, we identified common themes that led to a working definition:

DAH recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms, DAH focuses on health-care professionals' approach to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.

Organisational barriers to introducing DAH were (1) no single group in a NHS Trust was responsible for young people, (2) there was perceived (incorrectly) to be a small number of young people attending hospital, (3) the mindset and skill set of many staff were often not ready and (4) good practices led by enthusiasts in one child specialty rarely generalised to other child health specialties or to adult specialties. Organisational solutions to introducing DAH were (1) buy-in and formal support resting at chief executive and board level, and with senior managers in both adults' and children's services; (2) planning that engaged, from the outset, adults' and children's services; and (3) a trust-wide strategy on, and training about, DAH.

We developed a toolkit to assist the introduction of DAH (www.northumbria.nhs.uk/?s=dahtoolkit).

Work package 3.2: commissioning for transition

Commissioners and providers of adults' services regarded transition as the responsibility of commissioners and providers of children's services to deal with and improve. This is inappropriate given that transition extends to approximately the age of 24 years.

Many commissioners did not regard transition as a priority.

Transition was not usually monitored by commissioners, partly because there were no nationally agreed outcome and quality indicators.

Strengths

A young person's advisory group was involved throughout the 5 years of the programme.

The sample for the longitudinal study generated the largest study of its kind.

The young people invited to join the longitudinal study were representative of all young people with one of the three chosen conditions, and appeared to remain representative after analysis of non-participation and attrition. In Northern Ireland, there was a small effect of deprivation on the attrition of those with cerebral palsy.

Our study did not include young people with a learning disability, so the results cannot be generalised to this group.

The research into commissioning for transition is the first work of its kind.

The trusts varied greatly in the number and variety of the PBFs they offered. Thus, there was sufficient variety to examine the effects of these features on outcomes, without the analysis being dominated by a combination of features from a few sites.

Limitations

There was uncertainty about whether or not the regions and trusts in the longitudinal study were representative; however, we recruited from 27 trusts, widely spread over England and Northern Ireland, and the trusts varied greatly in the number and variety of proposed beneficial features offered.

The quality of delivery of each PBF was not assessed.

Owing to the nature of the data, the economic modelling had to be exploratory rather than following a strict, formal approach. Therefore, the economic conclusions should be interpreted with caution.

Implications for transitional health care

Our results suggest the following:

1. There is an important role for commissioners of adults' services to commission transitional health care, in addition to commissioners of children's services with whom responsibility for transitional health care currently lies.
2. 'Developmentally appropriate health care' is a crucial aspect of transitional health care. Our findings indicate the importance of health services being commissioned to ensure that providers deliver DAH across all health-care services, and that this will be facilitated by commitment from senior provider and commissioner leaders.
3. It is important for NHS Trusts to adopt a trust-wide approach to implementing transitional health care. Setting up a Transition Steering Committee in a NHS organisation is an effective way to improve service quality.
4. Joint planning between adult health-care providers, children's health-care providers and primary care is likely to improve both the transfer of individual young people and the further adoption of ways of working that improve care for this population.
5. Adults' and children's health-care providers could explore with a young person how they approach transition, thereby personalising their clinical approach. We found that young people adopted one of four interaction styles when approaching transition: 'laid back', 'anxious', 'autonomy seeking' or 'socially oriented'.
6. We found that three service features were associated with better outcomes – 'appropriate parent involvement', 'promotion of young person's confidence in managing their health condition' and 'ensuring young people and parents meet the adult team before transfer'. These findings provide practical content to be considered in NHS commissioning specifications.
7. Maximal service uptake would be achieved by a service that encouraged appropriate parental involvement, emphasised the importance of good communication with young people and encouraged young people to make decisions about their care. A service involving 'appropriate parental involvement' and 'promotion of a young person's confidence in managing their health condition' may offer good value for money. A service involving a 'transition manager for clinical team' or an 'age-banded clinic' is unlikely to offer value for money.

Recommendations for research

1. What are the most effective and efficient ways for the findings of the programme to be introduced and implemented by health commissioners and health-care organisations?
2. What are the most effective and efficient ways for primary health-care services to be involved in improving transition, and in following up young people after transfer (whether or not they meet criteria for adults' services)?
3. What are the most effective and efficient methods of enabling young people with long-term conditions to successfully manage their own health?

Study registration

This study is registered as UKCRN 12201, UKCRN 12980, UKCRN 12731 and UKCRN 15160.

Funding

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SYNOPSIS

Setting the scene

All young people – defined by the World Health Organization as any person between the ages of 10 and 24 years¹ – experience transformations in their lives and their understanding of the world as they grow older. Although it may not be possible for all, young people need to achieve four crucial developmental tasks: (1) consolidate their identity, (2) achieve independence from their parents, (3) establish adult relationships outside their families, and (4) find a vocation.² A fundamental principle is that when young people have a need for health care, this care must be provided in a manner that is appropriate to their stage of development. The term used to describe this principle is developmentally appropriate health care (DAH). DAH should underpin all health care for young people and in particular for those with a long-term condition. However, the term has been ill-defined and used inconsistently; in turn, this has made it difficult to assess whether or not it has been implemented in reported studies.^{3,4}

Furthermore, a young person with a long-term condition has to move from children's to adults' services. This process is called 'transition' and is defined as the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic physical, neurodevelopmental and medical conditions as they move from child-centred to adult-oriented health care systems.⁵ 'Transfer' is the formal 'event' when the medical care of a young person is moved from children's to adults' services.

The UK and Australia are the only two high-income countries with national guidance on transition, although academies and specialty groups also make recommendations.⁷⁻⁹ The need for improved transitional health care is set out in recent policy and recommendations, such as advice from the Department of Health and Social Care in 2006¹⁰ and 2008,¹¹ recommendation 23 from the 2010 Kennedy Report,¹² the 2015 Care Quality Commission report *From the Pond to the Sea*¹³ and National Institute for Health and Care Excellence (NICE) guidance on transition in 2016.¹⁴ Commissioners, provider organisations and clinicians have a role to play in such improvements.

The number of young people surviving to adulthood is increasing; many children with long-term conditions that once commonly caused death in childhood now live into adulthood. In a typical NHS Trust serving a population of 270,000, about 100 young people with chronic illness, a complex physical impairment or a neurodevelopmental disorder reach the age of 16 years each year.¹⁵ As transition takes place over about 7 years, the number in transition at any time in a typical trust is approximately 700.

New understanding of adolescent and young adult brain development and its associations with behaviour¹⁶ further reinforce the need for transitional health care to be set in a developmental context.

Transition is important because:

- Many young people with a range of long-term conditions have poor social outcomes, following transition, in areas of social participation, employment or further education. For example, young adults with long-term conditions, such as cancer, congenital bowel anomalies and renal disease,¹⁷ congenital heart disease¹⁸ and chronic physical disability,¹⁹ and those with chronic illness,^{20,21} have demonstrated delays in autonomy, psychosexual and social development. Furthermore, few young adults with neurodevelopmental disorders, such as autism spectrum disorder (ASD), attain their potential for participation in society.²²

- Chronic illnesses, such as diabetes mellitus and renal disease,²³ are prone to deteriorate during the adolescent years; they need frequent medical monitoring and treatment optimisation. Young people reported finding it difficult to negotiate transition in services for haematology,²⁴ type 1 diabetes mellitus,²⁵ epilepsy,^{26,27} physical disability^{28,29} and rheumatology.³⁰ Conditions such as cerebral palsy give rise to symptoms that interfere with daily living, such as pain, spasticity and seizures. Most mental health disorders of adults develop during adolescence just at the time when the commissioning and provision of services is most likely to move from child- and family-focused to adult symptom-orientated mental health services. There are concerning rejection rates after solid organ transplants.³¹
- Some adults' services are not routinely provided (e.g. for adults with attention deficit hyperactivity disorder³² or ASD). Other adults' services, such as physiotherapy and mental health services,³³ have different, and usually narrower, entry criteria. Some services that require multidisciplinary co-ordination (e.g. for those with cerebral palsy) are provided in childhood but are rarely provided in adulthood.³⁴

Central government guidance and direction has sought to improve services for transitional health care but there remains a need to improve services.^{13,14} In 2017, a national CQUIN (Commissioning for Quality and Innovation National Goals)³⁵ was introduced around transitions from children to young people's mental health services.

Developments in health-care transition during the period of the research programme

Since the start of the programme in 2012, there have been developments in the field of transition of which we have taken account.

Results of published evaluative studies remain difficult to generalise from because they are usually about an intervention in one clinical setting, for one condition and using a locally designed intervention. The Cochrane review³⁶ of interventions to improve transition, published in 2016, confirmed the lack of good evidence. Studies with more rigorous protocols have since been conducted.³⁷⁻⁴⁰ A systematic review⁴¹ in 2017 reported the limitations of methods used in comparative studies of transition interventions. It found, for example, that most were small, single-condition studies, used unvalidated questionnaires, and did not report the age of transfer or the age at and time of questionnaire completion. In designing our research, we had anticipated such methodological limitations and addressed them in the methods we used for the longitudinal study [work packages (WPs) 2.1, 2.2 and 2.3].

Two Delphi studies proposed a suite of outcomes⁴² and process measures⁴³ for evaluating transition. Our choice of outcomes in the longitudinal study is in line with these international studies.

A synthesis of qualitative studies of young people's views about transition⁴⁴ confirmed that there is much literature about the issues and difficulties encountered, and supported our decision not to undertake further exploratory work with young people.

As anticipated, arrangements for commissioning NHS services have continued to change during the research programme. However, the commissioning focus of our research concerns 'what' and 'how' to commission. We intended that our findings would be relevant to any commissioning structure, including whether or not commissioning and service provision are brought together in the same organisation.

Aims and objectives of the research programme

The overall aim of the programme was to promote the subjective well-being and health of young people with long-term conditions by generating evidence to enable NHS commissioners and trusts to facilitate the successful transition of young people from children's to adults' health care, thereby improving health and social outcomes.

To address this aim, the programme had three objectives:

1. to work with young people with long-term conditions to determine what successful transition means to them and what is important in their transitional health care
2. to identify the features of transitional health care that are effective and efficient
3. to determine how transitional health care should be organised, provided and commissioned.

Three separate WPs addressed each of these objectives. We present a summary of each WP and then bring together the results of all nine strands to inform our conclusions and their implications. As an overview, and to aid orientation, the WPs are summarised in *Box 1*, followed by *Figure 1*, which shows how the WPs influenced each other.

At the end of the account of each WP, we indicate its links to the other WPs and how each WP contributed to the seven main implications of our work.

In *Appendix 1* is a summary of work we completed before applying for a Programme Grant.

In *Appendix 2* are the management arrangements for the programme and a diagram showing how key groups interacted.

BOX 1 Overview of the WPs

Objective 1

Work package 1.1

- To form and maintain a young people's advisory group for the programme.
- To consult with the young people's advisory group on all aspects of the programme.

Work package 1.2

- To explore the usefulness of a 'health passport' through research co-led by the young people's advisory group.

Work package 1.3

- To explore the importance that young people attach to different components of successful transition.

Objective 2

Work package 2.1

- To examine whether or not the proposed beneficial features of services predict outcomes for young people with type 1 diabetes mellitus, cerebral palsy or ASD and an associated mental health problem.
- To determine the resource use and costs of care.

Work package 2.2

- To investigate the factors that promote or inhibit the introduction of the proposed beneficial features of services.

Work package 2.3

- To assess the relative efficiency of illustrative models of transition.

BOX 1 Overview of the WPs (*continued*)**Objective 3****Work package 3.1**

- To identify, describe and understand the factors that enable or inhibit the introduction of organisation-wide DAH for young people.

Work package 3.2

- To identify the structures, processes and relationships between commissioning entities in the NHS and other agencies relevant to transitional health care.
- To identify the facilitators of and barriers to commissioning for transitional health care.
- To identify how transitional health care could be better commissioned.

Work package 3.3

- To synthesise learning from the research programme on 'what' and 'how' to commission.
- To learn about the most useful way to provide research-based evidence to inform commissioners.

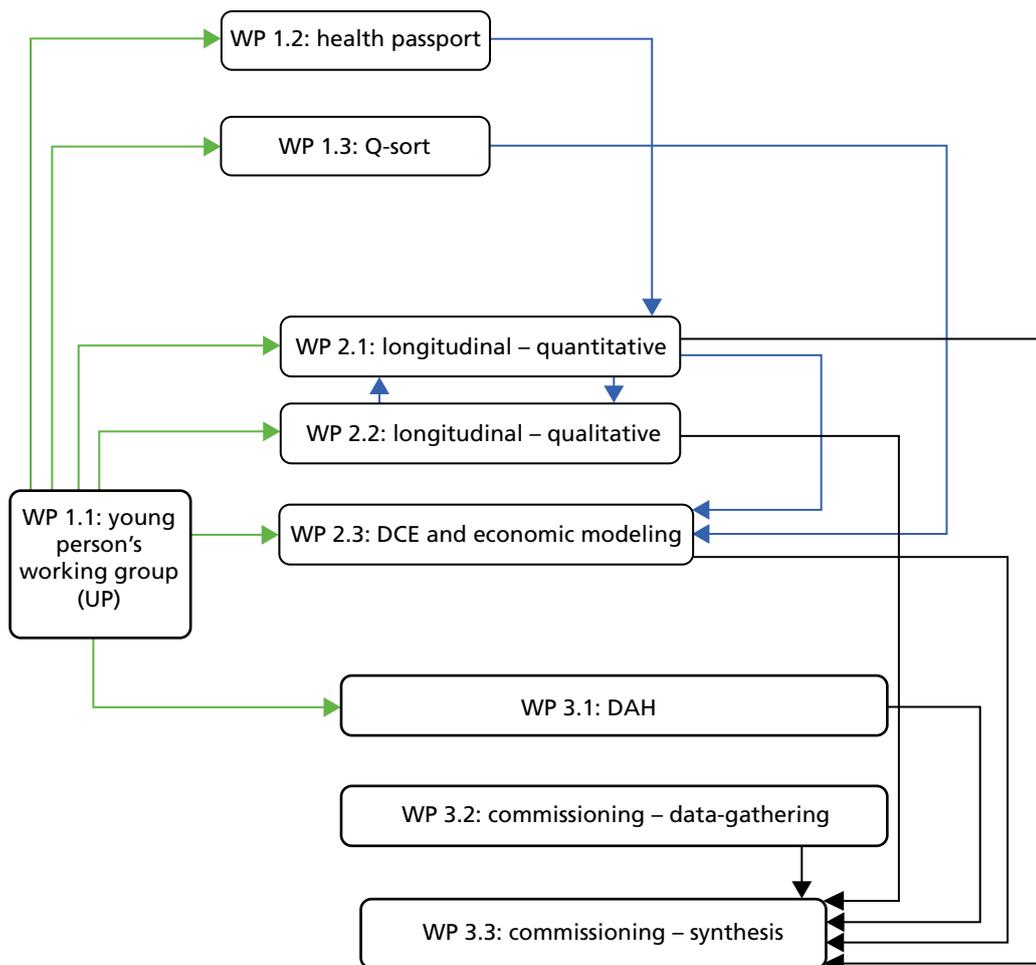


FIGURE 1 How the WPs influenced each other. DCE, discrete choice experiment; UP, United Progression.

Work package 1.1: work of the United Progression group

Addressing objective 1: to work with young people with long-term conditions to determine what successful transition means to them and what is important in their transitional health care

We ensured that the contributions of the young people were integrated with the research programme in meaningful ways for the young people and the research. Funds from the programme ensured that enough staff time was available to facilitate meaningful involvement of young people throughout the 5-year programme.

The young people called their group United Progression (UP; the term UP will be used in the remainder of this report).

Aims

- To form and maintain UP.
- To consult with UP throughout the duration of the programme.

Method

Preliminary work during the development of the grant application

Discussion between a time-limited young person's group and co-applicants concluded that a 'partnership' approach to involvement should be the fundamental value. Development of skills and confidence would be required to enable young people to contribute to a research programme. Peer support workers would be recruited to facilitate the induction and skills development of the advisory group.

Development of and recruitment to UP

Three part-time peer support workers were appointed. Recruitment to UP was undertaken by the programme's patient and public involvement (PPI) lead.

At the start of the programme, UP members were aged between 15 and 20 years. All had experience of accessing a range of health-care services. Recruitment occurred in a range of ways: via young people's health services, local schools and local young people's health action groups. With membership growing steadily in the early months, the group consisted of over 20 members, and active participation fluctuated over time in line with exams, family events and other commitments. Most meetings had around eight members present. UP had 26 members over the 5 years. By the end of the programme, eight of the original members still attended regularly; this was crucial, as they brought their 5-year insights to the final research outputs.

UP met monthly over the 5-year programme. UP members had a hot meal and socialised before meetings began.

UP members were involved in advisory, consultative and dissemination roles – not as research participants.

Maintaining and sustaining the engagement of UP

Induction for UP members included a description of the project, a meeting with members of the management team, a glossary of research terminology, and attending and presenting at the programme's launch.

Each monthly meeting was planned to be enjoyable for UP, and to ensure that there was enough guidance and support for the tasks that UP had agreed to do. Careful planning was needed for communication between UP and the programme management board to ensure fruitful interaction. The PPI lead was the link between UP and the board. The board set out timely, structured commissioning briefs for the PPI lead, rather than sending direct requests to UP. The PPI lead ensured that tasks were relevant and achievable and that young people had the skills to deliver them.

Impact on the programme

UP provided input to many WPs. For example, UP piloted the Q-sort tool in WP 1.3. UP commented on the 'proposed beneficial features' (PBFs) that were central to the longitudinal research described in WP 2.1; subsequently, two features ('transfer readiness' and 'direct payments') were dropped as they were unclear or not relevant to health-care transition. UP designed recruitment and retention materials for the longitudinal research of WP 2.1. UP responded to the findings of WPs; for example, they made a training DVD (digital versatile disc) on the importance and implementation of DAH for WP 3.1.

UP contributed directly to dissemination activities throughout the programme. They presented at the launch in Newcastle upon Tyne in October 2012, and ran a session at the final dissemination conference in London in October 2017. They wrote blogs for the programme's website. UP representatives sat on the interview panels for the research associates and contributed to their induction, and sat on the external advisory board.

UP advocated for the programme and offered their skills and expertise to local and national groups. UP helped to develop training materials for doctors in partnership with the Royal College of Paediatrics and Child Health, MindEd and the Association for Young People's Health. This generated several videos. UP represented the Transition programme at the Department of Health and Social Care's 'Takeover Day' in London in 2015.

Finally, UP worked with the Council for Disabled Children to disseminate their experiences and present early results of the programme to other young people's groups between autumn 2015 and spring 2017. These meetings also enabled young people involved in research elsewhere to share their experiences with UP. In these meetings, UP disseminated results of the programme relating to the Q-sort study (WP 1.3), health passport work (WP 1.2) and the concept of DAH (WP 3.1). Meetings took place with Child Health Action Team (CHAT) North Tyneside; two Croydon groups; Together for Short Lives young person group; St Oswald's Hospice, Newcastle upon Tyne; Transition2 group in Derby; and the Chatterboxes youth group in Bournemouth. Three facilitator guides (one example is given in *Appendix 10*) were developed for other groups to use, especially voluntary organisations.

In *Appendix 3* are the certificate UP designed for participants in the longitudinal study (WP 2.1); UP's Microsoft PowerPoint® (Microsoft Corporation, Redmond, WA, USA) presentation for the programme's launch; and one of the conference posters prepared by UP.

Key findings

- UP influenced many of the WPs of the programme, and was involved in a wide range of dissemination and advocacy activities.
- As the members of UP grew in confidence, their contributions became increasingly useful to the programme. The support and training offered to UP were very important, although they were resource intensive.
- Members of UP reported that they enjoyed the challenges, the relationships they formed with other young people and their greater understanding of research.

Inter-relationships with other parts of the programme

UP influenced many aspects of the programme through their input to several WPs. The only two WPs they did not influence directly were those (WPs 3.2 and 3.3) on commissioning for transition.

Further analysis and discussion of the role of UP is presented in *Involvement of patients, the voluntary sector and the public*. This section also summarises the internal evaluation of the work UP undertook and points to our published paper.⁴⁵

Although not unique to our programme, when professionals, managers and commissioners attend meetings where young people contribute and have been closely involved in the work presented, such young-person involvement strengthens the assurance that the audience attaches to the work.

UP thoughts and opinions directly influenced implication 2 on DAH and the toolkit we developed to assist with introduction of such care across an organisation. By advising on questionnaire content, wording and feasibility, UP directly influenced both what research participants were asked to complete and the key implications of our work, namely implication 4 concerning joint planning, implication 5 concerning young people's approaches to transition, implication 6 concerning features associated with better outcomes and implication 7 concerning features likely to optimise service uptake.

Work package 1.2: health passport

Addressing objective 1: to work with young people with long-term conditions to determine what successful transition means to them and what is important in their transitional health care

We determined that engaging UP in a research study co-led by them would help them better understand research processes and generate knowledge important to the programme. UP chose 'health passports' as the focus of their work. These are usually a portable means of recording health information.^{46,47}

Aim

- To explore the usefulness of health passports in a project co-led by UP.

Methods

UP examined a range of passports designed to help young people navigate health services and concluded that there was no clear definition of what a 'health passport' was. As there were many health passports already available, UP decided that it would not be useful to develop another one. However, as no robust analysis of health passport use has been undertaken, UP aimed to examine the use and usefulness of some health passports already used by young people with long-term conditions.

UP contacted health-care professionals from a children's hospital, a physical disabilities team, an adolescent rheumatology team and a voluntary organisation. UP asked professionals about their experience of health passports and this helped to identify questions and issues to explore with young people, such as:

- What kind of passports are used and what are their essential components?
- Who uses health passports and who benefits from them?
- How are they used and how are young people supported to use them?

UP then worked with the patient satisfaction team in the lead trust to devise a questionnaire to assess the views of young people about health passports. Then the professionals in the above organisations helped UP link to young people who used health passports. However, this proved difficult as ethics and research governance permissions were required; it was impossible to achieve this across several organisations within the available time.

Analysis

Young people from one service returned questionnaires ($n = 13$) and, although the response rate was low (20%), interesting findings emerged. None of the 13 participants said that they completed the health passport alone; the majority said that they thought passports were 'useful', but half of them never took them to health-care appointments. The passports were considered more useful to health professionals than to young people themselves.

Strengths and limitations

This work identified some qualitative findings about health passports. However, the work did not generate, as intended, enough quantitative data from which to draw definitive conclusions. It was difficult to obtain all of the research governance permissions in a timely manner to enable UP to approach as many young people as they had intended. The approaches also depended on the willingness and time of local health professionals to approach young people. For other parts of the programme, all such preliminary contacts and undertakings had been formalised before the programme started. For this work, co-generated by UP, planning could not begin until UP had worked through its ideas, which was at least 1 year into the programme.

Such challenges have been reported before. A Dutch group undertook participatory research with young people with chronic illness⁴⁸ and concluded that, although the activity benefited the young people, it was an inefficient and unreliable way to gather research data. Similar benefits to young people were reported in a study in Vancouver.⁴⁹

Key findings

- There is a lack of conceptual clarity and no clear definition about what is meant by 'health passport'.
- The work raises questions about whether or not a health passport is a tool truly held by young people. Who should complete it and when? Do young people really want it to 'travel' with them to appointments and between services?
- Even studies by enthusiasts for health passports found difficulties. Participants used their document only occasionally and its perceived utility was modest;⁵⁰ only one-quarter completed a survey, and, of those who then agreed to a telephone discussion, only one-third had used their passport.⁴⁶

Inter-relationship with other parts of the programme

This WP contributed directly to the longitudinal study WP 2.1. A health passport was discussed as a candidate PBF of transitional health care. However, the initial work that UP undertook indicated that 'health passport' meant different things to different people, and although it was considered useful by some professionals, young people appeared to value it much less. We therefore decided not to include health passport as a PBF. This decision was vindicated by the subsequent survey work that UP undertook.

The confidence that members of UP gained by carrying out their research and their greater appreciation of research methodology enhanced the quality of all of their contributions to the programme, which were set out in the earlier account of WP 1.1. It also increased their self-confidence, and this is discussed in *Involvement of patients, the voluntary sector and the public* and in our associated published paper.⁴⁵

UP presented the health passport work at the Department of Health and Social Care's 'Takeover Day', where interest was expressed in taking the passport work forward nationally.

UP presented their work as a poster at several meetings, including the final dissemination meeting at The King's Fund, London, in October 2017. UP's poster presentation is in *Appendix 4*.

Work package 1.3: Q-sort study

Addressing objective 1: to work with young people with long-term conditions to determine what successful transition means to them and what is important in their transitional health care

Qualitative research undertaken with young people during and after transition has been systematically reviewed. The first review⁵¹ identified four main issues: young people's feelings and concerns, young people's recommendations about components of transition services, outcomes after transfer and mode of transfer. The second review⁴⁴ examined the point of transfer and identified four themes: facing changes in significant relationships, moving from a familiar to an unknown ward culture, being prepared for transfer and achieving responsibility.

The work of this WP has been published in Hislop *et al.*⁵² and material in this section is based on that paper. Reprinted from *Journal of Adolescent Health*, Vol. 59, Hislop J, Mason H, Parr IR, Vale L, Colver A, Views of young people with chronic conditions on transition from pediatric to adult health services, 245–53, Copyright 2016, with permission from Elsevier.

Aims

- To explore the views of young people about transition.
- To identify and describe these views using Q-methodology.

Methods

Q-methodology combines quantitative and qualitative methods to investigate the range of possible views on a subject. It involves the rank ordering (Q-sort) by participants of a set of statements (Q-set) about a topic, after which a by-person factor analysis of the Q-sorts is used to reveal shared perspectives on the topic. Further details are in our published paper.⁵²

The Q-set of statements relevant to young people in transition was generated using quotations from two reviews of qualitative studies^{44,51} and our own mapping review of service models.⁵³ These were coded into a set of emergent themes, 'planning', 'staff related', 'maturity', 'parent-related' and 'other', which were then recategorised into several subthemes. One representative statement from each subtheme was selected. Following consultation with UP, the wording was adjusted and each final statement was prepared for sorting by participants onto a triangular grid. The statements are set out in table 1 of the published article.⁵²

Q-methodology requires that individuals in the sample are likely to hold different views. Therefore, maximum variation sampling was used, by age, gender, health condition and whether or not the young person had transferred. We sought 45 young people, aged 14–22 years, with a long-term condition that would soon require or had recently required them to transfer from children's to adults' services. Those with intellectual disability who could not complete the Q-sort were excluded. The number of participants is usually, but not necessarily, smaller than the Q-set.⁵⁴ The aim is to have four or five persons defining each anticipated viewpoint; there are often two to four, and rarely more than six. Accordingly, the breadth and diversity of viewpoints is probably best achieved when a participant group contains between 40 and 60 participants.⁵⁵

Clinicians from 10 adults' and children's specialties in a NHS Trust with tertiary and secondary care responsibilities invited young people with long-term conditions to participate. Q-sorts were administered face to face by the researcher.

Analysis

The degree to which an individual's Q-sort corresponds to each factor derived from the factor analysis is given by their 'factor loading'. This is a correlation coefficient between +1 and -1; the closer to 1, the more similar an individual's Q-sort is to the factor. Individuals are 'exemplars' for a factor if they have a significant factor loading on that factor alone ($p \leq 0.01$). We used PQMethod software (version 2.11; Peter Schmolck, University of the Bundeswehr, Munich, Germany) with centroid factor analysis followed by varimax rotation.⁵⁶ Outputs include the number of exemplars per factor, eigenvalues and factor variance, which provide information on the proportion of variance for the entire study explained by each factor. These are used alongside the postsort qualitative information to determine the 'factor solution': the final number of factors identified.

For each factor, an idealised 'composite' Q-sort is computed, illustrating how a person with a factor loading of 1 would have laid out their statement cards. Attention is paid to statements that characterise each factor, for example those placed in the +3 and -3 position on the grid, and those statements that distinguish between factors.

We found that a four-factor solution was optimal from a statistical viewpoint and most meaningful in clinical terms.

Factor 1: young people with a 'laid back' approach to transition

These young people were not particularly worried about transition. They did not think that transition would make much difference to them and expected their new health team to provide similar care to that which they had experienced in children's services. They were happy to be guided by staff on how to manage their condition and wanted continued involvement of their parents in their care. They also wanted to be well informed about their condition.

Factor 2: young people with an anxious approach to transition

For these individuals, transition mattered very much; it worried them, they did not want transfer to happen at a set age, and they wanted a written plan in place for this. They wanted to be able to say goodbye to their current doctors, and they thought that the post-transfer service would provide different care, and that seeing different staff might not help build trust. They thought that their condition was difficult to live with and all areas of their life were affected by it. They did not know what kinds of support would be available to them in future. They wanted their parents involved in their care.

Factor 3: young people with an autonomy-seeking approach to transition

These young people wanted independence and autonomy during transition and were characterised by their wish for the withdrawal of parental involvement in their care. They wanted doctors to speak to them, rather than to their parents. They wanted doctors to offer suggestions and choices but allow them to make decisions. They were more developmentally mature in terms of their responses to statements about leaving home and living independently. They preferred flexible timings for clinics and wanted to leave the paediatric environment. They showed that they wanted to meet adult staff before transfer, and then see the same doctors in order to develop trust.

Factor 4: young people with a socially oriented approach to transition

These young people valued social interaction with family, peers and professionals to assist transition. They thought that it was important to interact with those involved in their care. They wanted to meet others in a similar situation and wanted their parents to remain involved in their care. They were comfortable with other staff being present at consultations and, for example, did not find it difficult if students were present. They felt attached to doctors (wanting a chance to say goodbye before transfer) and wanted a particular person at the clinic to help them plan the practical side of managing their condition.

There is more discussion of these factors in our published paper.⁵²

Strengths and limitations

Owing to the purposive sampling, claims cannot be made about how many individuals hold each point of view. Nor can inferences be made about subgroup sizes based on gender, age or condition.

We do not know if the four styles are stable over time. The views of some young people might relate to underlying personality characteristics and, therefore, might not change substantially. Alternatively, preferences may change as young people develop or as their health or health care changes.

Key findings

- Reviews of qualitative studies^{44,51} of transition have not revealed how individuals approach the dilemmas they face. Our results add a new dimension.
- Four factors or interaction styles of approaching transition were identified: 'laid back', 'anxious', 'autonomy-seeking' and 'socially oriented'.
- These four diverse styles show that there is not one view on transition. Thus, a 'one size fits all' approach is inappropriate and tailoring care to each to each young person is crucial.

Inter-relationship with other parts of the programme

The recognition of these four interaction styles for approaching transition is a new finding and yields one of the seven key implications of the programme: implication 5.

The Q-sort study contributed to the design of the discrete choice experiment (DCE) (WP 2.3), which identified aspects of transitional health care that young people are more likely to take up. This in turn informed the economic analyses (WP 2.3).

Work package 2.1: longitudinal study (quantitative)

Addressing objective 2: to identify the features of transitional health care that are effective and efficient

Although there is some preliminary evidence of the benefit of transition programmes in diabetes care,^{57,58} there has been little research with young people with complex physical impairments.⁵⁹ Furthermore, the lack of planned transfer to adult mental health services for young people with neurodevelopmental disorders has been highlighted.⁶⁰ Therefore, to be as generalisable as possible across long-term conditions, a cohort of young people with one of three very different conditions was recruited: individuals with type 1 diabetes mellitus as an exemplar of chronic illness; with cerebral palsy as an exemplar of complex physical impairment; and with ASD who continued to access children's services for an associated mental health problem as an exemplar of neurodevelopmental disorder.

Following examination of published policy documents and research literature, nine proposed PBFs of services were identified and defined for the study. These were age-banded clinic, meet adult team before transfer, promotion of health self-efficacy, written transition plan, appropriate parent involvement, key worker, co-ordinated team, holistic life-skills training, and transition manager for clinical team. The *Glossary* provides the definitions of the features. Table 2 of the published protocol⁶¹ gives the details of the policy documents and tabulation of the research literature justifying their inclusion.

The following papers have been published from this WP:

- Protocol⁶¹
- Analysis of baseline data⁶²
- Young people's experience of the PBFs⁶³
- Unmet needs of those with cerebral palsy⁶⁴
- Clinical course in diabetes mellitus⁶⁵
- Longitudinal analysis identifying that only three of the PBFs are associated with better outcomes.⁶⁶

Aims

To examine whether or not the PBFs of services are associated with better outcomes for young people with type 1 diabetes mellitus, cerebral palsy, or ASD and an associated mental health problem.

Hypothesis

In combination, and separately for type 1 diabetes mellitus, cerebral palsy and ASD, access to PBFs during the transition from children's to adults' health care predicts better health and social outcomes.

Methods

Sampling frame and site selection

In the UK, all young people with type 1 diabetes mellitus aged < 15 years attend secondary hospital care. Between June 2012 and October 2013, young people with type 1 diabetes mellitus were recruited from children's services in five UK health-care provider NHS Trusts that were at different stages of development of transitional health care. These five NHS Trusts were in Greater London and north, south-west and south-east England. Young people with ASD and an associated mental health problem were recruited from four NHS Trusts, two of which claimed to have a readily available adults' service to which to transfer young

people. Similarly, all young people with ASD and an identified mental health problem attend specialised secondary care services. These four NHS Trusts were in north and south-west England. Young people with cerebral palsy were recruited from one NHS Trust in south-east England and randomly sampled from two regional population registers, the North of England Collaborative Cerebral Palsy Survey⁶⁷ and the Northern Ireland Cerebral Palsy Register,⁶⁸ that covered 17 NHS Trusts.

We conducted a survey, before submitting our application, that showed that the trusts varied greatly in the extent to which they provided PBFs; this was confirmed by the formal survey in all the trusts described in the previous paragraph undertaken during the study (see *Proposed beneficial features*).

All participants were aged 14–18 years 11 months at recruitment and had not transferred to adults' services. Participants had no significant learning disabilities.

Procedures

Young people and their parent(s) were visited on four occasions, 1 year apart, by a locally based research assistant at home or at a clinic.

Information on date approached, date of birth, gender and postcode was collected. Postcodes were used in England to calculate the Index of Multiple Deprivation,⁶⁹ and in Northern Ireland to calculate the Multiple Deprivation Measure.⁷⁰ The Index of Multiple Deprivation and the Multiple Deprivation Measure are markers of community-level socioeconomic status; higher scores indicate more socioeconomic deprivation.

We defined 'date of transfer' as the date of the final appointment with a paediatrician or principal children's health specialist. This included when a young person saw a paediatrician and adult physician jointly to introduce a member of the adult team. If there was not a letter stating the transfer date, the date when the young person turned 18 years of age was recorded. At the study's end, the young person's status was recorded as still in children's services, transferred to adults' services, transferred to primary care, or left study.

To maximise the use of data, we carried out longitudinal analyses on the 'final' visit, defined as visit 4 unless there was a visit 3 that was not followed by a fourth visit, in which case visit 3 was used as the 'final' visit. At the 'final' visit, 274 young people (73.3%) had valid follow-up data for analysis (112 with diabetes mellitus, 74 with cerebral palsy and 88 with ASD).

Measures

We captured generic outcome measures about satisfaction with services, participation in life situations and well-being.

Parents and young people completed the Mind the Gap scale⁷¹ about their satisfaction with services. Satisfaction is conceptualised as the 'gap' between ratings of 'ideal' and 'current' care: the greater the 'gap' score, the lower the satisfaction. It yields an overall score and three subdomain scores.

Young people completed the Rotterdam Transition Profile,⁷² a nine-domain questionnaire on participation, defined as involvement in life situations.⁷³ For each domain, participants select the statement that best describes their current situation. Each statement represents one of three phases of transition: phase 1, childhood/dependence on parents; phase 2, experimenting and orienting to the future; and phase 3, adulthood/independence.

A three-item questionnaire captured the young person's independence in appointments, and had a score range of 3–15 (15 being the most independent).⁷⁴

At visits 3 and 4, young people completed a frequency of social participation questionnaire,⁷⁵ especially developed for adolescents; it has UK general population data available for comparison. Two 'factors' are captured: 'getting on with people' and 'community recreation'.⁷⁶

Young people completed the Warwick–Edinburgh Mental Wellbeing Scale (WEMWBS), a 14-item questionnaire developed in the UK and valid in the age range 13–21 years.⁷⁷ It has UK general population data available for comparison.

No further psychometric analyses were carried out on the Mind the Gap scale and the Rotterdam Transition Profile because they have been validated and used with young people with a variety of long-term conditions.^{71,72,78} However, for the WEMWBS, internal consistency was assessed using Cronbach's alpha with 95% confidence intervals to check that it was an appropriate measure to use in all three groups, particularly the group with ASD and an associated mental health problem.

In addition, the following condition-specific outcomes and process measures were captured.

- Type 1 diabetes mellitus. Participants were assigned to a 'satisfactory' or 'suboptimal' clinical course at visits 2, 3 and 4. Following consultation with specialists in adult and paediatric diabetes, participants were deemed to have a satisfactory clinical course if, for each year of the study, HbA_{1c} (glycated haemoglobin) level was < 7% above baseline, there were no hospital admissions for diabetic ketoacidosis, clinic attendance was > 75% and attendance for retinal screening was 100%.⁶⁵
- Cerebral palsy. An unmet-needs questionnaire was developed based on a model widely used in disability research.⁷⁹ The questionnaire was completed separately by the young person and the parent. Categorical principal components analysis identified two domains: daily activity health care and medical care.⁶⁴
- ASD and an associated mental health problem. Young people completed the self-report Hospital Anxiety and Depression Scale (HADS), which has subscales for anxiety and depression.⁸⁰ The psychometric properties of this scale have been shown to be valid for use with young people with ASD.⁸¹

Proposed beneficial features

A summary checklist about the PBFs was discussed by the research assistant with each young person at the first (baseline) visit. Then, at the second, third and fourth home visits, the checklist of PBFs experienced by the young person over each preceding 12 months was completed by the research assistants, in discussion with the young person (and with parents). This was supported by diary information recorded by the young person about their consultations. The research assistants also consulted health records to extract information about provision of PBFs; this included whether or not there was evidence that the clinic had a staff member with the role of transition manager for the clinical team (which was not directly asked to young people). Each PBF was recorded as received (or not) at least once during the year before the visit. For each PBF, we also established a trajectory of exposure, over the course of the study, deemed optimal or suboptimal according to whether or not:

- (a) In at least 1 of the 3 years there was exposure to the feature. This applied to the features 'age-banded clinic', 'meet the adult team before transfer', 'written transition plan, 'holistic life-skills training' and 'transition manager for clinical team'.
- (b) In at least 2 of the 3 years there was exposure to the feature. This applied to the features 'key worker' and 'co-ordinated team'.
- (c) In each of the 3 years there was exposure to the feature. This applied to the features 'promotion of health self-efficacy' and 'young person and/or parent satisfied with level of parent involvement'.
- (d) When visit(s) had been missed, and the trajectory could not be assessed, the trajectory was recorded as missing.

After the first year of the study, a questionnaire was sent to each of the 35 services attended by the young people recruited to ask whether or not their service aimed to provide each of the PBFs.

Analysis

Recruitment

Eight hundred and seventy-eight young people were approached and 374 were recruited to the study; 118 with ASD, 106 with cerebral palsy and 150 with diabetes mellitus. Further details and a flow diagram are in figure 1 of our published paper on baseline characteristics.⁶² Whereas recruitment rates were reasonably good for the ASD group (50.9% of those approached) and diabetes mellitus group (64.7%), the rate of recruitment of those with cerebral palsy was lower (25.6%). This may be due to the method of recruitment, which was to send letters of invitation rather than for their clinician to approach young people and their families directly.

As described in our baseline characteristics paper,⁶² participants with diabetes mellitus or cerebral palsy were comparable, in terms of condition severity, with larger population samples. However, for those with ASD this was more difficult to assess because we recruited individuals who also had an associated mental health problem.

The target of 150 in each group was achieved for young people with diabetes mellitus but not for those with ASD who were in contact with mental health services ($n = 118$) or for those with cerebral palsy ($n = 106$) (see *Appendix 5, Figure 12*). For each young person, a parent or carer was invited to participate; 369 agreed (367 parents, one grandparent and one foster parent). Thus, data from a parent or carer were available for 98.6% of the young people.

Participants did not differ significantly from non-participants by age or gender, as shown in table 1 of our published paper on baseline characteristics.⁶² Overall, participants had significantly ($p < 0.001$) lower scores on the Index of Multiple Deprivation (i.e. they were less deprived) than non-participants; however, the difference in overall Index of Multiple Deprivation score, on a continuous scale ranging from 0.5 to 87.8, was only 6.1.

Retention

Most of this analysis is reported in our published paper on the longitudinal analysis.⁶⁶ A total of 304 (81.3%) young people remained in the study by visit 2, with 259 (69.3%) by visit 3 and 243 (65%) by visit 4 (see *Appendix 5, Figure 13*). Forty young people became uncontactable (see *Appendix 6, Figure 13*). Among the 71 who told us that they wanted to leave the study, the main reason ($n = 22$) was 'no longer being interested'. Another 19 had other commitments that came with being older, such as sitting exams, university work, or part- or full-time jobs. Furthermore, some young people's mental health was too poor to allow visits. This highlights the natural challenges of undertaking longitudinal research during a life stage when so much change is happening.

A total of 274 (73%) young people had data for the 'final' visit (defined in *Methods* as visit 4 unless there was a visit 3 that was not followed by a fourth visit, in which case visit 3 was used). Of these 274 young people, 58% were male, and 112 had diabetes mellitus, 74 had cerebral palsy and 88 had ASD.

Text in the following paragraph is from our published paper.⁶⁶ This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made. The Creative Commons Public Domain Dedication waiver (<http://creativecommons.org/publicdomain/zero/1.0/>) applies to the data made available in this article, unless otherwise stated.

The mean time between the baseline and final visits was 2.9 years [standard deviation (SD) 0.4 years, range 1.8–3.9 years]. There were no significant differences between those remaining in the study and those not remaining with respect to sex ($p = 0.6$), age ($p = 0.6$), condition ($p = 0.6$), diabetes sites ($p = 0.4$) or ASD sites ($p = 0.6$) or condition severity (diabetes mellitus, $p = 0.7$; cerebral palsy, $p = 0.9$; ASD, $p = 0.7$).

However, in Northern Ireland, those with cerebral palsy who were lost to follow-up came from areas with, on average, greater socioeconomic deprivation ($p = 0.03$) than did those remaining in the study. On examining socioeconomic factors, based on actual circumstances rather than on area of residence, there was more loss to follow-up in families with single parents.

To where did young people transfer?

For the 274 young people with a 'final' visit, *Table 1* shows whether they remained in children's services or transferred to adults' services or primary care, by condition.

Of those with diabetes mellitus, almost all transferred to an adults' service, whereas the proportion of those with cerebral palsy who transferred to primary care was substantial, and this was even greater for those with ASD.

Baseline and subsequent changes in the outcome measures

A total of 304 (81.3%) of the young people took part in the second visit (diabetes mellitus, $n = 128$; cerebral palsy, $n = 85$; ASD, $n = 91$); 259 took part in the third visit and 243 took part in the fourth visit.

Satisfaction with services

Satisfaction with services was generally good, as the 'gap' scores (the difference between the respondent's ideal and current care) were small. Parents' satisfaction was significantly lower than their children's. Over the four visits, satisfaction with services did not change for those with diabetes mellitus, but for those with cerebral palsy or ASD it steadily worsened (*Figure 2*).

TABLE 1 Service attended by young people at 'final' visit

Status	Total, <i>N</i> (%) ^a	Condition, <i>n</i> (%)		
		Diabetes mellitus ^a	Cerebral palsy	ASD
Remained in children's service	49 (18)	19 (17)	10 (14)	20 (23)
Transferred to adults' service	148 (54)	89 (80)	35 (47)	24 (27)
Transferred to primary care	76 (28)	3 (3)	29 (39)	44 (50)

^a One young person had missing information.

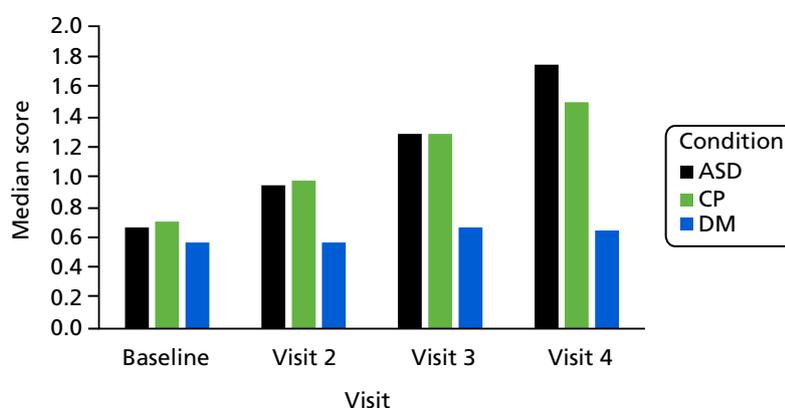


FIGURE 2 Mind the Gap median score, young person reported: change over time by condition. CP, cerebral palsy; DM, diabetes mellitus.

Well-being

The median baseline well-being scores of those with diabetes mellitus or cerebral palsy were similar to each other and to those in the general population, and significantly higher ($p < 0.001$) than the scores of those with ASD. In the general population of 13- to 16-year-olds, the median score on the WEMWBS was 48.8.⁷⁷ In those aged > 16 years in the general population in England, the median was 50.7.⁸²

Over the four visits, the well-being scores of those with diabetes mellitus, cerebral palsy or ASD were steady. Those with ASD continued to have significantly lower well-being scores ($p < 0.001$) (Figure 3).

Rotterdam Transition Profile

On every domain of the Rotterdam Transition Profile, except 'education and employment', significant differences were found between the three conditions (most p -values were < 0.01). A larger proportion of young people with diabetes mellitus were in a more independent phase of participation than those with ASD or cerebral palsy. Over the four visits, young people steadily moved to a more independent phase of transition on every domain. Those with diabetes mellitus remained further ahead than those with ASD or cerebral palsy (Figure 4). As the phase for the domain 'using specialist services for condition' was determined entirely by the structure of the services and could not be influenced by the young person, we dropped it from this and further analysis.

Social participation

The mean score for the 'getting on with people' domain was significantly lower ($p < 0.001$) for participants than in the general population, whereas the score for the 'community recreation' domain was similar (Table 2). Those with diabetes mellitus had higher mean scores than those with ASD or cerebral palsy for 'getting on with people', and higher scores than those with ASD for 'community recreation'. Scores for 'getting on with people' improved by visit 4 for all three conditions but remained lower than in the general population.

Independence in Appointments

The Independence in Appointments questionnaire was added from visit 2 onwards. At visit 2, the average score was 8. Those with diabetes mellitus had higher scores than those with ASD or cerebral palsy, and these differences persisted even though all scores increased, indicating more independence (Figure 5).

Time from final paediatric appointment to first appointment in adults' service

We could examine this only for young people with diabetes mellitus. For those with cerebral palsy, it was usually unclear with which professional the first appointment should be. For example, sometimes a young person had transferred to an adult physiotherapist but was still seeing a paediatrician.

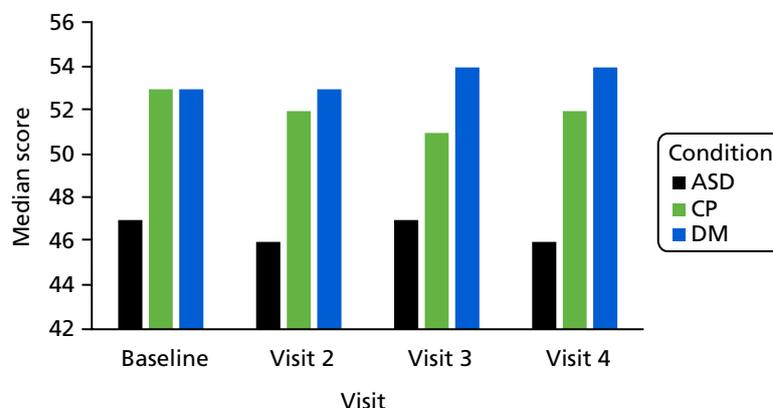


FIGURE 3 The WEMWBS: change over time by condition group. CP, cerebral palsy; DM, diabetes mellitus.

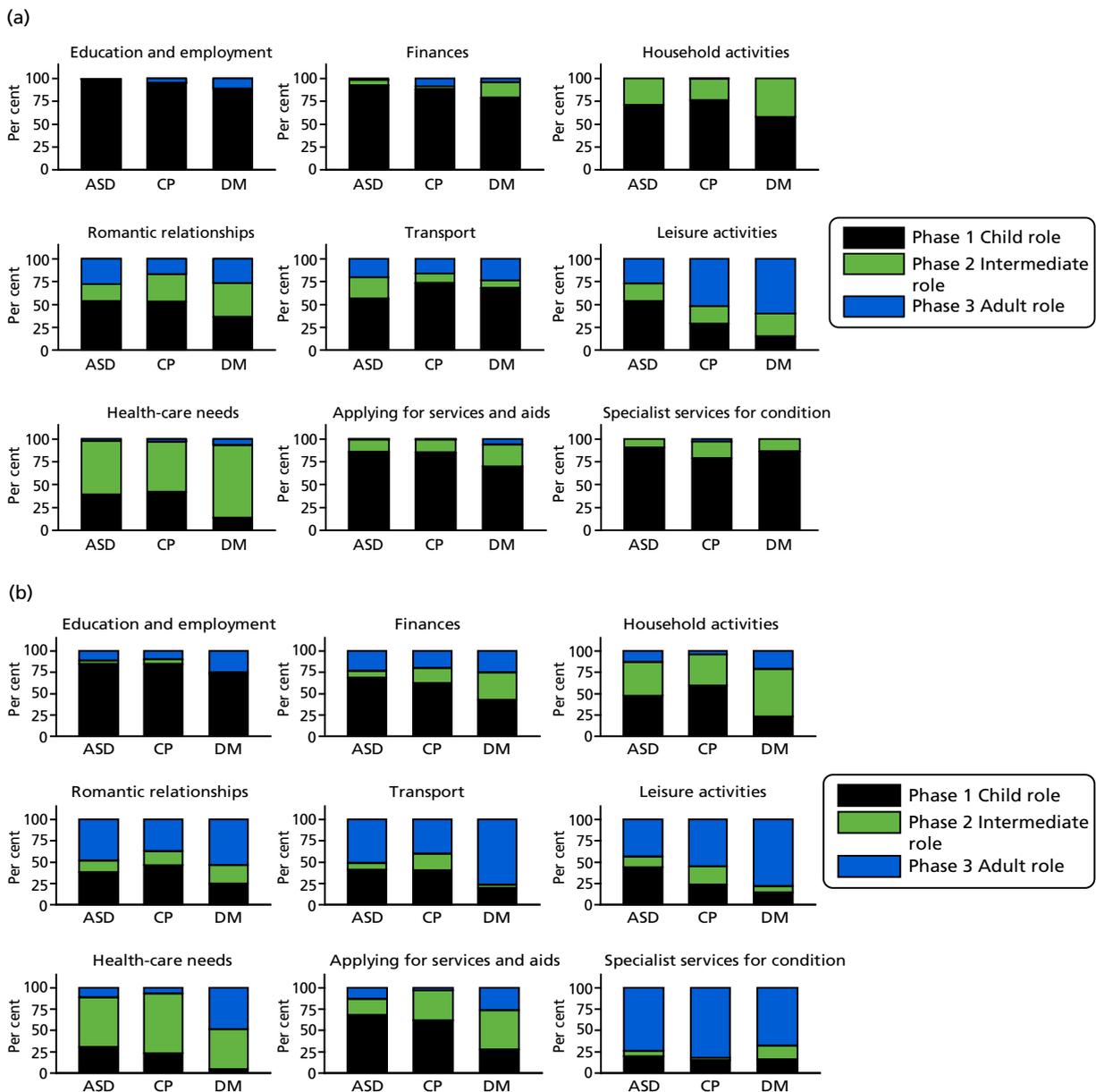


FIGURE 4 Rotterdam Transition Profile. Percentages of participants per phase at (a) baseline and (b) visit 4, by condition. CP, cerebral palsy; DM, diabetes mellitus.

TABLE 2 Social participation scores at visit 3, by domain, in general population and study population

Domain	General population		Study population	
	Number	Mean (SD)	Number	Mean (SD)
Getting on with people	478	0.004 (1.37)	253	-1.09 (1.79)
Community recreation	479	0.27 (0.15)	253	0.26 (0.17)

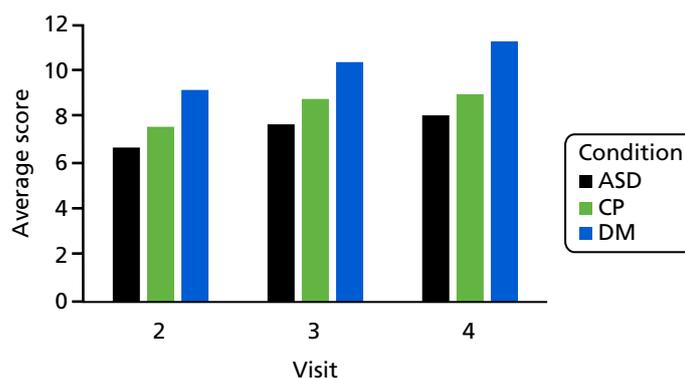


FIGURE 5 Independence in Appointments scale: change over time, by condition. CP, cerebral palsy; DM, diabetes mellitus.

For those with diabetes mellitus who had transferred, the mean time to adult appointment was 5.2 months (SD 4.9 months). The median time was 3.7 months [interquartile range (IQR) 3–6 months]. The proportion seen by adults' services within 6 months of final paediatric appointment was 75%.

Diabetes mellitus condition-specific measure of clinical course

The proportion of young people with diabetes mellitus with satisfactory clinical course reduced over the study period (clinical course was determined from a composite score from HbA_{1c} value, eye screening, clinic attendance and no diabetic ketoacidosis):⁶⁵

- by visit 2, 65 out of 128 (51%) had a satisfactory clinical course
- by visit 3, 49 out of 112 (43%) had a satisfactory clinical course
- by visit 4, 32 out of 108 (29%) had a satisfactory clinical course.

These results, and further reporting in our published paper⁶⁵ (in which we report only on the 108 who had full data to visit 4), indicate that the well-being of young people with diabetes mellitus and their satisfaction with transition services were not closely related to the condition's clinical course.

Cerebral palsy condition-specific measure of unmet need

As reported by parents, the proportion of young people with cerebral palsy with some unmet needs increased during the follow-up on the 'daily living health care' and 'medical care' domains.⁶⁴ As reported by the young person, an increase in unmet needs was seen only in the 'daily living health care' domain (Figure 6). When considering only those with some unmet needs, mean scores decreased slightly for the 'daily living health care' domain and remained the same for the 'medical care' domain, as reported by both young people and parents. These results were for the 64 young people who provided data at every visit. The results were similar when we examined data from each visit, whether or not data were available from other visits.

These results draw attention to the need for more co-ordinated care in adults' services for those with cerebral palsy. We discuss this further in our published paper⁶⁴ and compare UK practice with that of other countries.

Autism spectrum disorder condition-specific measure of anxiety and depression

The proportion of young people with ASD and an associated mental health problem with an 'abnormal' score on the 'anxiety' and 'depression' domains (as measured by the HADS) remained similar between baseline and visit 4 ('abnormal' means above the recommended threshold score for a likely disorder) (Figure 7). The results were similar if analysed for the participants with data at baseline or visit 4, or if analysed for only those participants with data at baseline and visit 4.

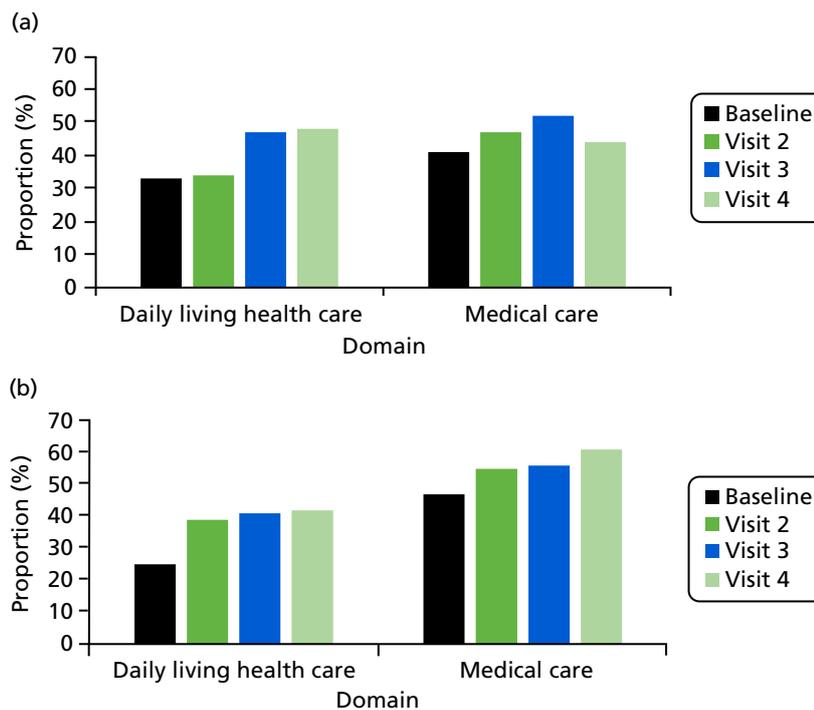


FIGURE 6 Needs reported by (a) young person; and (b) parent.

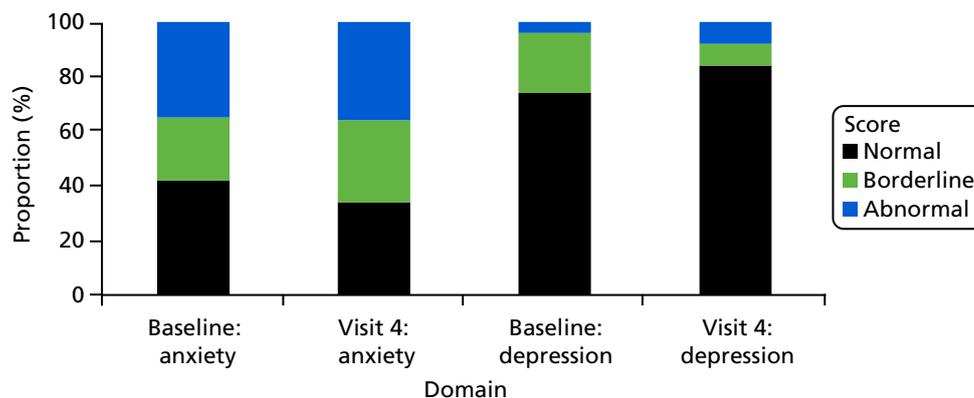


FIGURE 7 Proportions of normal, borderline and abnormal scores from the HADS at baseline and visit 4.

Further analysis of those with ASD is provided in *Appendix 5*. Having an additional diagnosis of attention deficit hyperactivity disorder or taking medication were predictors of a transfer to adult mental health services. Overall, the young people in our sample appeared to be doing reasonably well, with 67.5% in full-time education (either school or college) at the end of the study. Under one-third were in neither education nor employment. Analysis of HADS trajectories found that some young people were doing well, managing their mental health and able to engage successfully with services. However, the majority were experiencing episodes or continued levels of high anxiety. Qualitative data revealed that many young people struggled when faced with more challenging academic and social environments.

Proposed beneficial features

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appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made. The Creative Commons Public Domain Dedication waiver (<http://creativecommons.org/publicdomain/zero/1.0/>) applies to the data made available in this article, unless otherwise stated.

The proposed beneficial features that services reported that they provided over the first year (i.e. before visit 2)

The following paragraph is covered in more detail in our published paper.⁶³ Overall, the nine PBFs of services for transitional health care were often not offered to young people in our study by NHS services. Fewer than half of the 35 services stated that they provided an ‘age-banded clinic’, ‘written transition plan’, ‘transition manager for clinical team’, ‘protocol for promotion of health self-efficacy’ or ‘holistic life-skills training’. Features were offered by services most often for young people with diabetes mellitus and least often for those with cerebral palsy (Figure 8).

The proposed beneficial features that young people reported that they experienced over the first year (i.e. before visit 2)

The content of the following paragraph is covered in more detail in our published paper,⁶³ which integrates the findings from this WP and the qualitative work of WP 2.2. At visit 2, young people often reported that they had not experienced the features that services said they provided. Agreement between the young person’s report and what the service said it offered was 30% for ‘written transition plan’, 43% for ‘holistic life-skills training’ and 49% for ‘key worker’. Agreement was better for ‘appropriate parent involvement’, at 77%; for ‘age-banded clinic’, at 77%; for ‘promotion of health self-efficacy’, at 80%; and for ‘co-ordinated team’, at 69%.

Associations of proposed beneficial features with outcomes

Two approaches were adopted to assessing the associations of PBFs with outcomes. In both, we used the young person’s account of whether or not they had experienced a PBF, rather than what the service reported that it provided or aspired to provide.

In the first approach, it was established at each research visit whether or not the young person had experienced each PBF at least once in the previous year, and this was recorded as yes or no. A separate analysis was then conducted for each PBF (as the independent variable) against the outcomes. This was undertaken for each annual period. Thus, this approach is a series of analyses that examine associations over 1 year, directly related to what the young person is experiencing at the time.

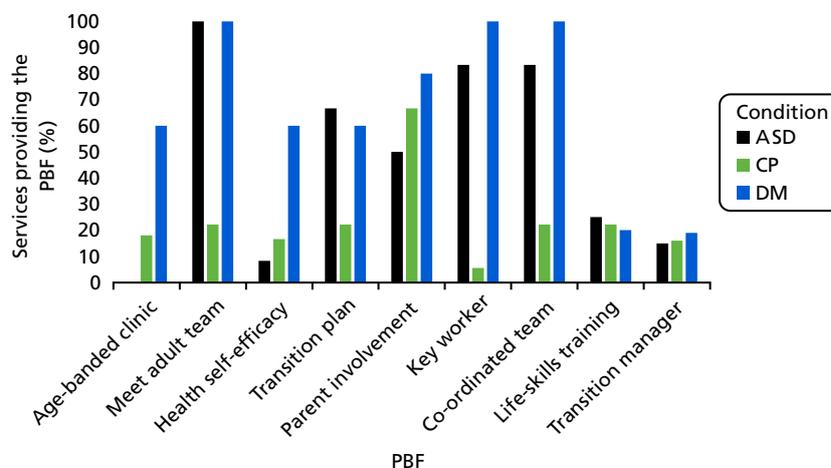


FIGURE 8 Percentage of ‘yes’ responses from each service by condition, stating whether or not the PBF was offered. CP, cerebral palsy; DM, diabetes mellitus.

In the second approach, a consolidated indicator was compiled for each PBF for the duration of the study. The criteria for being optimal or suboptimal varied by PBF and was calculated as outlined in *Methods*. The proportions of young people experiencing optimal or suboptimal consolidated indicators are shown in *Table 3*. In the analyses, the independent variable was whether the consolidated indicator was optimal or suboptimal for each PBF; the dependent variables were the outcomes captured at the 'final' visit.

TABLE 3 Consolidated indicator of PBFs at final visit, by condition group

PBF	Consolidated indicator	All, n (%)	Diabetes, n (%)	Cerebral palsy, n (%)	ASD, n (%)	p-value
Age-banded clinic	Optimal	145 (53)	109 (97)	16 (22)	20 (23)	< 0.001
	Suboptimal	111 (40)	2 (2)	54 (73)	55 (62)	
	Missing	18 (7)	1 (1)	4 (5)	13 (15)	
Meet adult team before transfer	Optimal	111 (40)	73 (65)	16 (22)	22 (25)	< 0.001
	Suboptimal	133 (49)	31 (28)	54 (73)	48 (55)	
	Missing	30 (11)	8 (7)	4 (5)	18 (20)	
Promotion of health self-efficacy	Optimal	116 (42)	76 (68)	18 (24)	22 (25)	< 0.001
	Suboptimal	151 (55)	29 (26)	56 (76)	66 (75)	
	Missing	7 (3)	7 (6)			
Written transition plan	Optimal	48 (17)	32 (29)	11 (15)	5 (6)	< 0.001
	Suboptimal	185 (68)	62 (55)	59 (80)	64 (73)	
	Missing	41 (15)	18 (16)	4 (5)	19 (21)	
	N/A	2 (1)		1 (1)	1 (1)	
Both young person and parent happy with parent involvement	Optimal	93 (34)	36 (32)	28 (38)	29 (33)	0.444
	Suboptimal	141 (51)	55 (49)	33 (45)	53 (60)	
	Missing	38 (14)	21 (19)	12 (16)	5 (6)	
	N/A	2 (1)		1 (1)	1 (1)	
Key worker	Optimal	79 (29)	56 (50)	3 (4)	20 (23)	< 0.001
	Suboptimal	170 (62)	47 (42)	68 (92)	55 (62)	
	Missing	25 (9)	9 (8)	3 (4)	13 (15)	
Co-ordinated team	Optimal	167 (61)	104 (93)	25 (34)	38 (43)	< 0.001
	Suboptimal	66 (24)	2 (2)	40 (54)	24 (27)	
	Missing	25 (9)	6 (5)	4 (5)	15 (17)	
	N/A	16 (6)		5 (7)	11 (13)	
Holistic life-skills training	Optimal	132 (48)	74 (66)	18 (24)	40 (45)	< 0.001
	Suboptimal	117 (43)	28 (25)	52 (70)	37 (42)	
	Missing	25 (9)	10 (9)	4 (6)	11 (13)	
Transition manager for clinical team	Optimal	60 (22)	27 (24)	14 (19)	19 (21)	0.947
	Suboptimal	143 (52)	67 (60)	34 (46)	42 (48)	
	Missing	71 (26)	18 (16)	26 (35)	27 (31)	
Total (n)		274	112	74	88	

N/A, not applicable.

All models were adjusted for age, sex, condition and potential for clustering by site. Significant associations ($p < 0.05$) from these models were further adjusted for transfer status, time since transfer to final visit (if applicable) and time to first adult appointment (if applicable).

Examining the Rotterdam Transition Profile, we performed the logistic regression by comparing phases 1 and 2 with phase 3.

Table 4 sets out the effect sizes for all associations that reached significance of $p \leq 0.05$.

Interpretation of the associations of proposed beneficial features with outcomes

This is presented in more detail in our published paper.⁶⁶ This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made. The Creative Commons Public Domain Dedication waiver (<http://creativecommons.org/publicdomain/zero/1.0/>) applies to the data made available in this article, unless otherwise stated.

Three PBFs of transitional health care had significant ($p \leq 0.01$) positive associations with better outcomes, namely 'appropriate parent involvement', 'promotion of health self-efficacy' and 'meeting the adult team before transfer'. The b-coefficients indicated changes of approximately 0.5 SDs with respect to the satisfaction with services scale (SD 1.5 in our population), well-being (SD 7.0 in our population) and autonomy in appointments (SD 3.0 in our population). The odds ratios indicated increased likelihoods of being in a more independent phase of transition.

The other six PBFs had few statistically significant positive associations ($p \leq 0.01$) with better outcomes in the year-by-year analysis, had a number of negative associations and had no positive associations with the consolidated indicator of exposure to PBFs.

'Appropriate parent involvement' and 'promotion of health self-efficacy' were reported to have been experienced satisfactorily by fewer than half of participants across transition across the three conditions. However, they were experienced by more young people with diabetes mellitus than those with cerebral palsy or ASD. For 'meeting the adult team before transfer', around two-thirds of young people with diabetes mellitus reported that they had met a member of the adult team, but fewer than one-quarter of those with cerebral palsy or ASD had done so. Thus, we found a different quality of experience of transitional health care between young people with a long-term illness (diabetes mellitus) and those with a long-term disability.

Strengths and limitations

Looking first at the strengths, our study drew 374 young people from across the UK and from many NHS Trusts. This is the largest sample for research in the UK in terms of examining transition longitudinally and collecting hypothesis-driven data from young people at home visits (compared with data-linkage studies from administrative data sets). Although we cannot be certain of representativeness and, therefore, generalisability across UK regions and NHS Trusts, we studied individuals from Greater London; north, south-east and south-west England; and Northern Ireland. Furthermore, we drew individuals from 27 NHS Trusts, and the trusts varied greatly in the number and variety of the PBFs they offered (see Figure 8).

We recruited from all young people with cerebral palsy in two population registers and all young people with diabetes mellitus or ASD and an associated mental health problem in nine NHS Trusts widely distributed across England (all such young people are seen in secondary care). Thus, complete populations of individuals with one of the three conditions were sampled from (e.g. rather than those attending particular schools, specialised tertiary health-care services or voluntary support groups).

TABLE 4 Associations of PBFs with outcome measures

PBF	PBFs by 'year-by-year' visits					Consolidated PBF indicator at final visit			
	Period	Outcome	Whether regression b-coefficient or odds ratio	95% confidence interval	p-value	Outcome	Whether regression b-coefficient or odds ratio	95% confidence interval	p-value
Appropriate parent involvement	1	MTG: total	-0.48	-0.76 to -0.19	0.001	MTG: total	-0.67	-0.97 to -0.37	< 0.001
	1	MTG: environment	-0.57	-0.92 to -0.21	0.001	MTG: environment	-0.71	-1.17 to -0.26	0.006
	1	MTG: provider	-0.52	-0.82 to -0.22	0.001	MTG: provider	-0.75	-0.99 to -0.52	< 0.001
	1	RTP: domestic	[0.14 ^a]	0.03 to 0.67	0.01	RTP: finances	[0.6 ^a]	0.92 to 0.39	0.02
	1	RTP: health care	[0.35 ^a]	0.17 to 0.72	0.004	WEMWBS	2.18	0.21 to 4.15	0.03
	1	RTP: services and aids	[0.42 ^a]	0.18 to 0.97	0.04				
	2	MTG: total	-0.60	-1.00 to -0.21	0.003				
	2	MTG: environment	-0.65	-1.08 to -0.21	0.004				
	2	MTG: provider	-0.48	-0.90 to -0.06	0.03				
	2	MTG: process	-0.82	-1.32 to -0.31	0.002				
	3	WEMWBS	4.47	1.96 to 6.97	0.001				
	3	MTG: total	-0.87	0.45 to 1.29	0.001				
	3	MTG: environment	-0.91	-1.44 to -0.37	< 0.001				
	3	MTG: provider	-0.95	-1.37 to -0.52	< 0.001				
	3	MTG: process	-0.63	-1.18 to -0.07	0.03				
3	WEMWBS	3.45	0.92 to 5.99	0.008					

continued

TABLE 4 Associations of PBFs with outcome measures (continued)

PBF	PBFs by 'year-by-year' visits					Consolidated PBF indicator at final visit				
	Period	Outcome	Whether regression b-coefficient or odds ratio	95% confidence interval	p-value	Outcome	Whether regression b-coefficient or odds ratio	95% confidence interval	p-value	
Promotion of health self-efficacy	1	MTG: total	-0.51	-0.87 to -0.15	0.006	MTG: total	-0.32	-0.62 to -0.03	0.04	
	1	MTG: environment	-0.63	-1.06 to -0.18	0.005	MTG: environment	-0.57	-1.03 to -0.11	0.02	
	1	MTG: provider	-0.47	-0.85 to -0.09	0.02	MTG: process	-0.37	-0.70 to -0.04	0.03	
	1	MTG: process	-0.46	-0.91 to -0.01	0.04					
	1	RTP: finances	[0.26 ^a]	0.07 to 0.93	0.04					
	1	RTP: domestic	[0.04 ^a]	0.01 to 0.21	0.001					
	2	MTG: total	-0.51	-0.91 to -0.11	0.01					
	2	MTG: provider	-0.49	-0.90 to -0.08	0.02					
	2	MTG: process	-0.70	-1.21 to -0.19	0.007					
	2	MTG: total	-0.60	-1.01 to -0.20	0.004					
	3	MTG: environment	-0.90	-1.40 to -0.40	< 0.001					
	3	MTG: provider	-0.52	-0.95 to -0.11	0.01					
	Meet adult team before transfer	1	RTP: domestic	6.29 ^a	1.60 to 24.80	0.009	RTP: education/employment	2.33 ^a	1.21 to 4.55	0.01
		1	RTP: health care	2.71 ^a	1.24 to 5.90	0.01	RTP: finances	2.78 ^a	1.10 to 7.14	0.03
1		RTP: services and aids	5.15 ^a	2.08 to 12.78	< 0.001	RTP: services and aids	2.50 ^a	1.06 to 5.88	0.04	
1		RTP: transport	2.01 ^a	1.06 to 3.79	0.03	Autonomy in appointments	1.60	0.32 to 2.87	0.02	
1		RTP: education/employment	3.24 ^a	1.09 to 9.65	0.04					

TABLE 4 Associations of PBFs with outcome measures (*continued*)

PBF	PBFs by 'year-by-year' visits					Consolidated PBF indicator at final visit			
	Period	Outcome	Whether regression b-coefficient or odds ratio	95% confidence interval	p-value	Outcome	Whether regression b-coefficient or odds ratio	95% confidence interval	p-value
Meet adult team before transfer (<i>continued</i>)	1	Autonomy in appointments	1.69	0.80 to 2.58	< 0.001				
	2	RTP: finances	2.64 ^a	0.92 to 6.62	0.02				
	2	RTP: transport	2.08 ^a	1.11 to 3.90	0.02				
	2	Autonomy in appointments	1.00	0.01 to 2.0	0.05				
	3	RTP: health care	2.11 ^a	1.03 to 4.34	0.004				
	3	Autonomy in appointments	1.46	0.34 to 2.59	0.01				
Key worker	1	RTP: leisure	[0.56 ^a]	0.32 to 0.96	0.04				
	2	MTG: provider	-0.66	-1.04 to -0.28	0.001				
	2	MTG: process	-0.69	-1.17 to -0.21	0.005				
	3	RTP: education/employment	[0.40 ^a]	0.20 to 0.95	0.02				
Holistic life-skills training	1	RTP: domestic	[0.19 ^a]	0.04 to 0.93	0.04				
	1	RTP: services and aids	[0.34 ^a]	0.12 to 0.94	0.04				
	2	MTG: provider	[0.43]	0.03 to 0.84	0.04				
	3	MTG: total	-0.46	-0.87 to -0.05	0.03				
	3	MTG: provider	-0.57	-0.99 to -0.14	0.009				
	3	RTP: domestic	2.47 ^a	1.10 to 5.58	0.003				
	3	RTP: romantic relationships	[0.52 ^a]	0.26 to 0.98	0.04				

continued

TABLE 4 Associations of PBFs with outcome measures (*continued*)

PBF	PBFs by 'year-by-year' visits					Consolidated PBF indicator at final visit			
	Period	Outcome	Whether regression b-coefficient or odds ratio	95% confidence interval	p-value	Outcome	Whether regression b-coefficient or odds ratio	95% confidence interval	p-value
Written transition plan	1	RTP: romantic relationships	[0.43 ^a]	0.19 to 0.96	0.04				
	2	MTG: total	-0.72	-1.39 to -0.04	0.04				
	2	MTG: process	-1.19	-1.39 to -0.04	0.007				
Co-ordinated team	1	RTP: domestic	[0.19 ^a]	0.04 to 0.93	0.04	MTG: provider	-0.67	-1.25 to -0.09	0.03
	3	RTP: health care	[0.17 ^a]	0.04 to 0.82	0.03	RTP: education/employment	[0.31 ^a]	0.11 to 0.82	0.02
	3	RTP: services and aids	[0.22 ^a]	0.06 to 0.81	0.02	RTP: domestic	[0.41 ^a]	0.19 to 0.91	0.03
Transition manager for clinical team		No associations				RTP: domestic	2.63 ^a	1.16 to 5.88	0.02
						RTP: services and aids	[0.41 ^a]	0.20 to 0.86	0.02
						RTP: romantic relationships	[0.52 ^a]	0.31 to 0.89	0.02
Age-banded clinic	1	WEMWBS	3.08	0.18 to 5.98	0.04				
	1	Autonomy in appointments	1.44	0.48 to 2.4	0.003				
	2	RTP: education/employment	5.22 ^a	1.21 to 22.53	0.03				

MTG, Mind the Gap; RTP, Rotterdam Transition Profile.

^a Odds ratio.

Notes

Coefficients and odds ratios 'year-by-year' and for the consolidated PBF indicator have suboptimal PBF delivery as the reference group.

A higher Mind the Gap score means less satisfaction with services than a lower score.

Numbers in square brackets indicate a negative association, i.e. satisfactory PBF was associated with worse outcome.

Bold indicates $p \leq 0.01$.

The three conditions chosen were exemplars of chronic illness (diabetes mellitus), complex physical impairment (cerebral palsy) and neurodevelopmental impairment (ASD); they were deliberately chosen because they varied in terms of health needs, psychosocial complexity and availability of adults' services. Thus, we consider that generalisability to other conditions is likely.

The 374 participants did not differ significantly from those declining to take part, other than for a small effect of deprivation. The distribution of severity of the three conditions was similar to that in national samples.⁶² Those with the conditions had a wide range of severity; for example, the young people with cerebral palsy ranged from wheelchair users to those with independent ambulation. Attrition did not appear to create bias, as there were no significant differences between those remaining and those not remaining in the study with respect to sex, age, condition, diabetes site or ASD site. In Northern Ireland, there was a small effect of deprivation on the attrition of those with cerebral palsy. Thus, we think that, after non-participation and attrition, our study group continued to be representative of those we aimed to recruit.

Turning to the limitations, our study did not include young people with a learning disability because in the UK there is already a lifespan service for such individuals, and we would not have been able to base our quantitative studies on self-completed questionnaires, nor our qualitative work on interviews with young people. However, the exclusion of such individuals means that our results cannot be generalised to them.

Recruitment, especially of those with cerebral palsy, was more difficult than we expected. A possible explanation may be the method of recruitment, which was letters of invitation, rather than the young people's clinician approaching them directly, as was undertaken for those with diabetes mellitus or ASD. Overall retention at 70% was acceptable in comparison with other longitudinal studies of adolescent populations.³²

It might be desirable to follow up young people for longer in adults' services to assess later outcomes of transitional health care, but this is unlikely to be feasible. The fact that some young people were still in children's services does not invalidate analyses; our study was about transition, not specifically health-care transfer. *Table 1* shows the number still in children's services.

Because of their personal circumstances, there was variability in precisely when the young people were seen by researchers. This is one reason why we chose the 'final visit' to be visit 4 or visit 3 (if the young person did not have a visit 4). Some of the visit 3s were considerably delayed and too close to a fourth visit to justify further data collection during the study. We examined the association of exposure to a PBF over the previous year in relation to outcomes. However, what constitutes optimal exposure over 3 years when, for instance, exposure occurs in one year but not the others? We made a clinical judgement about this for each feature for the consolidated longitudinal analysis. The decisions were agreed among our group, but others might have made different judgements.

Some PBFs, such as 'written transition plan', were infrequently provided and therefore we had less statistical power to detect associations with outcomes.

Key findings

- There were striking mismatches between the PBFs of transitional health care that a service said it provided and the features that young people reported to have experienced.
- PBFs were both provided and experienced less often in services for those with cerebral palsy and ASD than for those with type 1 diabetes mellitus.
- Average satisfaction with services was reasonable at baseline (rating of ideal service only slightly higher than rating of actual service). It remained steady for those with type 1 diabetes mellitus but worsened significantly over the study period for those with ASD or cerebral palsy.

- The well-being scores for each group remained similar over time. Those with type 1 diabetes mellitus or cerebral palsy had an average subjective well-being at baseline similar to that of the general population. Those with ASD and an associated mental health problem reported significantly lower well-being than those in the other two groups, and this difference persisted over the course of the study.
- For participation in life activities, there were significant differences between the three conditions, with young people with type 1 diabetes mellitus in more independent phases of transition than those with ASD or cerebral palsy. All made progress over time, but those with type 1 diabetes mellitus remained more independent.
- Condition-specific outcomes worsened during the study for those with type 1 diabetes mellitus or cerebral palsy. The proportion of young people with ASD with so-called 'abnormal' anxiety and depression scores remained the same from baseline to visit 4, with over one-third having abnormal levels of anxiety.
- The features of services for transitional health care associated with better outcomes were 'appropriate parent involvement', 'promotion of health self-efficacy' and 'meeting the adult team before transfer'.

Inter-relationship with other parts of the programme

We were guided by advice from UP (WPs 1.1 and 1.2) in determining the wording of some questionnaires, which PBFs to include, how to approach young people and how to interpret the differences between what PBFs services said they provided and what young people experienced.

A subsample of the cohort in this WP were recruited to the qualitative longitudinal sample for WP 2.2.

Work package 2.3 constructed the DCE that was administered at visit 3.

This WP addressed the main hypothesis of the programme. In drawing conclusions about the clinical significance and validity of the findings (see *Conclusions*), we were further influenced by discussions with UP (WPs 1.1 and 1.2); we triangulated the findings with the results of the qualitative work in WP 2.2 and the health economic analysis in WP 2.3.

The findings of this WP informed the content of the DAH toolkit in WP 3.1b.

The findings of this WP contributed directly to implication 6 of the programme.

Work package 2.2: longitudinal study (qualitative)

Addressing objective 2: to identify the features of transitional health care that are effective and efficient

Recent reviews have explored different aspects of transitional health care, focusing on the experiences of young people^{44,51} and parents.⁸³ This work shows how transitional health care disrupts the lives of young people and their families. That by Lugasi *et al.*⁵¹ shows how young people describe children's services as 'a familiar and comfortable environment, and reported feelings of trust toward their health care providers'. A young person's feeling of certainty in children's services and uncertainty about what to expect in adults' services was confounded by direct or second-hand experiences of suboptimal care from adults' services.^{44,51} Transfer can be experienced as an 'abrupt event' by young people as a result of lack of knowledge and information about what to expect.^{44,51} Reviews of models and strategies of the delivery of transitional health care^{53,84} have offered ideas about how specific practices might minimise this disruption.

Aim

The aim was to investigate how young people with long-term conditions experience services for transitional health care.

Methods

More information about methods is in *Appendix 6*, which includes the interview guide.

A longitudinal multimethod qualitative study was conducted with young people recruited from the longitudinal quantitative study (WP 2.1). Young people were initially approached by a member of the WP 2.1 study team and, if they wanted more information, they were contacted by telephone or e-mail by WP 2.2 researchers previously unknown to them.

Data collection took place between June 2013 and June 2016. Recruitment was driven by criterion sampling (i.e. diagnosis, age, service) and theoretical sampling (i.e. experience of service, comorbidities, social network).⁸⁵ Young people were aged between 14 and 18 years at the first interview. Each young person identified a 'significant other' person in their life and a health professional significant to their health care whom they wanted to include in this qualitative study, and to nominate one consultation that the researcher could observe. Thirteen young people took part in this study. Family members who took part were 10 mothers, three fathers or stepfathers and one brother. Nineteen health professionals were also identified: seven paediatric consultants, five paediatric nurses/allied health professionals, three adult consultants and four adult nurses/allied health professionals. We interviewed 13 of these: nine from children's services and four from adults' services.

Thirteen young people received a first interview, of whom four were interviewed again at least 18 months later. They were interviewed on their own or with a relative, if they wished, at their home or at a clinic. Fourteen family members received a first interview, of whom eight were interviewed again at least 18 months later. In total, we undertook 40 first interviews (*Table 5*). In 30 of these, the young person was pre transfer to adults' services and in 12 they were post transfer.

Observations were recorded in contemporaneous field notes. Formal interviews (face to face or by telephone) lasting between 30 and 120 minutes were audio-recorded, transcribed and edited to ensure respondents' anonymity and then analysed alongside anonymised field notes. All analysis was conducted

TABLE 5 Participants recruited by condition, identity and method of data collection

Participants	Diabetes mellitus	Cerebral palsy	ASD	Total
Took part in first interview				
Young person	4	5	4	13
Family member	4	6	4	14
Health professional	4	4	5	13
Total	12	15	13	40
Participants observed in consultations				
Young person	3	2	2	7
Family member	3	3	2	8
Health professional	6	3	2	11
Total	12	8	6	26

according to the standard procedures of qualitative analysis.⁸⁶ We used procedures from first-generation grounded theory (coding, constant comparison, memoing⁸⁷), and from analytic induction (deviant case analysis⁸⁸). Data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored in subsequent ones, including in follow-up interviews. We undertook independent coding and cross-checking, team data sessions and data triangulation (different times and persons) and between-method triangulation (interview, observation).

Analysis

The full report is in *Appendix 6*. The report focuses on the observational data and interviews, with accompanying commentary and quotations in relation to the nine PBFs. The work is summarised below under three headings:

1. disrupting relationships of trust
2. supporting successful transfer
3. enabling in(ter)dependence.

Disrupting relationships of trust

As one parent outlined, the actual process of transfer from children's to adults' services 'takes 5 minutes'. However, crossing this organisational boundary was reported to take practical, cognitive and emotional work, often over a long time.

The family, especially the mother, had usually developed good understanding of how to support the management of the young person's health condition, and how to navigate the children's health service. The children's health professionals often had significant knowledge of the young person and their wider psychosocial context. In most cases, young people had a long relationship with a particular service, and so they had built up trust over time with health professionals they saw regularly.

The organisational process of transfer ended those relationships of trust with known children's health professionals and so called into question the expectations, knowledge and practices of the young people and their families. Transfer is a disruption or, following Garfinkel,⁸⁹ a breach in taken-for-granted experiences, knowledge and expectations. It involves young people and parents having to adapt to a new set of circumstances.

Supporting successful transfer

All professionals were aware of the implications of 'unsuccessful' transition and how people could 'drop off the system' or 'disengage'. All children's health-care professionals had implemented formal or informal plans for transfer that sought to prepare the young person and their family (*Table 6*, which relates to evidence of implementation of PBFs). Children's health-care professionals stated that they sought to introduce the idea of transition and transfer within consultations over time. Plans about transition were, generally, 'something we talked about, there wasn't really anything written down' and, ideally, 'tailored to the young person's needs'. Such plans might also be 'weaved into clinic letters'.

TABLE 6 Factors that promote or inhibit implementation of the PBFs

PBF	Evidence of implementation	Determinants of implementation ^a
Age-banded clinic	Limited: seen only in diabetes services	Often not feasible because of the logistics of managing appointments, space restrictions or small numbers of young people. In practice, situated alongside other adult clinics, with parents and professionals alarmed by visibility of ill adults. Young people report 'not being fussed'
Meet adult team before transfer	Variable: some services offer a single joint meeting or shared appointments	Dependent on relations with adult team(s). In services that provide it, meetings do not always happen. Problematic when low frequency of meetings, young person has moved away (e.g. to university), adult practitioner is not the person who will provide care, or general practitioner is not known to young person (i.e. transfer to primary care)
Promotion of health self-efficacy	Variable: some services provided but in an informal, ad hoc way	Can occur in context of long-term, trust-based relationships with a specific health professional. Minimal health promotion if lack of continuity of personnel or low frequency of visits, or when not part of service culture
Written transition plan	Very limited: one service offered formal plan	One service had implemented, but withdrew because of lack of resources and motivation. Some professionals resisted written plans, saying that these get forgotten or lost, and that personal interaction is far more important. However, informal practices can lead to lack of awareness, knowledge and understanding of transfer process
Parents engaged appropriately	Extensive: all services report engaging parents	Service norm for some practitioners. Some see interdependence as demonstrating problematic attachment, and so seek to minimise parental involvement, often referring to legal issues around patient confidentiality
Key worker	Variable: services may report key worker, but young people and parents often unaware	In practice, most young people and families name 'their' de facto key worker as someone whom they trust and see consistently, and is supportive and accessible. Often, a parent – usually the mother – takes this role
Co-ordinated team	Variable: some services demonstrated some aspects	Largely dependent on service structures. Collaboration and co-ordination between team members can occur formally and informally
Holistic life-skills training	Very limited: some services provided elements albeit in an informal, ad hoc way	Some services had not considered this, whereas others had but thought that it was not their responsibility. Education, social services, charities and family often provided this; if not, young people, parents and services thought that they should. All thought that young people should be signposted to relevant services outside the NHS
Transition manager for clinical team	Very limited: one service reported recent introduction	One service saw this as a need, but was still developing a remit for the role. Many services would like to implement this, but it is dependent on resources and competing demands

^a (In general, these observations were made by parents, young people and professionals; for full details, see *Appendix 6*).

Meeting members of the adult team before transfer was crucial for the young people and parents who experienced it; this generally happened at a single face-to-face meeting. Such meetings, however fleeting, offered symbolic and practical benefits and initiated relationships. The meetings helped young people and their parents to manage potential anxiety and offered more certainty about the health-care transfer process.

For young people and families, developing an adequate awareness of the transfer process itself and learning about the people and expectations of adults' services was important. Some young people and family members said that they had not received any support or information about the process. This was most marked when young people's appointments were infrequent or where services were in flux. Faced with such uncertainty, some young people and families felt abandoned, and unsure about many aspects of the new service they were about to transfer to.

Enabling in(ter)dependence

At the heart of transition is the aim to shift responsibility for managing health and health services from parents to the young person. This WP highlighted that the support of family, especially mothers, was central to enabling this 'independence'. Family members play a significant role and often contribute much effort to the negotiation of the multitude of transitions that the young person experiences, especially the health-care transition.

Within the children's health context, family members may act as 'key worker' in the clinic and home, providing the young person with some continuity of care, a point of reference and a source of emotional support. They can also act as advocates, offer practical support in managing health-care needs, facilitate access to services, prompt or ask questions, research available evidence, gather information and check a young person's understanding. For the most part, health professionals in adults' and children's contexts are aware of the work of young people's families in supporting and enabling them. New routines, norms and expectations evolve so that health professionals, families and young people in adults' and children's contexts can experiment with new ways of being interdependent.

Immediately leading up to and after transfer, young people may experience tensions; for example, 'legal' independence is thrust on them, but they still prefer interdependence. Some services or health professionals can compound this tension, especially in adult contexts, where parental involvement is considered an example of 'overattachment' or 'overdependence' and is therefore seen as problematic and to be discouraged. Working with the 'parent team' can support a shift towards more 'partnership', 'shared care' or 'consulting' roles.

Strengths and limitations

Conducting serial and triangulated interviews enabled us to confirm stories and capture evolving perspectives. Observing consultations enabled us to compare what people do against what they said they did in these contexts. Although both the form and the content of health care received may differ among the three exemplar groups, the organisation and experiences of the transition and transfer process showed many more similarities than differences.

The findings have face validity, as they relate well to the findings in other WPs and other studies in the literature, especially how transition and transfer can be disorientating for young people and their families.^{44,51,83} This study strongly echoes work on how young people build relations of trust with health professionals and services,^{44,51} especially where those relations are consistent and supportive,⁵⁸ as well as work on how the family, especially the mother, have built relations of trust with health professionals and services.⁸³

In its nature, qualitative work is in-depth but small-scale, a consequent strength being the richness of data and a weakness being the small number of case examples. We aimed to recruit 15 families and achieved 13. We had difficulties in recruiting young people, with many seeing the breadth and depth of data collection as

an additional burden while they were already taking part in WP 2.1. The retention of young people for follow-up and/or post-transfer interviews was poor, so learning about the adult context was limited. We were unable to contact some young people, and some of those we did contact declined follow-up interviews; they either withdrew or suggested that we speak to their parents or health professionals. Thus, our findings are valid in relation to the data we collected; however, it is possible that we did not identify key messages that would have been relevant after the transfer to adults' services.

Key findings

- Transition and transfer are disorientating for young people and their families. They have practical, cognitive and emotional impacts. Importantly, they disrupt often hard-earned knowledge of how best to navigate the children's health-care system effectively.
- Health professionals need to help young people and their families adjust to and mitigate these disruptions. The key practices that minimise this disruption are being clear in discussions and documents about processes, discussing how adults' and children's practices differ, undertaking joint clinics and meetings with members of the adult team that the young person will actually be seeing and including family members in the process.
- Transition is about enabling young people to become responsible for their own health care. However, family members remain crucial. Such involvement is normal, not dysfunctional, and for people in other age groups is largely accepted. Family members can be helped to adjust their roles to have more partnership and sharing of care and consultation with their son or daughter.

Inter-relationship with other parts of the programme

This WP, 2.2, was informed by WP 1.1 in which the UP group commented on the draft interview schedule and the practicalities of the planned visits to young people and clinic consultations.

The sample for WP 2.2 was a subsample of that in WP 2.1 and so the two WPs worked closely together.

Our published article,⁶³ on intended provision of PBFs and whether or not they are experienced by young people, integrated quantitative findings from WP 2.1 with qualitative findings from this WP 2.2. Our article directly influenced our decision to use the young person's experience of each PBF as the exposure in our regression analyses, rather than what the service said it aimed to provide.

The findings of this WP influenced interpretation of the three PBFs associated with improved outcomes in the conclusions section. This discussion informed one of the seven key implications of the programme, implication 6.

Work package 2.3: discrete choice experiment and economic analysis

Addressing objective 2: to identify the features of transitional health care that are effective and efficient

This WP examines the economic aspects of transition. It has two parts:

1. discrete choice experiment
2. economic modelling.

Discrete choice experiment

Discrete choice experiments are regularly used in health economics to elicit preferences for health-care products and programmes, and in the valuation of preferences for health states.^{90–92} Further details are in *Appendix 7*.

Aim

The aim was to quantify the strength of young people's preferences for aspects of health services for transition using a DCE.

Methods

A DCE describes a service in terms of a number of characteristics, or 'attributes' (e.g. the flexibility of appointments, parental involvement). The extent to which an individual values an intervention is expected to depend on the 'level' these attributes take (e.g. can appointments be made outside office hours or not?). Thus, a DCE explores relative preferences about how services can be organised, by choosing between services with differing levels of their attributes.⁹³

The design and conduct of the DCE involved four steps.

Step 1: identifying attributes and levels

Attributes and levels were informed by the Q-sort (WP 1.3). Other information was drawn from previous research about important features of transition.⁹⁴ The design and presentation of the DCE were undertaken with the members of the transition research programme's Collaborative Group and with UP. The chosen attributes and levels are shown in *Table 7*.

Step 2: experimental design

The number of attributes and levels described in *Table 7* give 128 possible combinations. Statistical manipulation, using Ngene software (2017; ChoiceMetrics, Sydney, NSW, Australia), reduced the number of scenarios. The resulting D-efficient design had 24 questions, which were further reduced by 'blocking' them into three groups, so that each respondent needed to complete only eight questions. Young people also answered questions about their current care, defined by the same attributes and levels used in the DCE. For each question, respondents chose between two hypothetical ways in which a service might be organised (see *Appendix 7* for specimen questions).

Step 3: data collection

The DCE was completed at visit 3 of the longitudinal study (WP 2.1). Several decision aids were piloted and then used to assist young people who had difficulty completing the DCE (see *Appendix 7*).

TABLE 7 Attributes and levels of the DCE

Attribute	Number of levels	Description
Flexibility	2	0 = does not offer appointments outside office hours 1 = offers appointments outside office hours
Staff at appointments	4	0 = do not see the same staff at my appointments and do not have a key worker 1 = do not see the same staff at my appointments but have a key worker 2 = see the same staff at my appointments but do not have a key worker 3 = see the same staff at my appointments and have a key worker
Staff communication	2	0 = yes 1 = no
Parental involvement	2	0 = discouraged 1 = welcomed 'if I want it'
Decisions about care	2	0 = staff discuss my care with me but they make the decisions 1 = staff give me choices but expect me to make the decisions
Extra support	2	0 = no 1 = yes

Step 4: data analysis and interpretation

Data were analysed within a random utility model framework using logistic regression techniques. The analysis estimated the predicted uptake of the service: the more an attribute is preferred, the higher the predicted uptake.

Analysis

In total, 247 participants completed at least one DCE question (fully completed, $n = 223$; partially completed, $n = 24$); 101 participants did not complete the DCE as they had withdrawn or were lost to follow-up. Young people with ASD were significantly less likely to respond than those with diabetes mellitus [16/87 vs. 7/112 ($\chi^2 = 10.50$, degrees of freedom = 2; $p \leq 0.001$)].

Appendix 7 presents detailed results. In summary, 43 respondents always chose current care and 60 never chose current care. Those not currently receiving any service were significantly less likely to choose current care ($p < 0.001$). Each attribute and level was often preferred by many young people, as was current care. *Table 8* shows that in a service where none of the attributes was present, the uptake of the service would be 78%. Adding a new service attribute, such as flexible appointments, predicted an uptake of 81%.

When demographic characteristics (gender, age at data collection and condition) were taken into account, all attributes, except flexibility of appointments, were preferred to a service with none of the attributes (see *Appendix 7, Table 23*).

Preference for current care was stronger among young men than among young women. Preference for current care was also stronger among those who had not transferred from children's to adults' services than among those who had. Young men had a stronger preference for out-of-hours clinics than young women did, and a weaker preference for making their own decisions about treatment. Young people with ASD had weaker preferences for parental involvement, and for being the ones to make decisions about their treatment, than those with cerebral palsy.

TABLE 8 Predicted probabilities of uptake of services as attributes are added

Attribute	Probability of uptake (95% confidence interval)
Current service (none of the attributes)	0.78 (0.75 to 0.81)
New service with flexible appointments	0.81 (0.78 to 0.84)
New service with a key worker	0.79 (0.74 to 0.85)
New service seeing the same staff at each appointment	0.90 (0.85 to 0.94)
New service seeing the same staff and having a key worker	0.88 (0.84 to 0.92)
New service with good staff communication	0.93 (0.91 to 0.95)
New service with parental involvement	0.93 (0.90 to 0.95)
New service offering young people decisions about treatment	0.91 (0.88 to 0.93)
New service offering extra support to young people for their future	0.86 (0.83 to 0.89)

Strengths and limitations

A DCE can be demanding to complete. Although most young people were able to respond, proportionately fewer with ASD did so. It is possible that these young people have different preferences from those who did complete the DCE. Furthermore, it is possible that the DCE failed to accurately capture the preferences of those young people who completed it. On this latter issue, some reassurance was provided by the broad similarities between the DCE findings and the ranking exercise. The advantage of the DCE over the ranking exercise was that the DCE provided an indication of the relative importance of each attribute.

Discrete choice experiments are widely accepted as a methodological approach preferred by many organisations. For example, they form the basis of eliciting EQ-5D-5L (EuroQol-5 Dimensions, five-level version) population tariffs throughout the world⁹⁵ and the Center for Devices and Radiological Health has stated that DCEs are a suitable method of eliciting patient preferences.⁹⁶ The approach we adopted was consistent with best practice. The aids to completion of the DCE might have infringed strict DCE methodology, but they enabled young people, with a wide range of confidence, intellectual ability and flexibility of thinking, to complete it. Indeed, the use of aids to completion has been advocated.^{97–99}

A fixed-effects modelling assumed that respondents were consistent in their choices over time. Although such an approach was not incorrect, more sophisticated econometric modelling could be used to explore heterogeneity and whether or not participants considered only a subset of attributes when choosing among alternatives. This might help explain why an appreciable proportion of respondents always chose current care.

Key findings

- Young people with long-term conditions, including those with ASD, could complete a DCE.
- In total, attributes were preferred to them not being present, except for flexibility of appointments.
- Preference for current care was strong and more pronounced among young men than among young women. This preference was stronger among those who had not transferred.
- Most young people (and especially women) least valued being able to have appointments outside office hours.
- Young people valued services in which information was passed to the right person, parental involvement was welcomed, staff offered choice and allowed young people to make decisions about their care, the same staff were seen at each clinic appointment and extra support was available for preparation for everyday life. Young people valued seeing the same staff at each clinic appointment more than having a key worker.

Inter-relationship with other parts of the programme

From WP 1.1, UP contributed much to the design of the DCE questionnaire. DCEs have not been undertaken often with young people. The understanding of the choice options was therefore discussed and piloted with UP.

The content of the DCE was, in part, informed by the Q-sort study of WP 1.3.

The DCE was administered at visit 3 in the longitudinal study WP 2.1.

This WP, 2.3.1, informed WP 2.3.2 on economic analysis.

The results of this WP led directly to one of the implications of the programme, implication 7, concerning elements of service that would make it more likely that transition services were taken up by young people.

Economic analysis

We assessed the relative efficiency of illustrative models of transition. WP 2.1 captured information from health records on the PBFs received by young people, their use of health services (and hence cost), and their health-related quality of life (HRQoL). We estimated the relative cost-effectiveness and presented the economic data and other study findings in a balance sheet.

The full account of the methods and analysis are in *Appendix 7*.

Aims

- To determine the resource use and costs of the PBFs.
- To assess the relative efficiency of illustrative models of transition.

Methods

Using the same decision rule as in WP 2.1, a trajectory for each PBF, deemed satisfactory or unsatisfactory, was assigned to each participant based on the data captured from the health notes.

Costs to the NHS covered the costs of consultations, medication and investigations. Data needed for costing were obtained by the research assistants from the health records, with additional information on service use gathered at each annual visit after the baseline visit. To aid recall, young people had kept diaries of contacts with health and personal social services. A unit cost was then applied to each service accessed using routine sources.^{100,101} Average pre- and post-transfer costs were then calculated.

Costs were then analysed to estimate the annual cost for a service where there was a PBF and for a service where there was no PBF. These costs were further split according to whether the young person was pre or post transfer, and, if post transfer, whether to primary or secondary care.

Young people completed the EQ-5D-Y at each of the four annual visits. This instrument captures HRQoL for use in economic analyses.¹⁰² Data from the EQ-5D-Y were converted to utility scores using the value set for adults.¹⁰³ Utility scores range from 0 to 1, with 1 indicating best health. A simple scoring system was also adopted for the EQ-5D-Y. Each of its five domains was assigned equal weight, and each level of each domain was scored 1, 2 or 3, depending on severity. Thus, each domain scored from 1 to 3, with 3 being worst health. Summing the scores for each domain generated a 'sumscore' that ranged from 5 to 15, with 15 being worst health. A similar approach to analysing these data was adopted for cost.

The data on costs and HRQoL were incorporated into a simple Markov model (*Figure 9*) in which all young people start in children's services, aged 14 years, and are followed for 10 years, the time over which a young person would be expected to be undergoing transition. The model considers a hypothetical cohort of 1000 young people. Each year, they have a probability of transferring from children's services to primary care or moving into adults' services. If, in any year, they do not make the transfer, then they remain in children's services, indicated by the ellipse connected to the children's services state. The chance of being in a given state in a given year (the 'rate of transfer'; see *Appendix 7*) was calculated by considering the number of people who transferred from children's services each year, and the ratio of young people transferred to adults' services to those transferred to primary care.

Those remaining in a given year in the children's services state are represented by the ellipse connected to the children's services state.

For each state in *Figure 9*, an annual cost, utility and sumscore value was assigned as described above. Cumulative costs, quality-adjusted life-years (QALYs) and sumscores were estimated for the 10-year time horizon, and all costs and effects were discounted at the UK recommended rate of 3.5% per annum.

The results of the model and the DCE were combined with findings from other areas of the research programme in a balance sheet analysis. In this analysis, we present those outcomes that could favour a hypothetical intervention compared with a situation in which there was no support during the transition from children's to adults' services.

Analysis

Estimation of use of health services and costs

There were 7755 health-care contacts over the study period. Another 627 scheduled contacts were cancelled in advance or without enough prior notification (classified as 'did not attend'). The numbers of participants providing data were 286 (76.2%) at visit 2, 249 (66.4%) at visit 3 and 216 (57.6%) at visit 4.

The median number of health-care contacts across all years was 19 (IQR 20). This varied by condition, ranging from 14 (IQR 27.8) for those with cerebral palsy to 16 (IQR 23) for those with ASD and 23 (IQR 13.8) for those with diabetes mellitus. Over time, the median number of visits decreased. Visits for those with cerebral palsy dropped from 7 to 5, for those with diabetes mellitus dropped from 8 to 7, and for those with ASD increased from 5 to 6. Full details are in *Appendix 7*.

Combining data on use of services with unit cost data allowed an estimation of the cost of care for each young person. Data were available on 301 young people (78.6%). The overall median cost per participant was £4954 (IQR £6103). Diabetes mellitus was the costliest condition, and cerebral palsy the least costly, with considerable variation between individuals. The difference between the cost for those with diabetes mellitus and the cost for those with ASD was statistically significant ($p < 0.001$). The difference in pre- and post-transfer costs was not statistically significant ($p < 0.05$), although there was a trend both overall and by condition (*Table 9*).

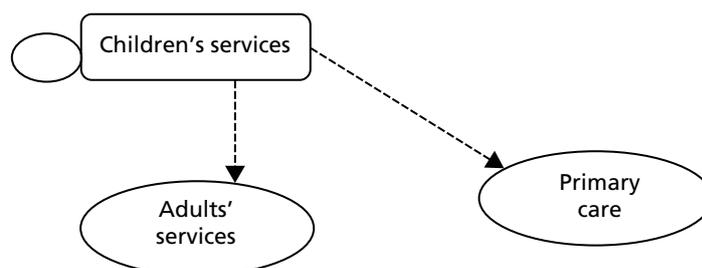


FIGURE 9 Structure of the economic model.

TABLE 9 Estimated median costs by condition, both overall and pre and post transfer

	All (IQR)	ASD (IQR)	Cerebral palsy (IQR)	Diabetes mellitus (IQR)
For all				
Number	301	96	77	125
Median costs (£)	4954 (6103)	2351 (4211)	2394 (5606)	7003 (3667)
Median costs per annum (£)	2307 (2705)	1659 (2573)	1447 (2725)	2915 (2422)
For those pre transfer				
Number	279	88	67	121
Median costs (£)	2420 (4506)	1694 (2454)	1370 (4215)	4434 (5136)
Median costs per annum (£)	1673 (2242)	915 (1277)	949 (1974)	2410 (1587)
For those post transfer				
Number	194	56	48	87
Median costs (£)	2080 (3470)	1262 (2540)	1395 (3015)	3114 (3440)
Median costs per annum (£)	1371 (1862)	645 (1883)	707 (1673)	1849 (1193)

Estimation of health-related quality of life

Data from the EQ-5D-Y were available for 373 respondents at baseline and for 244 respondents by visit 4. The median sumscore score was 5 for every domain at every time point (i.e. half of the respondents reported 'no problems'). The mean sumscores increased over time (i.e. health worsened), as did the scores for each domain. During the follow-up period, the proportion of individuals experiencing problems on each domain (a score of 2 or 3) increased significantly ($p < 0.001$) for each of the five domains (see *Appendix 7*).

The median sumscore for all participants across all time points was 6 (IQR 2.79), which indicates that at least half of participants experienced a problem on at least one domain. Average sumscores were not associated with gender, and nor were pre- or post-transfer scores. In addition, there were significant differences in sumscores by condition, as participants with diabetes mellitus had significantly lower scores (i.e. better health) ($p < 0.001$) at all time points (*Table 10*).

The median utility score across all participants was 0.83 (IQR 0.30). Average utility scores were not associated with gender, or pre- or post-transfer scores. However, the scores of those who had transferred were significantly higher for those transferring to adults' services (median 0.86, IQR 0.37) than for those transferring to primary care (median 0.78, IQR 0.38). As we found for the sumscore, participants with diabetes mellitus had significantly higher utility scores ($p < 0.001$) at all time points (*Table 10*).

Experience of proposed beneficial features

Data on experience of the PBFs are reported in *Appendix 7, Table 34*. These and the economic evaluation used two methods to determine whether or not a PBF had been experienced.

A form was completed each year by the research associate from data in the young person's health records. It consisted of details of clinic visits, professionals in attendance, medical tests undertaken and whether or not PBFs had been experienced. This was called the 'final account of consultation'. Following the home visits with further discussion of appointments and PBFs and completion with the young person of a questionnaire, it became clear that the final account was incomplete for some young people. Therefore, analysis was also undertaken with data combined from both sources.

TABLE 10 Summary sumscore and utility score by condition, pre and post transfer

	All (IQR)	ASD (IQR)	Cerebral palsy (IQR)	Diabetes mellitus (IQR)
For all				
Number	301	96	83	122
Median sumscore	6 (2.79)	7 (2)	7 (2.98)	5.20 (1)
Median utility score	0.83 (0.30)	0.75 (0.26)	0.70 (0.43)	0.94 (0.14)
For those pre transfer				
Number	269	86	70	113
Median sumscore	6 (2)	7 (2)	7 (3)	5 (1)
Median utility score	0.85 (0.27)	0.75 (0.26)	0.72 (0.43)	0.95 (0.13)
For those post transfer				
Number	230	68	66	96
Median sumscore	6 (3)	7 (2)	7 (2.75)	5 (1)
Median utility score	0.82 (0.29)	0.76 (0.24)	0.70 (0.33)	0.95 (0.16)

Economic evaluation model

The parameter values used in the economic model are reported in detail in *Appendix 7*. The analysis considered each PBF separately and, given the limited data available, should be considered exploratory. Given the exploratory nature, a probabilistic sensitivity analysis was not conducted as there was considerable imprecision in the results. The results are best considered as either illustrative of the approach taken or hypothesis-generating about possible PBFs to consider when developing an intervention to improve transition.

Tables 9 and 10 show the estimated costs and effects (sumscore and QALYs). *Table 11* shows the incremental cost-effectiveness for a service incorporating each PBF alone compared with a service where no features were present. We could not compare individual PBFs with a situation in which all PBFs were provided, as only one participant had experienced all PBFs. As the presence of PBFs is based on face-to-face discussions and health records, a sensitivity analysis was performed using both data sources.

Experience of proposed beneficial features

The data reported in *Table 34* (see *Appendix 7*) and in *Table 11* illustrate that the results are sensitive to the methods used to decide whether or not a PBF was experienced. The higher the incremental cost-effectiveness ratio, the less likely it is that an intervention would be considered value for money.

Three PBFs performed better regardless of whether the determination of 'satisfactory' PBF exposure was based on the final account or on the data from both sources. These PBFs were 'provision of holistic care', 'having a key worker' and 'promotion of health self-efficacy'.

'Meeting the adult team' was sensitive to the source of data and was considerably more advantageous when the estimates were based on the data from both sources. 'Having a written transition plan' and 'having a transition manager for clinical team' performed relatively poorly.

TABLE 11 Incremental cost per QALY gained

PBF	ICER using PBFs captured from final account (£)	ICER using PBFs captured from both sources (£)
Meet adult team before transfer	Dominated ^a	7121
Age-banded clinic	36,487	13,176
Holistic life-skills training	10,991	5618
Key worker	15,259	4811
Transition manager for clinical team	64,359	12,592
Appropriate parent involvement	N/A	7070
Promotion of health self-efficacy	N/A	5127
Co-ordinated team	52,100	8596
Transition plan	N/A	11,259
Cost per 1 unit change in sumscore		
Meet adult team before transfer	15,092	7011
Age-banded clinic	22,693	12,662
Holistic life-skills training	5692	4563
Key worker	13,363	3878
Transition manager for clinical team	23,364	7114
Appropriate parent involvement	N/A	5345
Promotion of health self-efficacy	N/A	5341
Co-ordinated team	12,746	7700
Transition plan	N/A	8947

ICER, incremental cost-effectiveness ratio; N/A, not applicable.

^a PBF on average more costly and less effective. Therefore, it is dominated by a service without that PBF.

Balance sheet

Using data from the economic analyses and from elsewhere in the programme, a balance sheet was developed to summarise the pros and cons of providing a service with a PBF compared with a service without PBFs (*Table 12*). The development and implementation of a service containing one or more PBFs would incur a cost of a magnitude determined by how that PBF was delivered.

The limited data available from the economic model suggest that implementation of a new service will increase the use of NHS services at least over a 10-year time horizon for a young person aged 14 years entering a ‘transition’ service. There appear to be no harms to the young person from any of the PBFs.

Strengths and limitations

A concern was whether or not the HRQoL instrument was sufficiently sensitive to capture an influence of PBFs. The study was powered not on the EQ-5D-Y but rather on the outcomes used in WP 2.1. We did have sufficient power to identify clinically significant changes in the EQ-5D-Y but, for analysis by condition, sample size meant that some real effects of difference may not have been detectable. In relation to the PBFs, power was limited if a feature was often absent.

Alternatively, the HRQoL instrument might have been sufficiently sensitive, but follow-up was too short to capture any influence of PBFs.

TABLE 12 Balance sheet

Favours service containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the PBFs in the prospective study	Favours service not containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the PBFs in the prospective study	Source
	Avoided the currently unknown costs of providing beneficial features. Costs of some may be modest (e.g. a 'written transition plan') whereas others are substantial (e.g. adoption of a multidisciplinary team)	Costs not estimated
A service should be flexible enough to meet the needs of individuals; one size does not fit all and needs may change over time. A service needs to consider the condition, the stage of development and the young person's personality		Q-sort (WP 1.3) and DCE (WP 2.3.1)
	High predicted uptake of a service with no PBFs (78%, 95% confidence interval 75% to 81%)	DCE (WP 2.3.1)
Predicted uptake of a service is higher when the service includes parent involvement, when the same staff are seen at each clinic appointment and where the young receive good communication and are offered the opportunity to make decisions	From the DCE: a strong preference for current care; no strong preference for a 'key worker' or flexibility of appointments	DCE (WP 2.3.1)
Increasing engagement may help prevent deterioration of the young person's condition over time		Anticipated impact not measured in study
'Appropriate parent involvement', 'promotion of health self-efficacy' and 'meeting the adult team' improved outcomes		Analysis of longitudinal data (WP 2.1)
Estimated additional benefit to health service of adopting any of the above features, except 'being cared for by a co-ordinated team'	Estimated additional cost to health services of adopting any of the PBFs	Economic model analysis (WP 2.3.2)
Longer-term model cautiously suggests that 'holistic life-skills training', 'having a key worker' and 'promotion of health self-efficacy' might be value for money	Longer-term model cautiously suggests that 'transition manager for clinical team', 'age-banded clinic' and 'meeting the adult team before transfer' might not be value for money'	Economic model analysis (WP 2.3.2)
No evidence of a difference		
Lack of clarity about what was meant by a health passport, something that might be valued but was rarely used		Works conducted by UP (WP 1.2)
During transition, there was no evidence of any effect on outcomes of 'having a transition plan', 'attending an age-banded clinic', 'being cared for by a co-ordinated team', 'being part of a service with a transition manager for clinical team' or 'having access to holistic life-skills training'		Analysis of longitudinal data (WP 2.1)
Over the duration of the longitudinal study, there was no evidence of any effect on costs or HRQoL of 'having a transition plan', 'attending an age-banded clinic', 'being cared for by a co-ordinated team', 'being part of a service with a transition manager for clinical team' or 'having access to holistic life-skills training'		Analysis of costs and EQ-5D data in the economic analysis (WP 2.3.2)
EQ-5D, EuroQol-5 Dimensions.		

The DCE suggested that experiencing some of the PBFs might increase young people's engagement with health services, which, in turn, might alleviate longer-term harms (and costs) due to inadequate health care. The economic evaluation was exploratory and compared only services with individual PBFs with a service with no PBFs. Therefore, no probabilistic sensitivity analysis was conducted, as is normally recommended for health technology assessment economic evaluations; a quantified estimate of the effect associated with various combinations of PBFs was not possible. Therefore, the economic conclusions should be interpreted with care.

It was necessary to annuitise the cost data for participants to allow a comparison with the EQ-5D-Y data. Thus, certain costs for participants for items mentioned occasionally, but likely to apply over the course of the study, were calculated as a daily rate following the aggregation of the visit data. For example, as insulin prescriptions were not consistently reported in the data, these were costed separately according to existing literature and then inflated to the current price year. We think that this made best use of the available data and is unlikely to have distorted the results.

The data collected on outcomes, costs and health service use were complex to interpret because there was loss to follow-up and differing health-care transfer arrangements, and the intervals between the annual visits by the research assistants were not always exactly 1 year. Strict econometric modelling, despite considerable efforts, proved to difficult to undertake. Therefore, a less robust exploratory analysis was adopted, which drew out key implications and generated a balance sheet. Conclusions were not wholly in concordance with some conclusions from other parts of the programme, but the triangulation of findings allowed key consistent conclusions and implications to be identified and reported.

Key findings

- There were significant differences in both costs and HRQoL between conditions.
- The average utility and sumscores were similar in those pre and post transfer.
- The median annual cost (covering the costs of consultations, medication and investigations) was £7003 for an individual with diabetes mellitus, £2934 for an individual with cerebral palsy and £2350 for an individual with ASD.
- Both costs and HRQoL declined over time for all conditions.
- A service involving a PBF is unlikely to reduce NHS costs over a 10-year time horizon but might increase them.
- We have examined the potential consequences of a service with flexible appointments and that encourages 'appropriate parental involvement' and 'promoting health self-efficacy'. A judgement is needed about whether or not such a service would be worth the extra cost, given that it may increase engagement with health services and prevent deterioration in health in the long term.

Inter-relationship with other parts of the programme

Data collected during WP 2.1 (the quantitative longitudinal study) about costs of consultations and exposure to PBFs were essential for the economics analysis.

The results from the DCE (WP 2.3a) contributed to interpretation of the economic analysis.

The results of this WP led directly to one of the implications of the programme, implication 7, concerning value for money.

Work package 3.1: introduction of developmentally appropriate health care

Addressing objective 3: to determine how transitional health care should be organised, provided and commissioned

This WP examined how DAH can be introduced across NHS Trusts. It had two parts:

1. WP 3.1.1: identification and description of factors that enable or inhibit the introduction of trust-wide DAH
2. WP 3.1.2: development of a toolkit for the introduction of DAH.

From our work, there are two published papers.^{3,4} The report on the implementation of DAH is in *Appendix 8*.

Work package 3.1.1

There is a need to provide health care that meets the needs of young people. Youth-friendly health services^{104,105} is one concept discussed in the literature. However, we need to move from the ad hoc provision of youth-friendly services to youth-responsive health systems¹⁰⁶ that respond to young people's changing developmental needs.²⁵ DAH recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In this WP we developed a working definition of DAH:

DAH recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms, DAH focuses on health-care professionals' approach to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.

DAH offers a foundation for good practice in the health care of young people and so it should underpin transitional health care.

Aim

The aim was to identify, describe and understand the factors that enable or inhibit the introduction of DAH across NHS Trusts.

Methods

We convened a 1-day seminar in Birmingham on DAH. This brought together 29 delegates with expertise and experience from health services research, public health, social policy, clinical practice and the voluntary sector.

A scoping review, using recognised methods,¹⁰⁷ was conducted to explore the use and meanings attributed to the concept of DAH. Articles were subjected to manifest and latent content analysis.¹⁰⁸

More detail about methods is in *Appendix 8*, which also includes the interview guide.

A qualitative, multisite, ethnographic study was then conducted across three hospitals in England: a district general hospital, a paediatric tertiary hospital and an adult tertiary hospital. Health professionals were recruited from six medical and surgical specialties (diabetes, emergency care, general paediatrics, outpatients, rheumatology, and trauma and orthopaedics) chosen to represent the heterogeneous services found in NHS

hospitals. In addition, individuals from chaplaincy, psychology, radiology and youth work, as well as those leading training sessions, were recruited to explore a broader range of the staff and contexts with which young people are engaged. Managers were recruited at each site if their roles were relevant to the provision of services for young people in paediatrics and/or adult care.

Data collection took place over three phases between June 2013 and January 2015. Recruitment was initially through gatekeepers, and then through a mix of snowball, criterion and theoretical sampling. A total of 192 participants were recruited. Approximately 1600 hours of non-participant observations were conducted, alongside 65 formal qualitative interviews (*Table 13*). Observations of interactions between staff, young people and family members and between staff (in departments, wards, clinics, team meetings and training workshops) were recorded in contemporaneous field notes. Interviews were audio-recorded, transcribed, edited to ensure anonymity and then analysed alongside field notes.

Analysis used qualitative methods⁸⁶ from first-generation grounded theory (coding, constant comparison, memoing⁸⁷) and procedures from analytic induction (deviant case analysis⁸⁸). Because data collection and analysis occurred concurrently, issues raised in earlier phases of fieldwork could be explored in subsequent ones. We undertook independent coding and cross-checking, team data sessions and member validation with some of the participants in the fieldwork. The analysis was informed by normalization process theory (NPT).¹⁰⁹

Analysis

Our scoping review³ found that there was no agreed definition of DAH. DAH was linked to domains of adolescent medicine, young people, chronic conditions and transitional health care, but there was much diversity in conceptualisation, terminology and age ranges.

The following summary of the implementation of DAH is described in more detail in *Appendix 8*. This cites many quotations from the interviews and observations and has accompanying commentary.

TABLE 13 Participants recruited, by site, type of staff and method of data collection

Participants	Site (n)			Total (N)
	District general hospital	Paediatric tertiary hospital	Adult tertiary hospital	
Participants observed				
Health professional	65	27	11	103
Manager	57	0	15	72
Total	122	27	26	175
Participants interviewed				
Health professional	13	18	10	41
Manager	13	6	5	24
Total	26	24	15	65
Overall participants				
Health professional	78	45	21	144
Manager	70	6	20	96
Total	148	51	41	240
Participants who were both interviewed and observed	39	5	4	48
Total number of participants	109	46	37	192

The core of DAH was that the young person's developmental stage should be the starting point for appropriate provision of services. We also found a wide variety of understandings of DAH across clinical and managerial staff in all the sites (see Farre *et al.*⁴). Some did not recognise it as a concept, to some it made little sense and others found it difficult to conceptualise: it was 'a bit amorphous'. Many focused on the need to create a more age-appropriate, youth-friendly environment¹⁰⁶ in the physical spaces of waiting room and wards (e.g. having age-appropriate leaflets and computer games). Others, especially those who worked with young people, were more likely to mention interpersonal aspects, such as developmentally appropriate communication, norms around confidentiality and a holistic focus. Using the concepts of NPT, we identified little coherence across sites and staff, the use of a variety of definitions ('differentiation'), a lack of shared understanding of the purpose of DAH ('communal specification') and diverse understanding of the potential impact of DAH on their work ('individual specification').

There were also different views on the worth of DAH ('internalisation') across sites and staff (see *Appendix 8*). The numbers of young people accessing health services were often perceived to be small, so in organisational terms they may be 'just below the radar'. Compared with the elderly, they were considered to be 'rarely unwell'. This may be compounded by the intermediate status of young people in the UK health-care system: one senior manager said 'adult services don't really want them because they are too young and the child services don't really want them because they are too old'. None of the sites had a senior clinical or management lead for young people. Although young people's champions were considered important, there were dangers in relying too much on key individuals. It should be 'about consistency of approach, not a person'. So, in NPT terms, there were key people driving DAH forward ('initiation'), but these were rarely senior members of staff. At times, we observed that when a young people's champion left a specific team, there was then a reduction in team members becoming involved in and staying committed (cognitive participation) to the implementation of DAH.

Across the three sites, local networks tailored services to the needs of young people. However, in all of the sites, DAH was unevenly distributed. Some thought that no 'special arrangements' were required and that, by implication, DAH was not a legitimate part of their work (legitimation). Informal networks of trust existed at each site, where certain people or teams were understood to have the right skill mix, or mindset, or access to resources, to work effectively with young people. In this way, specific groups of people or teams were willing to work with others to enable DAH (enrolment), were motivated to deliver DAH over time (activation), had the relevant mix of skills (skill set workability) and were able to deliver DAH (relational integration). Young people tended to be directed to such teams. Thus, some of the inequities in skills and experience across the organisations were self-sustaining.

In all sites, service development for young people rested with the informal, organisation-wide group of young people's champions. Such groups promoted initiatives to raise awareness across the organisation, create change, offer support and learn from each other.

In two of the sites, training took place at an annual study day. At another site, we observed training about DAH being planned and delivered by a group of managers, clinicians and allied health-care professionals who met every few months. At this site, dissemination reached well beyond the special interest group; it was clearly supported by the organisation ('contextual integration'). The training was linked to the development of a DAH strategy and consisted of 'delivering key messages' from various government policy initiatives, such as the You're Welcome Criteria.⁹⁴ This strategy was supported with resources from senior management. The focus of the strategy and training was on:

- organisational-level factors, such as provision of age-banded clinics and staff appraisal, which included training goals around young people
- clinic- and consultation-level factors, such as signposting to sexual health, drug and alcohol services, and copying clinic letters to young people
- training and awareness factors such as adolescent development and confidentiality.

Strengths and limitations

As detailed in-depth work was required, it was realistic to work in a small number of sites: three sites in two UK regions were studied. A limitation was that only three sites in two UK regions were studied. A significant number of staff participated and a wide range of settings were encompassed, including outpatient, inpatient and emergency care. Although the hospitals had a history of championing research and innovative service provision for young people, this did not include a defined service for adolescent medicine. In addition, the clinical specialties at each site were at different stages of understanding of DAH, thereby providing the study with ranges of experience. We think, therefore, that we captured a broad range of relevant views, but it is likely that not all were covered.

Key findings

- Although there were different understandings of DAH in the literature and across clinical and managerial staff, common themes led us to propose a working definition:

DAH recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms, DAH focuses on health-care professionals' approach to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.

- DAH is needed equally in adults' and children's services.
- The organisational barriers to introducing DAH were:
 - No single group was responsible for young people.
 - There was perceived (incorrectly) to be a small number of young people attending hospital; and also a perception that young people were rarely unwell.
 - The mindset and skill set of many staff were not ready.
 - Good practice led by enthusiasts was not sustainable.
- The organisational solutions to introducing DAH were to:
 - move beyond pockets of good practice to buy-in and formal support at NHS Trust board level and from senior managers in both adults' and children's services
 - ensure that planning engages adults' and children's services from the outset
 - ensure a trust-wide strategy and training about DAH.

Inter-relationship with other parts of the programme

The preliminary findings of this WP, together with the video created by UP, were presented at an external seminar held in Birmingham for invited delegates.

The immediate effect of this WP was to influence the content of the toolkit for implementation of DAH (WP 3.1.2). The findings shaped the format of the toolkit in terms of:

- the emphasis on different domains (e.g. consultation, team and organisation)
- the content – explicit description of DAH, references to resources used by people at sites, including training
- the examples of good practice.

Developmentally appropriate health care was an important topic in the discussions we had with commissioners (WP 3.3), and one of the key implications, implication 2, of our research is that the introduction of DAH across a NHS organisation be considered by commissioners and NHS provider organisations.

Work package 3.1.2

Aim

The aim was the development of a toolkit for the introduction of DAH.

Methods

We consulted with the Association of Young Person's Health, as it had experience in developing similar resources. We supplied it with the content and websites to which the content could be linked. After three revisions, the toolkit was piloted by requesting comments from 10 senior NHS managers, adult and paediatric health-care professionals, the research associates who undertook the ethnographic work, and the Royal College of General Practitioners. The toolkit was revised again and then launched at the dissemination conference of the research programme in October 2017. The toolkit is downloadable from the website of the sponsoring trust, Northumbria Healthcare, which also holds the copyright. Every 3 months we will ensure that the websites linked to the toolkit remain active; and every 12 months revise content if necessary. The URL of the toolkit is <http://research.ncl.ac.uk/transition/>.

Work package 3.2: commissioning – interviews and case studies

Addressing objective 3: to determine how transitional health care should be organised, provided and commissioned

‘Commissioning’ is the process by which public services are organised and contracted to meet population needs. Health-care commissioners follow a cyclical process of assessment of population needs, setting priorities, developing strategies in line with objective outcomes, procuring services and measuring outcomes.¹¹⁰ The need for better commissioning for transition was highlighted in recommendation 32 of the Kennedy Report,¹² which stated that:

Ensuring a smooth transfer between children’s and adults’ services should be a priority for local commissioners.

Kennedy, p. 110.¹² © Crown copyright. Contains information licensed under the Open Government Licence v3.0

The first objective of NHS England’s *Research and Development Strategy 2013–18*¹¹¹ is:

To identify and prioritise commissioning health services research topics and co-ordinate this work with the Department of Health, NIHR [National Institute for Health Research]. . .

*Department of Health and Social Care, NHS England, p. 8.¹¹¹
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From this work, we have published two papers.^{112,113} There is also a report on WP 3.2 in *Appendix 9*.

Aims

- To identify the structures, processes and relationships between commissioning entities in the NHS and other agencies relevant to transitional health care.
- To identify the facilitators of and barriers to commissioning for services for transitional health care.
- To identify how services for transitional health care could be better commissioned.

Methods

This work was overseen by an invited Steering Group, which met on four occasions.

The work was undertaken sequentially in six stages.

- Stage 1: literature review. A systematic review was undertaken to identify published peer-reviewed evidence about commissioning for transition.
- Stage 2: qualitative interviews with stakeholders. Twenty-nine interviews were conducted by telephone ($n = 3$) or in person ($n = 26$) with individuals from Clinical Commissioning Groups (CCGs), Health and Well-being Boards, local authorities, general practices and the third sector. Most of the interviews were conducted with people in north-east England. A second site in the Midlands was selected because the local Health and Well-being Board had transition as a priority, and there was a Commissioning Support Unit. Further details of the methods are in *Appendix 9*, which includes the interview schedule, and in our published paper.¹¹²

- Stage 3: case studies. Using the findings of the literature review and the interviews, criteria were developed for seeking sites at which transition was being formally addressed. Three sites, covered by three CCGs, were visited in the north-west, the south-west and the West Midlands of England. Across the three sites, 11 semistructured interviews were conducted. The details of the methods are in *Appendix 9*.
- Stage 4: seminar in London on commissioning for transition. This brought together additional expertise and experience from public health, social policy, commissioning and research into commissioning. Thirty invited delegates attended.
- Stage 5: interviews with commissioners for adults' services. We realised that we had talked with few commissioners for adults' services. Therefore, we arranged face-to-face interviews ($n = 5$) with commissioners for adults' services in two CCGs in north-east England ($n = 3$), a CCG in south-east England and a regional commissioner for specialised adults' services for NHS England in the Midlands.
- Stage 6: synthesis and conclusions.

Analysis

Stage 1: literature review

No published papers on commissioning for transition were identified. Of 66 publications whose full-text was reviewed, 17 were potentially informative for the wider work of the Transition programme, in particular recommendations for providers. The grey literature was then reviewed and revealed nothing of additional significance. The details of the analysis are in *Appendix 9* and in our published paper.¹¹²

Stage 2: qualitative interviews

A number of issues related to commissioning were identified, which clustered around four meta-themes: (1) policy and legislation; (2) organisational structures, processes and pathways; (3) professional roles and relationships, service-level co-ordination, signposting and support; and (4) commissioning process and practice, including outcomes planning and delivery, and contract evaluation. From this work, key factors were identified that seemed likely to facilitate commissioning for transitional health care. These were:

- commissioning within a CQUIN¹¹⁴ framework
- Commissioning for Transition co-ordinators, within a framework of DAH, to work across all services in an organisation rather than for a particular condition
- joint commissioning either as cross-sectoral in education, health and social care, or as within-health, including the involvement of general practice
- commissioners and providers jointly agreeing what should be commissioned.

Another issue raised frequently in the interviews was the need for 'outcomes-based commissioning'. We found great variability in what this meant and how outcomes might be measured. Furthermore, we could not identify a setting in which outcomes-based commissioning was happening.

Full details of the analysis are in *Appendix 9* and in our published paper.¹¹²

Stage 3: case studies with site visits

The full report is in *Appendix 9*, and some of the implications are reported in our published paper.¹¹³

Case study A

At this site, a CQUIN was considered a necessary first step to quality improvement, as it helped develop a culture, at least within children's services, of shared purpose and value around transition. The CQUIN was also perceived to be useful for standardising the introduction and use of the 'Ready, Steady, Go, Hello' forms,¹¹⁵ a set of documentation supported by NHS England. Participants reported that the implementation of the CQUIN contributed towards raising the profile and visibility of transition among clinicians.

Reported barriers included a lack of engagement of general adults' services. Sometimes, this was compounded by the lack of a specific adults' service for children to be transferred to. In other cases, the need for some young people to be transferred to other trusts was reported as difficult to plan. Furthermore, because CQUINs were assessed by numerical targets, rather than by factors shaping quality and innovation, this might negate quality improvement. Finally, concerns were raised that transition extends for many years beyond the time frame of a 1-year CQUIN.

Case study B

At this site, a lead nursing manager, funded by the Strategic Clinical Network, played a central role as a regional champion facilitating the implementation of a region-wide CQUIN. This leader worked across 14 NHS Trusts. All participants reported that this leadership played an important role in raising awareness and best practice about transition among commissioners and providers. At trust level, the CQUIN contributed to the development of a Transition Steering Committee and a trust-wide transition co-ordinator responsible for collaborating with professionals across specialties.

Reported barriers included a lack of engagement of adults' services in the meetings of the Transition Steering Committee and a lack of clarity about the role and responsibilities of commissioners of adults' care. Young people's participation and feedback was limited and fragmented across different services. Finally, echoing the findings of case study A, conceptualising the CQUIN in terms of indicators and targets did not necessarily translate into meaningful conversations about quality and innovation.

Case study C

At this site, there was a partnership whose overall aim was to develop and implement an integrated mental health service for those aged 0–25 years. This involved decommissioning the existing child and adolescent mental health services (CAMHS) and co-producing a new service specification. Participants reported that a key feature of the new service was the enthusiasm about and commitment of commissioners to improving transitional health care. Furthermore, participants emphasised the importance of health, social and third-sector involvement and co-production with service users of the new service specification. It was supported at national level by the National Clinical Director for Children, Young People and Transition to Adulthood, and at regional level by the Collaboration for Leadership in Applied Health Research and Care.

Reported barriers included uncertainty about transition after the age of 25 years and challenges relating to engagement of adults' services. In addition, negotiating the decommissioning process with the outgoing provider had been challenging. Participants thought that some stakeholders were reluctant to adopt the new service. Finally, inadequate information-sharing procedures were evident following the configuration of the new service.

Stage 4: seminar

Many views and insights were expressed, which are summarised in a report. The main benefit to the programme was how much the co-applicants learned about the NHS Commissioning Framework and how to influence commissioning.

Stage 5: further interviews with commissioners of adults' services

Further interviews with adults' services commissioners in CCGs revealed that transition did not get 'onto their radar'. Transition was acknowledged to be important but, as there was no national imperative, other priorities over-rode it. This is despite the introduction of a national CQUIN on transition in mental health services¹¹⁶ part-way through our research programme. The only meetings at which transition was ever mentioned were those about diabetes. The overarching opinion was that contracts with trusts covered broad strategic approaches to clinical care and were not specified at the level of detail that would include arrangements for transition. Rather, CCGs would assume that a health-care provider would deal with decisions about transition and transfer of health care as it saw fit.

Participants suggested that reasons why transition did not get ‘onto the radar’ included (1) commissioners had no ‘levers’ such as national quality indicators or resources for transitional health care (just talking with a trust does not make better transition happen), (2) commissioners could not show ‘return on investment’ (i.e. improved transition would not convert easily to more activity for the same money or to less activity for less money) and (3) other competing urgent priorities.

Most commissioners were aware of NICE guidance on transition but acknowledged that, like other NICE guidance, new guidance was considered in the context of local priorities. Furthermore, it was suggested that NICE guidance about a particular condition or disease is easier to use than guidance directed towards the operation of a complex intervention.

Commissioners who were also general practitioners made two important points. First, long-term conditions, such as non-severe asthma, allergy and some mental health disorders, are often currently managed entirely by primary care. Although transition occurs, there is no need for the transfer of health care. Second, even for conditions that need secondary care, ‘the role of primary care should start at the time of diagnosis’. The general practitioner commissioners were concerned that, in some instances, children’s health services appear to exclude primary care. This lack of joint working risks creating, for children, young people and their parents, a lack of confidence in their primary care team and an overdependency on secondary paediatric care, which in turn leads to a strong desire for secondary adults’ care.

Commissioners of adults’ services were well aware of the small number of young people with very complex care needs that required expensive, bespoke clinical and interagency care, but they were often not aware of the much larger numbers of adolescents with long-term conditions who were negotiating transition and attending community and hospital-based services.

Commissioners for specialised services at NHS England suggested that most specifications for children’s services included transition; and for some conditions, such as diabetes and renal services, a broad expectation about transition was also included in contracts for adults’ services. However, they acknowledged that most adults’ service specifications contained little, if any, reference to transition or health-care transfer. Furthermore, there was no monitoring of service delivery by commissioners of either transition more broadly or the transfer of health care from children’s to adults’ services. For some conditions, national audits of practice, which include examination of transition, were undertaken by professional groups.

Stage 6: synthesis

We prepared a first draft of our synthesis and proposals for discussion with commissioners, which was then refined; this is reported in WP 3.3.

Strengths and limitations

Despite increased awareness about transition since the publication of the NICE transition guideline¹⁴ and quality standard¹⁷ in 2016, commissioning for transition is a new field of enquiry. This means that our research conclusions are primarily based on the evidence generated during the research programme through research interviews, site visits and discussions with commissioning groups.

Given the fast pace of policy change, and with over 200 CCGs across England, one of the challenges of this WP was to capture a wide range of contemporaneous views and perspectives. We think that the combination of the range of methods employed (interview, seminar, site visits), the relatively broad geographical distribution across the UK, and engagement with CCGs and specialised commissioning at NHS England gave us a reasonably comprehensive understanding.

Key findings

- Commissioners and providers of adults' services regard transition as the responsibility of commissioners and providers of children's services to deal with and improve.
- Whether contract specifications include transition very broadly or in detail, implementation of transition is not usually then monitored by commissioners – partly because there are no nationally agreed outcome and quality indicators to use.
- Although a CQUIN for transition can raise the awareness of service managers and clinical teams about transition, the short-term requirement for indicators to be documented can make the introduction of a CQUIN a box-ticking exercise, rather than a commitment to organisational change that may in turn lead to quality improvement.
- A Transition Steering Committee and trust-wide transition co-ordinator in a NHS Trust are effective in discharging an organisation-wide commitment to improving transition.

Inter-relationship with other parts of the programme

Our understanding of commissioning processes developed from this WP allowed us to ensure, as far as possible, that we were well informed when we visited commissioners in WP 3.3. We were able to approach commissioners with specific questions and specific suggestions and then test these out. As will be shown in WP 3.3, we then formulated definitive conclusions with specific implications for commissioners. Our final conclusions are relevant, possible to implement and likely to be adopted by commissioners because of this sequential process of identifying issues and then testing them out with commissioners.

The findings of this WP informed the content of the DAH toolkit in WP 3.1b.

Through their effect on WP 3.3, the results of WP 3.2 directly determined what we included and how we framed implications 1, 2 and 6 of the programme.

Work package 3.3: commissioning – seeking consensus

Addressing objective 3: to determine how transitional health care should be organised, provided and commissioned

Aims

- To synthesise learning from the programme on what and how to commission.
- To learn about the most useful way to provide research-based evidence to inform commissioners, through local and national meetings and visits.

Methods

Using results from WP 3.2 on commissioning, from WP 3.1 on DAH and from WPs 2.1 and 2.2 on features of services for transitional health care associated with better outcomes, we developed two brief documents setting out for commissioners the preliminary key research findings and implications of the programme. We wanted to learn from commissioners whether or not we were presenting material that they thought was relevant and useful, and in an appropriate manner. We presented these documents to the following groups and individuals, modifying their contents as we proceeded:

- an academic at a university in south-west England who had undertaken research into evidence-based commissioning and what influences commissioners' decision-making
- a children's health commissioner (also general practitioner) in a CCG in north-east England
- chief executives of a CCG consortium in north-east England
- chief executives of a CCG consortium in south-east England
- the Clinical Leadership Committee for specialist services at NHS England
- three telephone interviews with members of the above Clinical Leadership Committee
- a commissioner of specialist services for mental health in north England
- a commissioner of specialist services for long-term conditions in adults in the Midlands.

Thus, we talked with seven commissioners individually and with three committees at which 21 commissioners were present.

During the consultation meetings, we presented the key findings about the outcomes and lessons from the programme, focusing on the commissioning pathway and guidance. We encouraged, through discussion with various stakeholders, critical reflection to ensure the relevance of the emergent findings, identify key lessons learned, and explore the implications of these lessons for developing a nationally consistent and comprehensive approach to commissioning for transition. The discussions were central to challenging, modifying and enhancing our guidance for commissioning for transitional health care for young people with long-term conditions.

We kept notes of the content of all the meetings.

Analysis

Below are summaries of our discussions based on the notes of the meetings. We used an iterative process, based on the advice and suggestions we received, to modify and revise the summary documents and the way we presented our proposals to commissioners.

Discussion with academic in south-west England

This person explained that commissioners are likely to be interested in our broader knowledge of transition, not just in the research findings. Commissioners regularly seek advice from colleagues and trusted experts. By showing that we are also keen to learn from them, we may come to be regarded as a trusted source of information.

We should avoid jargon and make sure our messages are demonstrably relevant to patients. We should aim to present three or four key messages that are clear, practical, evidence based and cost neutral or will save money. If we wish to draw the attention of commissioners to a particular problem, especially one that they may not have been aware of, then we also need to propose a solution – preferably one that reduces cost or at least does not cost more.

Discussions with Clinical Commissioning Groups

In general, CCG commissioners said that our proposed summary documents were useful, well written and articulated. Several commissioners were enthusiastic about our work and recognised the implications for their commissioning practice. We were advised to be explicit about how proposals from the research programme would yield improved outcomes.

All commissioners welcomed the concept of DAH, although many had not encountered it before.

Commissioners asked us how they would know that providers were improving transition in their services, or at least that they were doing what they had been commissioned to do.

Discussions with commissioners for specialist services at NHS England, both at regional level and centrally

The research programme should focus on solutions.

Although the key implications of the programme could be implemented within existing service provision, with little or no extra cost, we were advised that senior managers and health-care providers tended to request extra funds whenever change was proposed; we should try to anticipate such arguments.

We were advised to set out the risks of 'not transitioning well' as well as highlighting the potential longer-term poor health outcomes.

The toolkit on DAH was considered an excellent idea. Although directed to NHS organisations (managers, teams and individual clinicians), it should also be educational for commissioners.

Those young people for whom there was no equivalent specialist tertiary adults' service might be transferred to the CCG for secondary care or to primary care. These pathways should be stated explicitly by commissioners through service specifications and contractual arrangements.

Some specifications for specialist adults' and children's services do include specific mention of transition. However, commissioners may not then follow it through to hold trusts to account. There is a need for quality standards or indicators for transition.

There was general agreement that transition is currently considered to be the responsibility of children's commissioners and children's health-care providers. To achieve change, this underlying premise needs to be challenged so that arrangements for transition include adults' service commissioners and providers. All agreed the approach to improving transition should be owned at trust board level.

Synthesis

Almost all of the commissioners we visited thought that now was an opportune time to focus on transition, in the context of the publication of the 2016 NICE guidance¹⁴ and quality standard for transition.¹¹⁷

Many commissioners stated that they had been aware of the need to address transition but had not been certain about how best to achieve this; having a relatively small number of specific evidence-based proposals from our research programme was timely and useful.

Participants acknowledged that transition is currently considered the responsibility of children's commissioners and children's health-care providers; they thought that this should change, and that commissioners and providers of adults' health care should be equally responsible.

There was also recognition of the need to achieve an integrated approach to working relationships within health and between health and social care commissioning to support shared responsibility for and ownership of transitional health care of young people. In the light of the recent publication of the NICE guidance on transition, commissioners acknowledged the potential impact of integrated commissioning for transitional health care.

There was a general, but not universal, view that it was easier to be prescriptive in service specifications if there was evidence to support it. However, this depends on what is meant by evidence. Those trained in public health were more likely to use research evidence, but other commissioners were more likely to use local information and local experiences, with research evidence influencing only 20% of them.¹¹⁸ It was, however, acknowledged that the commissioning proposals from our research programme could support the development of evidence-based commissioning for transitional health care.

Strengths and limitations

This is, as far as we are aware, the first work to study commissioning for transition. We were able to identify some major issues for commissioning, and gain an understanding of the context in which commissioners work and the parameters they use to direct health-care provider organisations in commissioning transition.

As most commissioners we talked with agreed that transition was important and that now was an opportune time to introduce change, it would have been useful to meet with commissioners who were more sceptical about the importance of transition.

Our presentations to commissioners focused on a small number of implications for commissioners; these were refined as discussed above. This inevitably meant that we could not share the detail and complexities of all of the findings of the research programme.

We have published two papers on commissioning^{112,113} and we are preparing a third.

Key findings

Box 2 shows the final version of the document, after all of its modifications, that we discussed with commissioners. It is also the final version of the document for commissioners that we presented at the dissemination meeting at The King's Fund in October 2017.

Inter-relationship with other parts of the programme

The summary of findings for commissioners in *Box 2* includes proposals about DAH that were explored in WP 3.1 and about the PBFs that were explored in the longitudinal study WPs 2.1 and 2.2.

What we learned about the commissioning process in WPs 3.2 and 3.3 has directly informed our conclusions about how commissioning might be improved, and directly informed how best to present this evidence to those responsible for commissioning health care in different NHS settings.

This WP directly determined what we included and how we framed implications 1, 2 and 6 of the programme.

BOX 2 Early findings discussed with commissioners

Successful transition is a priority for all children with long-term conditions, not just the small group of young people with very complex needs who require integrated commissioning across CCGs, Health and Well-being Boards, education and social services to fund bespoke multiagency packages of care.

1. Our findings indicate that there is an important role for commissioners of adults' services to commission transitional health care, in addition to commissioners of children's services, with whom responsibility for transitional health care currently lies.

Commissioners and providers regarded transition as the responsibility of children's services. This is inappropriate, given that transition extends to approximately the age of 24 years.

2. 'Developmentally appropriate health care' is a crucial aspect of transitional health care. Our findings indicate the importance of health services being commissioned to ensure that providers deliver DAH across all health-care services, and that this will be facilitated by commitment from senior provider and commissioner leaders.

Developmentally appropriate health care is the subject of a toolkit we have developed in which DAH is defined, and that is a resource for education and training (www.northumbria.nhs.uk/?s=dahtoolkit).

One important element of DAH is that young people, in both adults' and children's services, need to be seen by themselves for at least some of the consultation. However, our research shows that the involvement of parents in a manner that suits both parties (and this will vary between different young person/parent dyads) leads to better outcomes, in terms of satisfaction with services, disease control, continuity of health care and maturation to adult roles. Currently, adults' services often exclude parents from consultation on the grounds of confidentiality. This should not happen provided that a young person gives permission for a parent to be present for some of the consultation.

3. Where an adults' service to which to transfer young people with a long-term condition is not commissioned, our findings indicate an important role for commissioners in setting out explicitly that the transfer arrangements will usually be to primary care, and require appropriate documentation and assistance to the young person to make their first appointment.

4. Our findings indicate the importance of commissioning to ensure that a young person and family meet the adult team before transfer.

Our research shows that meeting the adult team before transfer of health care predicts better adult outcomes. The joint appointment would involve the staff who will be caring for the young person in the adults' service or primary care.

5. Our findings indicate an important role for commissioners in ensuring that health-care provider organisations establish a Transition Steering Committee with a trust-wide transition co-ordinator.

Our research suggests that this enables an organisation to develop and deliver an organisation-wide approach. We found good practice led by enthusiasts rarely generalised to other specialties or adults' services.

The text presented in this box is derived from 29 telephone conversations with commissioners (2013/14), three site visits to commissioning organisations (2015/16) and from with 28 NHS commissioners at meetings over the period 2016/17. These commissioners may not have been typical of NHS commissioners, as we have set out in limitations.

Involvement of patients, the voluntary sector and the public

Work of UP

The research programme worked with a young person's advisory group that met once per month (named by the young people as UP). It was facilitated by Gail Dovey-Pearce, co-applicant and clinical psychologist, who also provided regular updates to the Programme Management Board. The work of UP is reported under WPs 1.1 and 1.2 and in *Appendices 3* and *4*.

Voluntary sector

The Council for Disabled Children was a co-applicant to, and received a budget from, the programme. Represented initially by Helen Wheatley as co-applicant and then by Caroline Bennett, the Council attended Programme Management Board meetings quarterly in Newcastle upon Tyne. The Council:

- Worked closely with Janet McDonagh and Gail Dovey-Pearce to establish UP and to plan the first external seminar on DAH in September 2014.
- Was a key member of the groups leading WPs 1.1 and 1.2 on young person involvement and WPs 3.2 and 3.3 on commissioning.
- Assisted UP to disseminate early results of the programme on the Q-sort study, health passports and DAH (WPs 1.3, 1.2 and 3.1, respectively). This dissemination reached 75 young people through discussion groups between autumn 2015 and spring 2017. The discussion groups were preceded by a planning meeting in Newcastle upon Tyne by a steering group of young people including two members of UP. The meetings took place with CHAT in North Tyneside, two Croydon groups, Together for Short Lives, Transition2 group in Derby, and Chatterboxes youth group in Bournemouth. The meetings generated three workbooks (see *Appendix 10*) for other groups to use, especially voluntary organisations in the health sector. Since 25 September 2017, the resources have been disseminated to 469 young people's organisations and have been shared with the members of the Council for Disabled Children's networks.

Association of Young People's Health: toolkit for introducing developmentally appropriate health care across a NHS Trust

The Association of Young Person's Health advised on and set the format and style of the toolkit, based on similar work it had undertaken with the Royal College of General Practitioners. The development of the toolkit is reported in WP 3.1 and *Appendix 8*.

National Institute for Health Research meeting in Exeter on patient and public involvement involving young people, November 2013

Gail Dovey-Pearce represented the programme at this meeting. She jointly led, with Chris Morris, Associate Professor in Child Health at the University of Exeter, a workshop on engagement of young people in PPI. The presentation included a video produced by UP.

Patient and public involvement representation on the External Advisory Board

The membership of the External Advisory Board included representation from one charity, two parents of disabled children, and two young people with long-term conditions. The board met five times during the programme. Meetings were arranged to accommodate the availability of its members and at points when the input of the External Advisory Board would be useful. UP sent a representative to each meeting on a rotational basis. An informal meeting was held on the morning of the External Advisory Board meeting during which only topics of likely interest to the young people and parents were discussed. The afternoon session followed a formal agenda.

Newsletters and circulation list

We distributed a 4-monthly newsletter to all registering interest in the programme. This included the voluntary sector and, in particular, the five organisations that had provided letters of support for the programme. We also circulated seven newsletters written specifically for participants in the longitudinal study WP 2.1 (see *Appendix 10* for an example).

Two external seminars funded by The Health Foundation

We applied successfully to The Health Foundation for funding for two external seminars. Their purpose was to help us consider two important aspects of our research programme: DAH and commissioning for transition. We brought together professional experts, the voluntary sector and young people from a much wider range of disciplines and expertise than were in the programme's team. Each seminar had about 30 invited delegates.

The first seminar, on DAH, was held in Birmingham in October 2014. UP and the Council for Disabled Children contributed a great deal to the planning and presentations of this seminar.

The second seminar, on commissioning for transition, was held in London in June 2016.

The National Institute for Health Research website

Based on the annual reporting of our PPI work to NIHR and the representation of UP on the External Advisory Board, NIHR placed details of the work of UP on the NIHR website in November 2014 as an example of excellent practice.

Plain English summary for the final report

The UP group and lay members of the External Advisory Group reviewed this summary.

Impact of UP

The sponsoring Trust (Northumbria Healthcare NHS Foundation Trust) funded a satellite study, led by Gail Dovey-Pearce, to examine and understand the factors that influenced involvement of young people in the programme and what the perceived impact and benefits were.

There are no pre-defined standards against which to measure PPI work; the field is still working towards defining the processes of involvement and the 'quality' of involvement work. In this mixed-methods study, the views of the adult researchers and young people working on the programme were explored.

The evaluation drew on existing proposals and theories, including the Medical Research Council's Public Involvement Impact Assessment Framework.¹¹⁹ Members of the transition team, with knowledge of most aspects of the programme's work, carried out the data collection using qualitative methods. Further details are in our published paper.⁴⁵

Having witnessed the impacts of young people's input, the adult researchers said that they attached increasing importance to it; they valued the 'authentic voice' that UP provided. The adult researchers noted the evolving process that took the work forward and the importance of not taking an overmechanistic approach, with overdefined, a priori goals.

The young people thought that they had received a structure with overall aims but with the freedom to work within those parameters. They experienced less anxiety than the adult researchers, who had raised questions about how this process would work in practice. The young people considered that they developed personally and professionally, and that they were making a difference to the NHS and to other young people using services.

Recently, there has been a call to move away from studies of 'what' involvement achieves to those of 'how' good involvement happens.¹²⁰ The findings of this satellite study suggest that cycles of active work allow involvement, thinking and practice to progress during a project. Every research study has its own opportunities and challenges to achieve active and meaningful involvement.

Conclusion to the patient and public involvement section

Overall, we consider that young people were involved throughout the programme, with defined input to most of the WPs. They received support and developed skills to be able to take active roles in partnership with the adult researchers. A ladder of young person engagement, proposed by Hart,¹²¹ is shown in *Figure 10*. Our research programme moved flexibly between the rungs of meaningful and active involvement (rungs 4–8), while avoiding the levels that are closer to tokenism and decoration (rungs 1–3).

There are no agreed methods for involving young people in a long-term health research programme. We were fortunate to have well-funded involvement resources to support young people, and this was key to carrying out a detailed analysis of our involvement work. We could have adopted a less time-consuming and less costly approach, which could have drawn on expertise from established young people's special interest groups. We do not know whether or not such an approach would have been as successful.

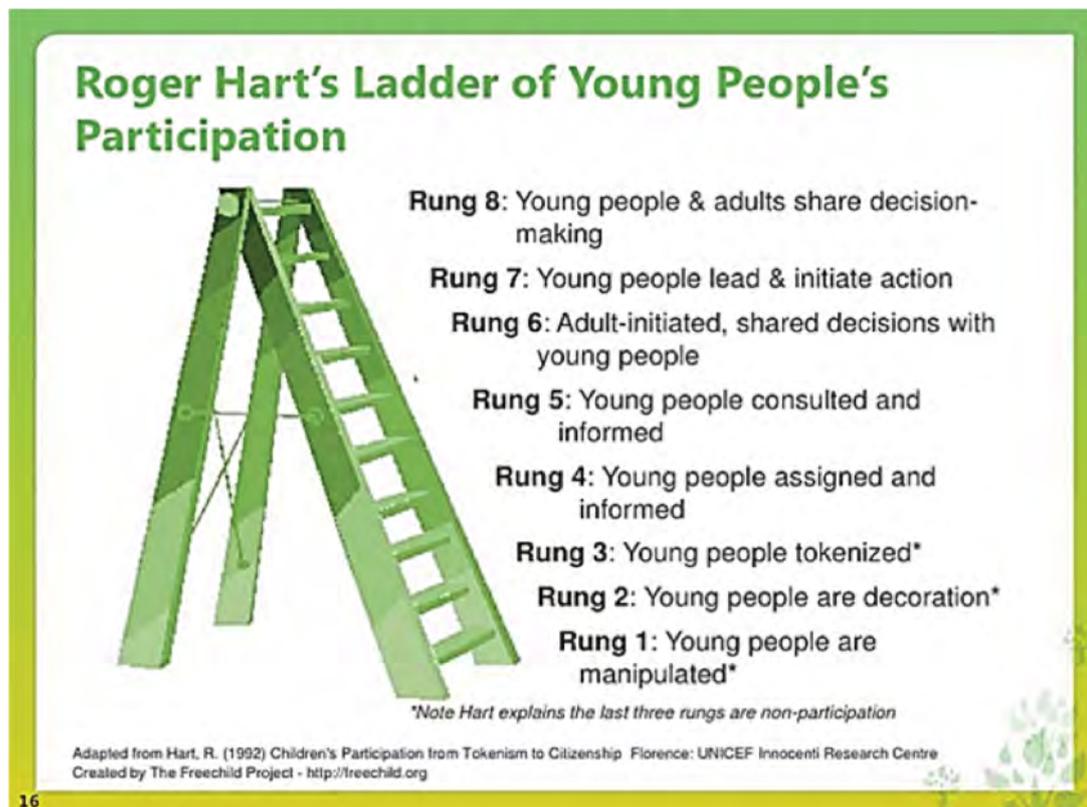


FIGURE 10 Hart's ladder of young people's participation. Reproduced with permission from Adam Fletcher, Common Action Consulting, 23 August 2017.¹²²

What was and was not successful?

What was successful?

Integration of work packages

We achieved our aim to have a set of nine WPs that were closely integrated. Our conclusions and their implications were informed by the input of young people, the longitudinal study and the work on implementation in trusts and with commissioners.

Patient and public involvement

Our PPI was of high quality. We formed this view based on the interest NIHR showed in highlighting the work of UP on its website, the invitation from the Department of Health and Social Care to UP to attend the 'take over' day, the views of the External Advisory Board and the internal evaluation undertaken by Gail Dovey-Pearce (reported in *Involvement of patients, the voluntary sector and the public* and in our published paper⁴⁵).

Small number of feasible implications

We succeeded in our intention to conclude with a small number of feasible implications that will have utility for NHS commissioners and for those responsible for the delivery of clinical services. During consultations, we were advised that documents containing large numbers of recommendations and aspirational statements are difficult for commissioners and chief executives to use.

What was not successful?

Administrative challenges

Research and development permissions

Obtaining NHS ethics permissions for the various WPs was relatively straightforward. However, obtaining research and development permissions from individual NHS Trusts was time-consuming and frustrating, not least because every trust had different procedures and expected different amounts of detail. Especially time-consuming was obtaining 'research passports' and 'letters of access' for staff who worked across universities and trusts.

Human resource issues

We experienced many staff changes over the 5 years at the levels of co-applicant, local principal investigator and research assistant. The reasons included career break, maternity leave, change of job, physical illness, mental illness and merging of NHS organisations. Despite our best efforts (which included new research assistants receiving detailed training at each change), these workforce disruptions led to some loss of continuity of contact with some young people. This may have had some adverse impact on retention rates in the longitudinal study.

Recruitment and retention of young people as research participants

Although recruitment rates were reasonably good for the ASD (50.9%) and diabetes mellitus (64.7%) groups, the rate for those with cerebral palsy was lower (25.6%).

The overall retention rate, at 70%, was in keeping with other studies.

Working with principal investigators at each site

The principal investigators had a genuine interest in research and in the Transition programme, but some had not appreciated how much time was needed to spend with their research assistant for high-quality supervision. Some of this, therefore, had to be done from Newcastle, which was sometimes challenging – not least because we could not directly influence human resource issues in each trust.

Conclusions

Introduction

Our research has taken a comprehensive approach to transition in the UK: we have involved young people, we have investigated key components of transitional health care rather than specific models and have identified components associated with better outcomes, we have examined how transition is commissioned (or, frequently, not commissioned) and we have examined how improving transitional health care in NHS Trusts could be managed.

A key theme in the qualitative research literature is that young people look forward to growing up, and look forward (albeit with some anxiety at times) to further education or training, having a job and leaving children's health services. Most studies that include young adults a year or so after transfer find that young adults say that they are pleased to have transferred to adults' health care and that most of their earlier anxieties have gone away.¹²³

Poor outcomes after transition cannot all be attributable to poor transitional health care. Young people may demonstrate poor outcomes and worrying health-related behaviour before their transition starts, which may then amplify during transition. For example, young people with poor adherence to medication for liver transplant after transfer had had poor adherence before transfer,¹²⁴ and young people with cerebral palsy have poor participation when aged 8–12 years.¹²⁵ In our research programme, we found in our baseline assessment of those joining the study that the participation of those with cerebral palsy or ASD was already lower than that of those with diabetes mellitus, and that the mental well-being of those with ASD was already lower than that of those with diabetes mellitus or cerebral palsy. Furthermore, young people's lives may be disrupted for mental health reasons or because of family or social circumstances. These young people need specialist care; however, the potential for poor outcomes should not be attributed solely to poor transitional health care but rather should take into account the problems that the young people pose for health services, regardless of their age or whether or not they are in transition.

Strengths

External evaluation of real world rather than internal evaluation of a locally developed intervention

Most groups undertaking research into transition evaluate their own interventions; essentially, they undertake an audit or clinical evaluation of their service. However, we have successfully completed a hypothesis-driven, longitudinal, observational study of features being provided, or not, across 27 NHS Trusts (35 services). We had a large cohort, and this was the first study of its kind.

Prospective data collection during transition

We captured data from young people while they were in transition and across their point of transfer. Therefore, we have information about young people's experiences and outcomes at the time they were receiving services, rather than on what they thought afterwards about what they had or should have received. This has rarely been done before and gives us confidence that our conclusions will be helpful to young people who are in the midst of transition.

Seeking findings relevant to a broad range of long-term conditions

We sought to identify the features of good transitional health care that were appropriate to those with any long-term condition. Although we selected specific conditions for the longitudinal study, they were

deliberately chosen as conditions that give rise to a wide range of different health needs, psychosocial complexity and availability of adults' services.

Engagement with commissioners

Our examination of commissioning is a novel aspect of the research programme. Arrangements for commissioning NHS services have continued to change over the period of the research programme and will continue to do so. However, the commissioning focus of our research concerns 'what' and 'how' to commission. Thus, our findings should be relevant to any commissioning structure, including whether or not commissioning and service provision are brought together in the same organisation.

Outcomes and processes measures (indicators) of transition

The range of outcomes we chose was informed by the *International Classification of Functioning, Disability and Health: Children and Youth Version*⁷³ and, after discussion with international transition researchers, conformed to many of the recommendations of later international Delphi surveys,^{42,43} as set out in *Table 14*.

Subjective well-being and participation in life (e.g. social, educational, workplace) are generic outcomes (i.e. they are not specific to a particular condition). Well-being has been emphasised as an important and often neglected outcome in the evaluation of transitional health care.¹²⁸

TABLE 14 Outcome and process measures of transition

Framework	Outcome or process measure	Captured by research programme	Instrument
NHS Outcomes Framework ¹²⁶	Preventing premature death	No	
	Enhancing quality of life for those with long-term conditions	Yes	WEMWBS
			Rotterdam Transition Profile
			Social participation questionnaire
		EQ-5D-Y	
	Helping people to recover from episodes of ill health	Yes	Condition-specific outcomes
	Ensuring that people have a positive experience of care	Yes	Mind the Gap questionnaire
	Treating and caring for people in a safe environment	No	
US Triple Aim ¹²⁷	Experience of care	Yes	Mind the Gap questionnaire
	Health of the specific population	Yes	Condition-specific outcomes
	Cost of care	Yes	EQ-5D-Y
			Capturing health-care provider contacts (and, thus, costs)
			Economic modelling

TABLE 14 Outcome and process measures of transition (continued)

Framework	Outcome or process measure	Captured by research programme	Instrument
Delphi North America ⁴²	Quality of life	Yes	WEMWBS Rotterdam Transition Profile Social participation questionnaire EQ-5D-Y
	Understanding one's condition, knowledge of medication, self-management, adherence to medication, understanding health insurance	No	
	Attending health-care appointments	Yes	We captured first appointments in adults' services
	Avoiding hospitalisation	Yes	Diabetic ketoacidosis in diabetes
	Social participation	Yes	Social participation questionnaire
Delphi International Indicators ⁴³	Patient not lost to follow-up	Yes	We captured appointments in adults' services
	Attending scheduled visits in adults' care	Yes	We captured appointments in adults' services
	Patient building a trusting relationship with adult provider	Yes	Mind the Gap questionnaire
	Continuing attention for self-management	Yes	One PBF was 'promotion of health self-efficacy'
	Patient's first visit in adults' care within 3–6 months of transfer	Yes	We captured date of first appointment in adults' service
	Number of accident and emergency visits for regular care in the past year	No	
	Patient and family satisfaction with transfer of care	Yes	Mind the Gap questionnaire
	Maintain/improve standard of disease control evaluation	Yes	Condition-specific outcomes
NICE Quality Standard ¹¹⁷	Planning for transition should start by age of 13 years	No	
	Young people should have an annual transition review meeting	No	
	Young people should have a 'named worker'	Yes	One PBF was 'having a key worker'
	Young people should meet adult team before transfer	Yes	One PBF was 'meeting adult team before transfer'
	Young people who miss their first appointment in adults' services should be contacted and given further opportunities to engage	No	

Few studies have addressed such generic, distal outcomes. Assessing such outcomes brings some attendant difficulties:

- Poor adult outcomes are not necessarily due to a failure of transition. For example, in complex physical problems such as cerebral palsy, participation outcomes for adults are particularly poor for those with more severe impairment,¹²⁹ yet participation is already much reduced in 8- to 12-year-old children with cerebral palsy.¹²⁵
- Many chronic illnesses such as diabetes mellitus, renal failure and cystic fibrosis generate more medical complications the longer the individual has the condition. Thus, even when process measures of optimal care may be satisfactory, health outcomes may worsen.

Process measures of transitional health care usually assume that providing services that young people like and maintaining a young person's contact with health services will yield better outcomes. However, although Betz and Smith¹³⁰ recognised that such measures may be relatively easy to collect, we do not know if they lead to an improvement in more distal outcomes.

Non-attendance at appointments might seem an easily captured and interpretable process measure, but we found that it is not. Many of the reasons for non-attendance are logical and valid, rather than indicating disengagement with services. In addition, rating by number or percentage of missed appointments is difficult to interpret. The number of expected appointments per year varies by condition (individuals with diabetes mellitus may expect at least four per year) and by disease activity (e.g. is the appointment for a routine follow-up or because of a worrying deterioration of disease control?).

In investigating relationships between process measures and outcomes, Cramm *et al.*¹³¹ found that satisfaction with transitional care was associated with better social and emotional quality of life 1 year later in those with diabetes mellitus or neuromuscular disorders. Sattoe *et al.*¹³² found that process measures such as 'patient not lost to follow-up', 'attending scheduled visits' and 'satisfaction with care' were not related to social participation. In their study, 'continuing attention to self-management' was the only process measure associated with better HRQoL.

Limitations

Quality of delivery of proposed beneficial features

The nine PBFs that we studied were carefully defined and captured but we could not assess the quality with which each feature was delivered. For example, 'meeting the adult team before transfer' might have been tokenistic in some trusts and carefully planned in others. However, we examined exposure to each PBF across many trusts and on three occasions, and we think that much of any variation in quality will have been ironed out by the statistical method we adopted.

Longitudinal representation of proposed beneficial features

It was relatively straightforward to examine the association of exposure to each PBF over the previous year with generic and condition-specific outcomes. However, it was more difficult to decide how to represent each PBF over the duration of the longitudinal study. What constitutes optimal exposure over 3 years when, for instance, exposure occurs in one year but not in the others? We made a pragmatic, clinically informed judgement about this for each feature. The decision tree (WP 2.1) was agreed by the team of the Transition programme, but others might have come to different judgements.

Social participation

After 1 year, we realised that the Rotterdam Transition profile was not sufficient to capture some aspects of social participation. We added a social participation questionnaire, but this could be administered only at the third and fourth visits, thereby limiting our longitudinal analysis of this outcome.

Self-reported questionnaires

Most outcome data are from self-reported questionnaires. We recognise that this may be influenced by individual reporting styles, which make valid comparisons more difficult. However, we used questionnaires that were well validated; we had a large sample size, which tends to minimise the impact of variation due to reporting style; the questionnaire completion was manualised and repeated each year so that any reporting styles would be consistent for each participant; we used a number of different instruments with score ranges suitable for group statistical analysis; and, finally, the constructs about which we were largely concerned were about young people's perceptions of their health, well-being and social participation.

Statistical power

In line with our original calculations, we had sufficient power to identify clinically significant changes in the outcomes. However, for analysis by condition, the sample size meant that some real effects of difference might not have been detectable. In relation to the PBFs, power was limited if a feature was often absent.

Economic modelling

The data collected on outcomes, costs and health service use were complex to interpret because there was loss to follow-up and differing health-care transfer arrangements, and the interval between the annual visits by the research assistants was not always 1 year (young people have a lot going on in their lives and visits often had to be rescheduled). Strict econometric modelling, despite considerable efforts, proved more difficult to undertake as a result of the nature of the data. A less robust exploratory analysis was adopted. This was able to draw out some key implications and generated a balance sheet. This was not wholly in concordance with some conclusions from other parts of the programme, but the triangulation of findings allowed key consistent conclusions and implications to be identified and reported.

Generalisability of the findings

With respect to young person involvement

Our work represents the views of young people because we consulted over 5 years with the UP group; UP disseminated findings to young-person groups across the UK; in the longitudinal study, young people with long-term conditions completed the questionnaires; and in the qualitative research work, young people were interviewed.

With respect to the longitudinal study

This is the largest sample for research in the UK in terms of examining transition longitudinally and collecting hypothesis-driven data from young people at home visits (compared with data-linkage studies from administrative data sets). Although we cannot be certain of representativeness and, therefore, generalisability across UK regions and NHS Trusts, we studied individuals from Greater London, north, south-east and south-west England, and Northern Ireland. Furthermore, we drew individuals from 27 NHS Trusts, and these trusts varied greatly in the number and variety of the PBFs they offered.

We recruited from all young people with cerebral palsy in two population registers and all young people with diabetes mellitus or ASD and an associated mental health problem in nine NHS Trusts widely distributed across England (all such young people are seen in secondary care). Thus, complete populations of individuals with one of the three conditions were sampled from (e.g. rather than those attending particular schools, specialised tertiary health-care services or voluntary support groups).

The three conditions chosen were exemplars of chronic illness (diabetes mellitus), complex physical impairment (cerebral palsy) and neurodevelopmental impairment (ASD); these were chosen deliberately to provide variation in health needs, psychosocial complexity and availability of adults' services. Thus, we consider that generalisability to other conditions is likely. This is supported by the fact that studies of young people with specific conditions usually conclude that the important issues are generic rather than

about the specific disease (e.g. diabetes mellitus,¹³³ inflammatory bowel disease,¹³⁴ cystic fibrosis,¹³⁵ attention deficit hyperactivity disorder,¹³⁶ urology¹³⁷ and disabilities¹³⁸).

However, as intended in our protocol, we did not include individuals with a significant learning disability, and our findings cannot generalise to this group. Nor did we include those with degenerative conditions. If progression is slow, as for instance with cystic fibrosis, transition is similar to that in other conditions and a formal transfer of health-care needs to take place. If progression is rapid, as for instance with some brain tumours, then the wider social and educational aspects of transition take place very differently. Furthermore, it may not be appropriate for transfer of health care to occur because it would be unnecessarily disruptive, with the young person likely to become incapacitated and/or die fairly soon after transfer; rather, advance care planning should be in place, as recommended by Together for Short Lives.¹³⁹

The 374 participants did not differ significantly from those declining to take part, other than for a small effect of deprivation. The distribution of severity of the three conditions was similar to that in national samples.⁶² Those with the conditions had a wide range of severity; for example, the young people with cerebral palsy ranged from wheelchair users to those with independent ambulation. Attrition did not appear to create a bias, as there were no significant differences between those remaining and those not remaining in the study with respect to sex, age, condition, diabetes site or ASD site. In Northern Ireland, there was a small effect of deprivation on the attrition of those with cerebral palsy. Thus, we think that, after non-participation and attrition, our study group continued to be representative of those we aimed to recruit.

With respect to commissioning

Our work is novel. We interviewed, carried out case studies and consulted widely with commissioners and senior managers, CCGs and specialised commissioning, and regional and national specialised commissioning, and in many locations across the UK. Thus, we think that our findings are generalisable to the UK and to other countries with well-developed health-care provision.

With respect to the economic analysis

As we state in our account of WP 2.3, strict econometric modelling, despite considerable efforts, proved too difficult to undertake because of the nature of the data, and a less robust exploratory analysis was adopted. This drew out some key implications and generated a balance sheet. This was not wholly in concordance with some conclusions from other parts of the programme, but the triangulation of findings allowed key consistent conclusions and implications to be identified and reported.

Interpretation of the findings in the light of current policy, practice and research

Policy context

In *Setting the scene* at the start of the *Synopsis*, we summarised the policy context that led to our application for a programme of research. Since then, there have been a number of key developments in England. NICE guidance on transition was published in 2016.¹⁴ A national CQUIN for transition of those with mental health problems³⁵ was introduced by NHS England in 2018. Guidance on commissioning for transition for individuals with special educational needs was published by NHS England in 2018.¹⁴⁰ Following the death of an individual with ASD just before the transfer of their care, in July 2018 the Healthcare Safety Investigation Branch published a report that included recommendations for improving the services for young people with mental health problems in transition.¹⁴¹

In 2018, the Chancellor of the Exchequer indicated that there would be considerable financial investment in the NHS over the following 10 years. We were asked, based on our research findings, to contribute a proposal for improving transitional health-care practice. Proposals about transitional care were subsequently mentioned in five places in the 2019 *NHS Forward Plan*.¹⁴²

Commissioning for transition

Our literature review (see *Appendix 9*) found no published or grey literature about commissioning for transition. Our discussions with commissioners showed that transition has been regarded as the responsibility of children's service commissioners and children's service providers. This is inappropriate as transition extends to approximately the age of 24 years. Commissioners also tend to consider the numbers of young people in transition to be small; this seems to be because commissioners may be actively engaged with only the small number of very complex cases of young people who require bespoke packages of care integrated across health care, social care and education. Commissioners also reported that a lack of evidence made it difficult for them to be prescriptive about transitional health care. We hope that our research programme will help in this respect. Similarly, commissioners found it difficult to be prescriptive because they lacked indicators with which to assess compliance. Development of indicators is needed, and a workshop on indicators for transition was led by NHS England at the meeting in London in October 2017 at which we disseminated our complete findings for the first time.

Developmentally appropriate health care

The concept of DAH is now widely accepted in the UK (e.g. by NICE¹⁴ and the Royal College of Physicians¹⁴³) and internationally (e.g. in Canada¹⁴⁴ and the USA¹²⁸). Good practice in adolescent and young adult health, of which DAH is the foundation, applies particularly to the group of adolescents and young adults in transition. This may suggest that those providing care need an appreciation of DAH, and this will be the case particularly for the care of young people with long-term conditions who may have additional conditions or complications requiring consultations in a range of settings with a number of specialists. Such care is equally important in adults' and children's services due to the ongoing development of young people up to the approximate age of 24 years. We have amplified the evidence base for the concept of DAH. We have shown, within England, the key organisational factors that promote and inhibit the implementation of DAH. A consequence of providing DAH across a NHS organisation is that the potential problem of 'at what age should a young person transfer' ceases to exist because the young person's developmental needs are taken into account by both adults' and children's services.

In WP 3.1, we identified the barriers to introducing DAH as (1) no single group in provider organisations being responsible for young people, (2) a perception (incorrect) that only small numbers of young people attend hospital and (3) concerns that staff may not have the necessary mindset or skill set. Our findings indicated the importance of health services being commissioned to ensure that providers deliver DAH across all health-care services, and that this could be facilitated by commitment from senior provider and commissioner leaders. Our work on commissioning in WPs 3.2 and 3.3 found that commissioners understood the importance of DAH and the need for it to be commissioned.

Although these organisational barriers and facilitators would apply to many health systems where change was sought, our work is the first to examine them in the context of DAH.

In WP 3.1, we developed a 'toolkit' to support the introduction of DAH; this is in *Appendix 8* and available at www.northumbria.nhs.uk/?s=dahtoolkit. Training of staff in NHS organisations in DAH will be needed. We hope that the toolkit will be useful both in itself and because it points to other training resources.

Engaging with clinical services: ensuring continuity

Our qualitative work in WP 2.2 found that the point of transfer (whatever the adult provision might be) is intrinsically disruptive for families and young people. Families and young people will have been familiar, often for many years, with how to navigate children's services, who to talk with if worried, where to get medication from and so on. Transfer disrupts their knowledge and relationships, and thus their confidence and trust, not because the adults' services are inherently better or worse but because of the change that, at first, families and young people do not fully understand or feel confident to engage with. Thus, there is a need to move away somewhat from asking how young people are helped to mature and adjust,

to asking how systems and processes for young people and their families might enable them to regain their knowledge, confidence and trust as quickly as possible. These processes might include ensuring that parents remain closely involved if the young person wants this (as they provide continuity); and meeting with the adult team before transfer (which may remove some uncertainty, especially if this meeting introduces the professional whom the young person will be seeing in future). These are two of the PBFs that were associated with better outcomes in WP 2.1. The above interpretation reinforces the conclusion of a major study by Allen *et al.*,^{58,145} albeit that it focused solely on those with diabetes mellitus.

Improving transition across a NHS organisation

Several of the trusts we visited, or whose managers we talked with in WP 3.2, had a Transition Steering Committee, chaired or convened by a trust-wide transition co-ordinator. These arrangements were effective in bringing about change across adults' and children's services and across specialties. They took advantage of the skills and enthusiasm of those already providing good practice and they organised trust-wide training that brought together those from different specialties and from adults' and children's services.

Young people's approach to transition

In WP 1.3, the Q-sort study identified four interaction styles that young people adopted when approaching transition: 'laid back', 'anxious', 'autonomy-seeking' and 'socially oriented' (welcoming support from, and frequent discussions with, family, friends and health-care professionals). Discussing and understanding young people's views and preferences about and during transition would be likely to help clinicians and young people develop personalised planning for transition, and effective engagement with adults' care.

In the discussions led by UP and the Council for Disabled Children with other young person groups (see *Involvement of patients, the voluntary sector and the public*), this finding was validated. Young people readily identified with one of the styles. However, some also said that their style had changed; for instance, when they were younger they might have been 'anxious' but some years on they were now 'seeking autonomy and being in control'.

The literature on asking young people about their transition is large (including systematic reviews^{44,51}) and we did not want to repeat such studies. However, 'Q-sort' methodology has not been used before in transition and, in identifying these four interaction styles, we have added new findings to the literature.

Changes in outcomes in the longitudinal study (work package 2.1)

Average satisfaction with services was reasonable at baseline (rating of ideal service only slightly higher than rating of actual service). It remained steady for those with diabetes mellitus but worsened significantly for those with ASD or cerebral palsy across the study period. The importance of transition has been recognised by diabetes services for over a decade, and the Diabetes Tariff¹⁴⁶ includes transition. It is probable that, in services for ASD and cerebral palsy, the transition process is less streamlined, with consequent reductions in young people's and parents' satisfaction with services.

For those with diabetes mellitus or cerebral palsy, their average subjective well-being at baseline was similar to that of the general population and remained so during the study. Those with ASD and an associated mental health problem reported significantly lower well-being than the other two groups and this difference persisted over the course of the study – almost certainly due to the impact of their mental health problem.

For participation in life activities, there were significant differences between the three conditions, with young people with diabetes mellitus in more independent phases of transition than those with ASD or cerebral palsy. All made progress over time but those with diabetes remained more independent.

Condition-specific measures worsened over the course of the study for those with diabetes mellitus or cerebral palsy. The proportions of young people with ASD with 'abnormal' anxiety and depression scores remained the same from baseline to the 'final' visit.

Proposed beneficial features

We found that the provision of our nine PBFs in 2013/14 was patchy. Fewer than half of the health services stated that they provided 'age-banded clinics', 'transition plans', 'transition manager for clinical teams', 'protocols for promoting health self-efficacy' or 'holistic life-skills training' (all but 'transition manager for clinical team' are recommended by NICE¹⁴). Features were provided less often in services for those with cerebral palsy or ASD than for those with diabetes mellitus. Thus, there is much room for improvement across all of the services attended by the young people recruited to this UK-wide study.

Three PBFs were consistently associated with better outcomes in the longitudinal study WP 2.1: 'appropriate parent involvement', 'promotion of health self-efficacy' and 'meeting the adult team before transfer'. We advise that strong effort be directed to maintaining or introducing them to a high standard.

In WP 2.1, 'appropriate parent involvement' was found to be associated with outcomes concerning satisfaction with services, well-being, some aspects of participation and meeting the health needs of those with cerebral palsy. Interviews in WP 2.2 revealed how important parents were to the process of transition. The involvement of parents as young people think appropriate is a crucial element of DAH. In WP 2.3.1, the DCE showed that 'appropriate parent involvement' was the second most highly rated choice. WP 2.3.2 (economic modelling) concluded that 'appropriate parent involvement' would be likely to maximise service uptake and may represent good value for money.

Allen *et al.*'s¹⁴⁷ study of diabetes and transition emphasised the importance of parents during transition. Heath *et al.*'s⁸³ systematic review of studies of parents' perceptions of their role in transition concluded:

Parents can be key facilitators of their child's healthcare transition, supporting them to become experts in their own condition and care.

Heath *et al.*⁸³

Two other recent reports^{148,149} investigated the parent/young person dyad and reached similar conclusions to ours: that the parent and young person need to share care but that this dynamic will continuously change. NICE¹⁴ emphasises 'appropriate parent involvement' throughout its report; it was an overarching principle in section 1.1.1, and sections 1.2.19–1.2.22 were devoted to the involvement of parents.

In WP 2.1, 'promotion of health self-efficacy' was found to be associated with outcomes concerning satisfaction with services and meeting health needs of those with cerebral palsy. Interviews in WP 2.2 revealed that both parents and young people thought that this was a central element of transition. The interviews also suggested that health self-efficacy may be not only about managing one's condition but also about how to manage one's health services. 'Promotion of health self-efficacy' is a central component of DAH. WP 2.3.2 (economic modelling) concluded that 'promotion of self-efficacy' would be likely to represent good value for money.

Klaasen *et al.*¹⁵⁰ developed a health self-management scale. Sattoe *et al.*¹⁵¹ found that 'continuing attention to self-management' was associated with better HRQoL. There is conflicting evidence about whether a structured approach, including motivational techniques for raising health self-efficacy in diabetes mellitus, influences glycaemic control.^{152,153} Mackie *et al.*¹⁵⁴ showed the benefit of a 1-hour, nurse-led intervention to promote knowledge and confidence about one's condition, in this case congenital heart disease. NICE¹⁴ (in section 1.2.17) recommends 'promotion of health self-efficacy'.

In WP 2.1, 'meeting the adult team before transfer' was found to be associated with better outcomes in participation and in diabetes management. There was a negative association between having met with an adult team and one of the Mind the Gap subdomains. We infer that lower satisfaction was due to the young person's lack of familiarity with the adult team. Interviews in WP 2.2 found 'meeting the adult team' to be important, although sometimes the arrangements rendered it ineffective because the young person could not attend if the opportunity was only offered once per year, or the young person met someone who was subsequently not responsible for their care. If undertaken well, the meeting really helped with the potentially disrupting and disorientating consequences of transfer described in WP 2.2. WP 2.3.2 (economic modelling) concluded that evidence of the value for money of 'meeting the adult team' was ambiguous.

Our definition of meeting the adult team before transfer included having clinics where adult and paediatric physicians consulted jointly. In other studies, such joint clinics have shown to lead to improvements in process indicators in renal services,¹⁵⁵ diabetes services,¹⁵⁶ urology services¹³⁷ and rheumatology services.¹⁵⁷ NICE¹⁴ (in sections 1.3.5 and 1.3.6) recommends 'meeting the adult team before transfer'.

One PBF, 'having a key worker', was significantly associated with greater service satisfaction only during the second study period (between visits 2 and 3); it had no associations with longitudinal analysis and some negative associations with participation.

Sloper *et al.*¹⁵⁸ found strong evidence for the value of key workers for families with children with special educational needs. NICE¹⁴ (in sections 1.2.5–1.2.10) calls for a 'named worker'.

The difficulty with 'key worker' may be the practicality of operationalising this rather than the principle of having one. Staff changes as a result of leaving post, restrictions in job plans, service restructuring, or sickness or maternity leave make it difficult to provide a key worker for all young people with long-term conditions, even though it may work well for the few for whom there is continuity.

Five PBFs had few significant associations with better outcomes: 'holistic life-skills training', 'transition plan', 'age-banded clinic', 'having a transition manager for clinical team' and 'co-ordinated team'. WP 2.3.2 (economic modelling) did not find any benefit in terms of costs or HRQoL. Nor were the last three recommended by NICE.¹⁴

Regarding 'having access to holistic life-skills training', our qualitative work in WP 2.2 found that all parents and young people thought that signposting to educational and social services and to charities was essential. Some services were more ambivalent, and were not even sure if it was their responsibility to probe these wider areas of a young person's life.

'Having a written transition plan' is recommended by NICE¹⁴ (in section 1.3.4) but it does not specifically mention that the plan should be a written document. Qualitative work in WP 2.2 found conflicting views about a 'written' plan: such plans take time to draw up, they become out of date and they get lost, and who should hold them? Some professionals said that personal interaction was far more important. On the other hand, the lack of a formal plan left many families disorientated and wondering if the service did not have the resources to provide for care after transfer.

These last six PBFs, for which we did not find evidence of benefit, were included in our programme because there had been a number of small studies, typically internal evaluations of local interventions, that suggested benefit (e.g. benefit of a transition manager for clinical team¹⁵⁹). We acknowledge that the absence of evidence is not the same as lack of benefit. However, our study was hypothesis driven and had clear, pre-identified outcomes. Even if these five PBFs should not be rejected, our findings indicate that resources (which include training) would be best directed first to embedding into service provision the three beneficial features for which we found convincing evidence of benefit.

Health economics

The short-term cost of introducing the three key PBFs that we found to be associated with better outcomes will depend on precisely how the feature is delivered. If a NHS organisation intends to adopt a trust-wide approach to transition, including ensuring that services are developmentally appropriate, then it could be advantageous for them to consider allocating sessions to a co-ordinator. Such a role could involve chairing a Transition Steering Committee and assisting directorates and teams of health-care professionals and providing instruction in DAH. The toolkit we have developed could assist this process (see *Appendix 8*).

Arranging for every young person and their parents to meet an adult team member before transfer will require organisation and clinic time. Where there are already clinics at which adults' and children's clinicians consult together, such meetings happen automatically. However, where care is being transferred to primary care, a meeting attended by a member of the children's services team may enable this feature and support the young person's confidence to make further appointments.

The DCE (WP 2.3.1) suggested that, over a 10-year time horizon, a service allowing appropriate parental involvement, where the same staff are seen at each clinic, and where young people have the opportunity to make decisions about care, would maximise uptake. A service involving 'appropriate parent involvement' and 'protocol for promotion of young person's confidence in managing their health condition' may represent good value for money, but a service involving a 'transition manager for clinical team' or 'age-banded clinic' might represent less value for money. However, the results are tentative as the economic evaluation was exploratory. The balance sheet highlighted that adoption of the new approaches to transition, outlined above, needs to balance the extra cost against the increased engagement with health services and prevention of deterioration in health in the long term.

Key implications for the practice of commissioners, managers and clinicians

Our findings indicate the following:

- An important role for commissioners of adults' services is in commissioning for transitional health care, in addition to the current commissioning that is undertaken almost solely by children's commissioners. Commissioners and providers regarded transition as the responsibility of children's services. This is inappropriate, given that transition extends to approximately the age of 24 years. Sometimes a specialist secondary care adults' service does not exist and transfer will occur from a specialist children's service to primary care. Our findings indicate an important role for commissioners in setting this out explicitly, including the need for appropriate documentation and assistance to the young person to make their first appointment.
- Developmentally appropriate health care is a crucial aspect of transitional health care. Our findings indicate the importance of health services being commissioned to ensure that providers deliver DAH across all health-care services, and that this will be facilitated by commitment from senior provider and commissioner leaders.

DAH recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms, DAH focuses on health-care professionals' approach to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.

- The importance of NHS organisations adopting a trust-wide approach to implementation of better transitional health care. In many trusts, good practice led by enthusiasts rarely generalised to other specialties or to adults' services. Where organisations had a Transition Steering Committee, chaired by a trust-wide transition

co-ordinator, this took advantage of the skills and enthusiasm of those already providing good practice, and assisted with training and consistent implementation in adults' and children's services and across specialties.

- The importance of joint planning between children's health-care providers, adults' health-care providers and primary care; this is likely to improve both the transfer of individual young people and the adoption of ways of working that improve care for this population.
- The importance of adults' and children's health-care providers exploring routinely with a young person how they approach transition, taking account of the young person's interaction style and personalising the clinical approach thereafter.
- Young people adopt one of four broad interaction styles when approaching their transition: 'laid back', 'anxious', 'autonomy-seeking' and 'socially oriented' (i.e. welcomed support from and frequent discussions with family, friends and all health-care professionals).
- The features 'appropriate parent involvement', 'promotion of health self-efficacy' and 'meeting the adult team before transfer' were associated with better satisfaction with services, participation, subjective well-being and measures of disease control. These findings provide practical content to be considered in NHS commissioning specifications.
'Having a key worker' inconsistently predicted better outcomes; 'having a transition plan', 'co-ordinated team', 'attending an age-banded clinic', 'having a transition manager for clinical team' and 'having access to holistic life-skills training' were not associated with better outcomes.
- Maximal service uptake could be achieved by a service that encourages parental involvement, ensures that the same staff are seen at each clinic, emphasises the importance of good communication with young people, and encourages young people to make decisions about their care. A service involving a 'parental involvement that suited both parent and young person' and a 'protocol for promotion of young people's confidence in managing their health condition' may offer good value for money, but a service involving a 'transition manager for clinical team' or an 'age-banded clinic' is less likely to offer value for money.

Finally

Parents and young people often have negative impressions of what care will be like in adults' services.¹⁶⁰ They may think that adults' services will be less supportive, more fragmented and not linked sufficiently to children's service providers. However, our findings indicate that there are benefits and positives of transferring to adults' health care, advantages that could be planned for and explained to young people and their parents by children's services. Transitions are a part of all of our lives, although planning for these normal developmentally appropriate changes may be more challenging for those with long-term health conditions.

Recommendations for future research

Recent years have seen an increase in research around transition, but most studies are small-scale and difficult to generalise from. Systematic reviews published during the research programme highlight the difficulties of drawing conclusions from the studies reviewed. The Cochrane review³⁶ and NICE guidance¹⁴ recognised that the evidence base was weak. We think that the next 2 years would be too early for a further major literature review.

We suggest, in order of priority, the following areas for further research:

1. How might the findings of the programme be introduced and implemented by commissioners and NHS organisations?
Although no study can be definitive, we think that we have reported sufficient evidence to justify research into observation and evaluation of the implementation of the findings in a range of trusts and long-term conditions. Our conclusions are drawn from triangulation of quantitative, qualitative and health economic studies.
2. The role of primary care. This was also a NICE research priority.¹⁴ What are the most effective and efficient ways for primary health-care services to be involved in improving transition and in following up young people after transfer, whether or not they meet the criteria for adults' services?
Such a study would also address the needs of young people with conditions such as moderate asthma or eczema, who are usually looked after entirely by primary care.
A systematic review of primary care interventions around transition found only three articles, of which only one was set in general practice, and that was in the USA.¹⁶¹ The review concluded that there was a need for intervention studies to guide improved integration of primary and secondary care over the period of transition.
3. Managing one's health. This was also a NICE research priority.¹⁴ What is the best way to support young people to manage their health?
We found that promotion of health self-efficacy during transition was associated with better outcomes. Sattoe and colleagues have completed a body of work investigating how to promote health self-efficacy.^{162,163} Further research is needed to understand how self-management training can be best built into transition planning, across a range of health conditions, including mental health. This, therefore, is a research question for clinical and health psychology research to understand the context and mechanisms of behaviour change during health-care transition.

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Chairperson: Simon Pleydell. Members: Shona Chambers (Cerebra), Lizzie Chambers (Together for Short Lives), Allan Colver (chief investigator), Jim Mackey and Chris Price (sponsoring trust), Carl May (medical sociology), Alison Murray (parent), Marij Roebroek (international advisor), AnneLoes van Staa (international advisor), Scott Wilkes (academic general practitioner), NIHR advisors, and rotating members from the programme's young's person advisory group, UP.

Programme Management Board

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Contributions of authors

Allan Colver is Professor of Community Child Health at Newcastle University and a Consultant Paediatrician. He was the grant holder and led the programme of research. He led WP 3.3 and was directly involved in all other WPs except 2.2 and 2.3. He drafted the final report and is responsible for the final version and submission to NIHR. He is the corresponding author and guarantor of the work.

Tim Rapley was Senior Lecturer in Medical Sociology at Newcastle University and is now Professor of Applied Health Care Research at Northumbria University. He was a co-applicant. He led WP 2.2, co-led WP 3.1 and was directly involved in WP 1.1. In WPs 2.2 and 3.1, this work involved designing the qualitative work, supervising research assistants and analysing the transcripts of qualitative data. He assisted with many aspects of the engagement of young people in the programme's work. He co-designed the DAH toolkit. He contributed detailed adjustments to the draft report and approved the final version.

Jeremy R Parr is Professor of Paediatric Neurodisability at Newcastle University and a consultant paediatrician. He was a co-applicant. He was directly involved in WPs 1.3, 2.1, 2.2 and 3.1. This work involved co-designing these quantitative and qualitative studies, contributing to supervision of research assistants, lead contacts with clinicians for the Q-sort study, overseeing recruitment of people with diabetes mellitus for the longitudinal study, assisting with design of the DCE, and co-designing the DAH toolkit. He contributed detailed adjustments to the draft report and approved the final version.

Helen McConachie is Professor of Child Clinical Psychology at Newcastle University. She was a co-applicant. She led WP 2.1. This work included involvement in the design of the original programme, co-design of the longitudinal study, arranging training of the research assistants, monitoring data collection and completeness, and advising on data analysis. She contributed detailed adjustments to the draft report and approved the final version.

Gail Dovey-Pearce is a Consultant Clinical Psychologist at Northumbria Healthcare NHS Foundation Trust. She was a co-applicant. She led WPs 1.1 and 1.2 and was directly involved in WPs 2.1 and 3.1. Her work involved leading on the engagement and involvement of young people, including setting up and running UP, supervising the collection of longitudinal data across two sites, and facilitating the qualitative interviews at one site. She contributed detailed adjustments to the draft report and approved the final version.

Ann Le Couteur is Professor of Child and Adolescent Psychiatry at Newcastle University and a consultant child and adolescent psychiatrist. She was a co-applicant. She was directly involved in WPs 2.1, 2.2, 3.2 and 3.3. This work included involvement in the design of the original programme, liaising with sites that recruited those with ASD, interviewing commissioners and critically reviewing qualitative and quantitative data. She contributed detailed adjustments to the draft report and approved the final version.

Janet E McDonagh is a Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology at the University of Manchester. She was a co-applicant. She co-led WP 3.1 and was directly involved in WPs 1.1 and 1.2. This work included involvement in the design of the original programme, being local principal investigator at one of the three participating sites of WP 3.1, interpreting data and writing papers from WP 3.1, providing direct input and support for the health passport work of WP 1.2, and identifying and

establishing links with relevant organisations elsewhere in the UK for WPs 1.1 and 1.2 to ensure generalisability of the outputs of the programme. She co-designed the DAH toolkit. She contributed detailed adjustments to the draft report and approved the final version.

Caroline Bennett is Assistant Director of the Council for Disabled Children, London. She was a co-applicant. She was directly involved in WPs 1.1, 1.2 and 3.1. This work involved regular assistance with the engagement of young people in the programme's work. She facilitated workshops in London and Newcastle that enabled young people from across the country to discuss preliminary results of the programme. She developed facilitator guides for the subsequent rollout of these workshops. She contributed detailed adjustments to the draft report and approved the final version.

Jennifer Hislop was a Research Associate in Health Economics at Newcastle University. She contributed to WPs 1.3 and 2.3. This work involved interviewing young people in the WP 1.3 Q-sort study and analysing the data. She contributed to one published paper. In WP 2.2 she developed a DCE and she modelled the health economic data. She contributed detailed adjustments to the draft report and approved the final version.

Gregory Maniatopoulos is a Senior Research Associate in Medical Sociology at Newcastle University. He led WP 3.2 and was directly involved in WP 3.3. His work involved analysis of qualitative data, three in-depth site visits, and contributions to two submitted papers, one of which he led. He contributed detailed adjustments to the draft report and approved the final version.

Kay D Mann was a Research Assistant in Epidemiology at Newcastle University. She contributed to WP 2.1. This work involved cleaning, coding and analysing data from all collection phases. She contributed detailed adjustments to the draft report and approved the final version.

Hannah Merrick was a Research Assistant at Newcastle University. She contributed to WP 2.1, drafted and distributed newsletters, organised internal seminars and identified relevant new publications in the field. The work in WP 2.1 involved collecting, checking and analysing data. She contributed to two published papers. She contributed detailed adjustments to the draft report and approved the final version.

Mark S Pearce is Professor of Applied Epidemiology at Newcastle University. He was a co-applicant. He was directly involved in WPs 2.1 and 2.3. This work involved supervision of a research assistant and detailed discussions about methods of analysis and interpretation of results. He contributed detailed adjustments to the draft report and approved the final version.

Debbie Reape was Deputy Director of Nursing at Northumbria Healthcare NHS Foundation Trust. She was a co-applicant. She was directly involved in WPs 1.1, 1.2, 3.1 and 3.2. This work involved assistance with many aspects of the engagement of young people in the programme's work. As senior manager in the sponsoring trust, she facilitated meetings and provided contacts for interviews with commissioners. She participated in data collection in WP 3.2 at meetings with commissioners. She contributed detailed adjustments to the draft report and approved the final version.

Luke Vale is The Health Foundation Professor of Health Economics at Newcastle University. He was a co-applicant. He led WPs 1.3 and 2.3 and was involved in WP 3.2. This work involved planning the economic work and supervising a research assistant in this work. He also supervised a research associate in the WP 3.2 on commissioning. He contributed to three published papers from these WPs. He contributed detailed adjustments to the draft report and approved the final version.

Publications

Watson R, Parr J, Joyce C, May C, Le Couteur A. Models of healthcare transition for young people with complex health needs: a scoping review. *Child Care Health Dev* 2011;**37**:780–91. <https://doi.org/10.1111/j.1365-2214.2011.01293.x>

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Data-sharing statement

Anonymised data will be made available to the scientific community with as few restrictions as feasible. Qualitative data cannot be released due to anonymity and consent concerns. All enquiries and data requests should be submitted to the corresponding author for consideration (using a specific form available on request). Access to data may be granted following review.

Patient data

This work uses data provided by patients and collected by the NHS as part of their care and support. Using patient data is vital to improve health and care for everyone. There is huge potential to make better use of information from people's patient records, to understand more about disease, develop new treatments, monitor safety, and plan NHS services. Patient data should be kept safe and secure, to protect everyone's privacy, and it's important that there are safeguards to make sure that it is stored and used responsibly. Everyone should be able to find out about how patient data are used. #datasaveslives You can find out more about the background to this citation here: <https://understandingpatientdata.org.uk/data-citation>.

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Appendix 1 National Institute for Health Research Programme Development Grant

In 2010, we were awarded a Programme Development Grant (RP-DG-1108-10015).

In summary:

- We learnt from a young person's group how to develop and run a young person's advisory group for a programme.
- We found widespread interest in the research from voluntary organisations; the Council for Disabled Children joined the application.
- We identified 10 NHS Trusts that would recruit participants to the programme.
- Meetings with trust chief executives led to modifications to the content of the proposal for a programme.
- A literature review found that few studies that evaluated transitional health care assessed whether or not the services were sustainable or what helped transition in the long term.
- We estimated the number of young people our work could benefit in the UK as 25,000 per year group.
- We piloted questionnaires. We researched different methods for approaching, recruiting and retaining young people in a programme.

Appendix 2 Management and governance of the research programme

An External Advisory Board met once a year, chaired by the chief executive of a NHS Trust (see *Acknowledgements*).

The programme was managed by the Programme Management Board. This was chaired by the chief investigator and consisted of the programme's co-applicants and two adult physician advisors. It met every 3 months.

A senior management team, consisting of the chief investigator and the leads for the qualitative, quantitative and health economic work, met every 2 weeks.

The programme's young people's advisory group (see WP 1.1) met every month.

Each year a report was submitted to NIHR and subsequently approved.

All studies received positive ethics opinions from either the NHS or Newcastle University.

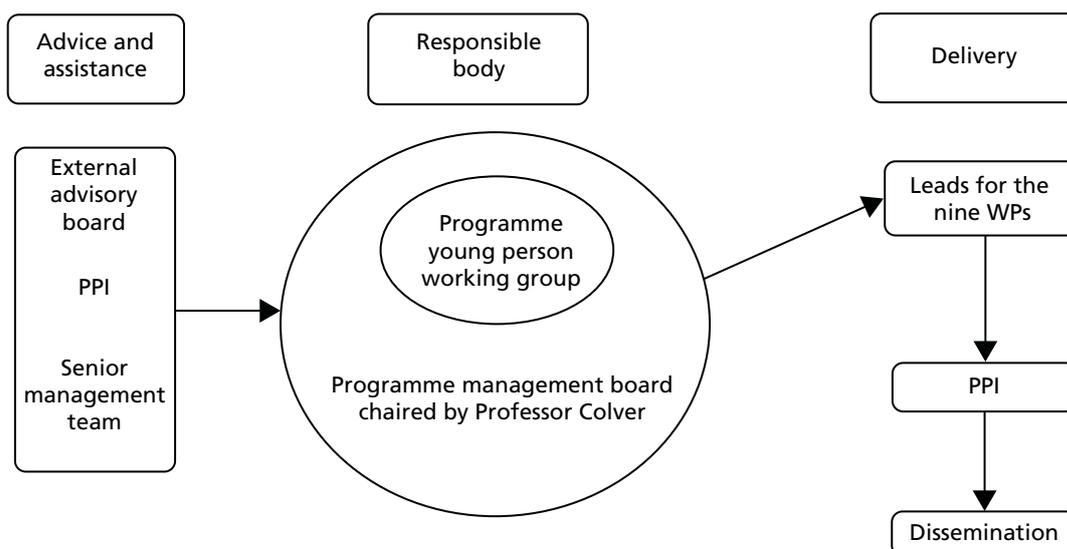


Figure 11 Management structure.

Appendix 3 Work of UP

In this appendix and *Appendix 4* we present some examples of the work of UP.

UP design: Certificate of achievement for research participants

Downloaded from <https://www.researchprotocols.org/2019/1/e14222/>



UP Launch presentation

Presentation Overview

- Welcome (Ed)
- Introduction (Sophie)
- The Role of UP (George)
- The Importance of Our Research & Case Study (Ed)
- Our Completed Achievements (Joseph & Sophie)
- Concluding Statements (Ed)



Introduction

- Led by NHCFT with researchers from Newcastle university
- Funded by the NHR
- 5 year study involving 500 young people
- Conditions which include Diabetes, Cerebral Palsy, Autism
- Aims – to improve care for teenagers as they move from children to adult healthcare services



The Role of

- To represent the voices of young people
- HONEST communication between UP and the PMB
- The opportunity for young people and professionals to work alongside as equals
- Democratic decision making paramount
- Work on serious issues and tasks in partnership with the PMB
- Question the decision making of the PMB



The Importance of Our Research

- We believe the NHS is not getting services right for young people
- We need to get it right for future generations
- We need to keep The World informed on new & important discoveries
- To leave a **GOLDEN** legacy for the future generations, to look UP to us!



Our Completed Achievements

- Peer support workers recruited research staff to assist
- Group formation & familiarization
- Group name and designed logo
- Code of conduct and contract
- Designed certificates
- Informed the Q sort study





UP Poster: What we've have been UP to

Funded by
NICE
National Institute for
Health Research

WHAT WE'VE BEEN UP TO

United Progression: The UP Group
The Young People's Working Group on the NHS Transition Research Programme

<p>Help With The Other Transition Programme Workstreams</p> <p>In answer to the question what is "Developmentally Appropriate Healthcare?", UP filmed 'Transition's Got Talent', which took a humorous look at the important issue of how health professionals interact with young people.</p> <p>https://research.ncl.ac.uk/transition/youngpeoplepage/theyoungpeopleworkinggroup-up/250079</p> <p>Developmentally Appropriate Healthcare is young-person-centred, flexible, and responsive to the changing developmental needs of young people.</p> <p>The DVD was shown at a Health Foundation seminar on Developmentally Appropriate Healthcare.</p> <p>Following the seminar, the National Institute for Health Research mentioned the film on its website, as part of an article showcasing UP's contribution to health research.</p> <p>Designed a recruitment poster and leaflet for the longitudinal study which followed young people for four years as they moved from paediatric to adult services.</p> <p>Designed certificates for young people completing every year of the 4-year longitudinal study.</p> <p>Analysed and commented on the 'Proposed Beneficial Service Features', being investigated in the main study, in line with their own experience of transition.</p> <p>Trialed and commented on the Young People's Preferences Study—Qsort tool, examining service features rated as important to young people themselves.</p> <p>Participated in the Impact Study, exploring the process and benefits of involving young people in the Transition Research Programme.</p>	<p>Linked UP With Local And National Organisations</p> <p>Takeover Day at the Department of Health, London, which allowed young people's voices to be heard. Showcased Transition & UP's research and also learned about other young people involvement groups.</p> <p>Contributed to the Royal College of Physicians talking heads video which is now used as part of their e-learning tool for clinicians.</p> <p>Provided case study material for the National Network for Adolescent Rheumatology report into the involvement of young people in health-related research.</p> <p>As part of the Transition research group our comments were included in feedback on the draft NICE Guidelines on Transition, since published in February 2016.</p> <p>Involvement with the Council for Disabled Children's North East event for Developmentally Appropriate Healthcare.</p> <p>Created a poster to summarise UP's involvement in research, and attended the Young Person's Advisory Group - North of England conference which was centred around the involvement of young people in research.</p>
<p>Running Of The Transition Programme</p> <p>Four young people were recruited as peer support workers for the newly forming UP group. They had experience of being involved in health services development and supported the researchers to recruit and form the UP group.</p> <p>Whilst the UP group was forming, these peer support workers were involved with the recruitment of the Transition programme research associates.</p> <p>They sat on interview panels for the recruitment of Transition research associates and participation worker posts</p> <p>They were involved in the training of these Research Associates.</p> <p>Transition Programme Launch Event; UP created a powerpoint presentation and presented and participated in a Q&A session.</p> <p>UP provided material and design input for the transition website, including personal blogs and quotes, the inclusion of a young person page with a sub-section of The Young People's Working Group – UP pages, and a link to the 'Transition's Got Talent' film clip.</p> <p>UP worked with Transition's External Advisory Board to give the young person's perspective to the national and international colleagues that were helping to govern the programme.</p>	<p>Showcasing Involvement Of Young People</p> <p>Produced press release for local media about the launch of Transition Research and the importance of getting it right for young people.</p> <p>Past, Present and Future Conference; presentation to local healthcare managers and researchers about involvement experience and health passport research pilot study. UP created an i-movie, powerpoint presentation and speeches.</p> <p>UP member received award from local newspaper in their annual awards ceremony in recognition of his work in the community.</p> <p>Youth Achievement Awards: UP members chose to capture their work as young researchers to achieve these awards.</p> <p>UP developed new skills, which they were able to transfer into finding employment and other opportunities.</p> <p>Peer support workers co-authored academic paper on young people's involvement.</p> <p>UP were acknowledged as co-authors of research paper on proposed beneficial features of transition services.</p> <p>Feedback to other research group on video 'Cracked', a documentary about young people suffering from psychosis.</p>

Useful Links:
<https://research.ncl.ac.uk/transition/>
<https://research.ncl.ac.uk/transition/youngpeoplepage/theyoungpeopleworkinggroup-up/>
<https://research.ncl.ac.uk/transition/newsevents/hardworkofupgrouprecognisedbynihhr.html>

Email: Transition@nd.ac.uk Telephone: Alison Mulvenna on 0191 282 1389 Write to: Transition Programme, Level 3 Sir James Spence Institute, RVI, Queen Victoria Road, Newcastle, NE1 4LP

You can also follow us on Twitter - @TransitionRieq

Acknowledgements: Laura Brodrick, Thinkbigpicture, Council for Disabled Children, DOH, Transition Collaborative Group & Programme Management Board and Team; Dr Janet McDonagh; Young people and staff from Walsall Physical Disabilities Team; Jo Mackintosh; Caroline Potts and Norma Cardill

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The views expressed in this poster are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Appendix 4 Health passport

UP Poster: Health passport



Health Passports

United Progression: The UP Group
The Young People's Working Group on the NHS Transition Research Programme



Background & Aims

We looked at Transition from our personal experiences and thought about what might have helped us through it.

A "survival guide" might have helped.

We looked at a range of Health Passports.

We found that lots of Health Passports were in use, but none had been evaluated.

We discovered that there was no definition of a Health Passport.

We thought there was no point in developing another new Health Passport and decided to evaluate existing ones.



Exploring Current Practice

We examined a range of existing Health Passports and wanted to explore:

WHO?
Who benefits from them?
Who wants them?
Are the views of parents/carers, health professionals and young people different?

HOW?
How are young people supported?
How are the Health Passports used in practice?

WHAT?
What kind of health passports are being used in the UK?
What are the essential points to making a really great health passport?
Do different groups of people need different things?
What is the potential role of technology, in terms of the design of these tools?





Image credit: Depicters.com

Developing Our Research Tools

UP consulted with healthcare professionals from Birmingham Children's Hospital and Walsall Physical Disabilities team about their experience of young people using Health Passports.

We examined a number of existing Universal and Condition Specific Health Passports.

We then devised our research questions.

We asked for help in streamlining the questionnaire and a member of the Patient Experience Team helped us look at phraseology of our questions and the design of our questionnaire.

1. Is your HP only useful for some appointments?
2. Do you feel you need to take it to your appointment?
3. Why don't you use your Health Passport?
4. Where else to you use your Health Passport?
5. Do you feel you've outgrown your Health Passport?
6. How long have you had your Health Passport?

We got Health Professionals to agree to distribute our questionnaire so that we could gather data from young people who were using Health Passports.

Findings/Conclusions From Young People

(n = 13)

100% don't complete Health Passports alone.

75% agreed they're useful.

46% sometimes take their Health Passport to appointments.

46% never take them to appointments.

8% always take them to their appointments.

25% were not sure if they were helpful.

38.5% thought they alone benefited from having a Health Passport.

38.5% believed both they and the health professionals benefited.

23% thought health professionals benefited.

There is no defined process in how Health Passports are used.

The process of using Health Passports needs to be clarified and supported.

The way forward.....mobile applications?



Useful Links:
<https://research.ncl.ac.uk/transition/>
<https://research.ncl.ac.uk/transition/youngpeoplepage/theyoungpeoplesworkinggroup-up/>
<https://research.ncl.ac.uk/transition/newsevents/hardworkofupgrouprecognisedbynih.html>
 Email: Transition@ncl.ac.uk Telephone: Alison Mulvenna on 0191 282 1389 Write to: Transition Programme, Level 3 Sir James Spence Institute, Royal Victoria Infirmary, Queen Victoria Road, Newcastle, NE1 4LP

You can also follow us on Twitter - @TransitionUK

Newcastle University Management Board and Team: Caroline Potts and Norma Cardill.

Acknowledgements: Laura Brodick, Thinkbigpicture; Council for Disabled Children; DGH/Transition Collaborative Group & Programme

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Northumbria Healthcare NHS
NHS Foundation Trust

Appendix 5 Longitudinal study (quantitative)

In this appendix we present some additional tables/figures mentioned in the synopsis and the draft of a paper submitted for publication.

BOX 3 Proposed beneficial features

Age-banded clinic. An intermediate clinic setting, such as a young person's clinic or a young adult team. In children's health services, it would mean that children younger than about 14 years would not be at the clinic. In adults' services it would mean that adults older than about 24 years would not be at the clinic.

Meet adult team before transfer. This could be in a joint clinic where senior paediatric and adult clinicians consult together, or the adult clinician might visit the children's clinic to be introduced, or the young person might be taken to the adult clinic by a member of the child team to meet the adult team.

Promotion of health self-efficacy. The young person is asked 'Have you received enough help to increase your confidence in managing your condition?' The clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition.

Written transition plan. This should be created some time before transfer. It should include plans for wider transition, not just the transfer to adult health services. The young person should have a copy of it and it should be updated.

Appropriate parent involvement in their child's care, but with changing responsibilities. Parent and young person are asked separately if they think that the level of involvement is appropriate. Involvement concerns what happens in the clinic (parent being present or not and who does the talking) and also discussions at home about the young person's health and how to manage it.

Key worker. This is a single person known to the young person whom they could easily contact or go to if there were any problems with co-ordination or misunderstandings that needed to be sorted out. The role could cross into education and social services. Although a clinic may have a policy to 'appoint' a key worker, the young person may report that it is someone else with whom they feel most comfortable.

Co-ordinated team. Some young people need to see a team of people. Those with diabetes mellitus may need to see a doctor, nurse, dietitian and psychologist. Those with cerebral palsy may need to see a doctor, physiotherapist and orthopaedic surgeon. The members of these teams need to work together and communicate well together, and demonstrate to the young person that this is happening. Co-ordination of appointments on the same day demonstrates this.

Holistic life-skills training for education, relationships, finances, employment, housing, social relationships, etc., as well as health maintenance. The young person is asked whether or not they have had any formal life-skills training offered because of their condition. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed.

Transition manager for clinical team. The individual who co-ordinates transition in a clinical team may not be known to the young person. The manager will facilitate good working relationships between adults' and children's services, ensure that there are appropriate materials available for things such as health education or the transition plan and monitor whether the young person has a suitable appointment in adults' services and whether or not the appointment is kept.

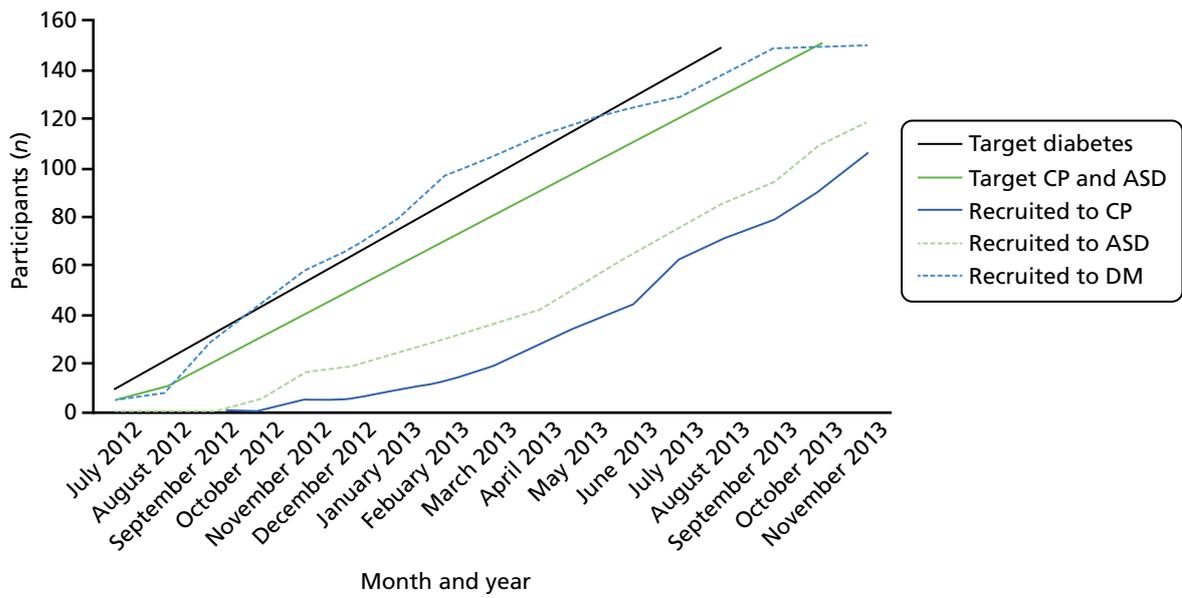


FIGURE 12 Recruitment of participants to WP 2.1. CP, cerebral palsy; DM, diabetes mellitus.

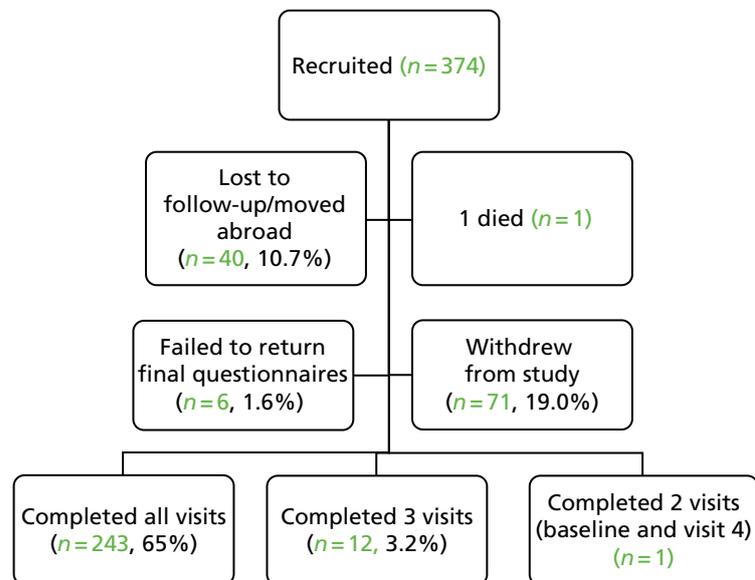


FIGURE 13 Retention to visit 4.

Work package 2.1: longitudinal study

TABLE 15 Reasons for dropout

Reason	Number of dropouts (n = 71)	Example
Not interested in taking part	22	
Other commitments	19	School, work, university
Personal issues	11	Young person was too ill, had recent surgery, was a victim of a crime
Family issues	8	Other family member having health issues
Questionnaires too difficult	4	
No reason given/recorded	4	
Do not like talking about condition	2	Young people were coping well with condition and just wanted to 'get on with their life' and not talk about their condition
Problems with health service	1	One family withdrew from the study because of problems they were experiencing with the service they attended

Note
There were no significant differences across the condition groups in the numbers that withdrew or were lost to follow-up.

Draft paper Young people with autism spectrum disorder

Title: Predictors and experience of transfer of young people with ASD from child and adolescent mental health services.

Authors: Hannah Merrick, Chris King, Helen McConachie, Jeremy Parr, Ann Le Couteur

Abstract

Transition to adulthood can be difficult for young people with ASD, as they juggle the challenges of adolescence and navigate leaving child and adolescent mental health services (CAMHS). This analysis describes the experiences and outcomes of a sample of UK young people aged 14-21 years, with ASD and additional mental health problems, as they were discharged from CAMHS. The young people were followed over 3 years. Measures of mental health and qualitative contextual (clinical, family, social, educational) information was used to capture their experiences. Having an ADHD diagnosis and taking medication were predictors of transfer to adult mental health services. The qualitative themes allowed us to understand the young people's transition experiences and identify variables associated with positive outcomes and ongoing problems.

Introduction

Transition into adulthood involves a number of different developmental tasks, including entering further education or employment, having meaningful social participation, and developing independent living skills or leaving home.¹⁶⁴ Transition for young people with autism spectrum disorder (ASD) to adulthood has been a topic of increased interest as it becomes evident that it can be a particularly difficult period for individuals and their families.¹⁶⁵ Some of these difficulties include low rates of post-secondary education and employment,¹⁶⁶ low social participation,¹⁶⁷ higher rates of bullying,¹⁶⁸ and struggles gaining autonomy and independence in young adulthood.^{169, 170} These difficulties have been identified for young people with high functioning ASD when compared with equally able young people in the general population.¹⁷¹

One aspect that may make transition particularly difficult for this group is the presence of additional commonly occurring comorbidities, including mental health problems such as attention deficit hyperactivity disorder (ADHD), anxiety, and emotional disorders.¹⁷²⁻¹⁷⁴ As well as managing several major life transitions, these young people with ASD and additional mental health problems also have to navigate the transition from children and adolescent mental health services (CAMHS).¹⁷⁵ Healthcare providers, parents and young people have reported concerns about healthcare transitions, in particular those with high functioning ASD.^{175, 176} Studies of the experiences of young people with ASD (without intellectual disabilities), and their parents, as they negotiate transition into young adulthood, report that the uncertainties about the challenges of accessing appropriate support and services was a worry, particularly in terms of the potential negative impact on the young person's wellbeing and mental health.¹⁷⁷ The presence of co-morbidities together with an ASD diagnosis may also be acting as an additional barrier to finding meaningful day time activities and potentially result in lower levels of social participation.¹⁷⁸

Most young people in England and Wales attending CAMHS are discharged to primary care services (family practitioner) rather than being referred onto adult mental health services (AMHS).¹⁷⁹ This can be due to a variety of reasons including no longer needing clinical mental health involvement, presenting problems not meeting criteria for AMHS, or disengagement from services.¹⁸⁰ For some young people discharge to primary care is an appropriate course of action. However, in a UK study of young people with ongoing mental health disorders, certain groups of young people such as those with emotional, neurodevelopmental (including ADHD and ASD), or emerging personality difficulties were found to be at an increased risk of not accessing adult services and were described as 'falling through the CAMHS-AMHS gap'.^{179, 181} There is then a concern that for some of these young people with neurodevelopmental disorders, their unmet mental needs may increase their risks of poorer outcomes with low levels of participation and wellbeing compared to other young people, crisis presentations at accident and emergency departments, or contact with criminal justice system. These young people may then at a later date be at an increased risk of presenting to adult services following a crisis, or with more serious and enduring mental health problem.

For young people with ongoing mental health needs that are referred from CAMHS to AMHS, poorly planned transitions can make the shift from the child-centred developmental approach of CAMHS to the adult-centred care of AMHS difficult for both the young people and their families.⁵ There are also reports of unmet need and dissatisfaction with care.¹⁸² This applies especially to young people with ASD who report a lack of support for both the ASD and the mental health problem, particularly when services are designed for neurotypical individuals.¹⁸³

In one UK study investigating predictors of service use outcomes for young people discharged from CAMHS,¹⁷⁹ found that being on medication at the time of transition and having a severe or enduring mental health condition, such as schizophrenia, bipolar affective disorder and psychotic disorders, were predictors of transfer to AMHS. This might raise an expectation that young people with ASD and ADHD and in particular those in receipt of regular medication, would be referred on to AMHS. However according to the UK NICE clinical guideline for individuals (children and adults) with ADHD (albeit not necessarily with additional ASD), shared care agreements with primary care (family practitioner) should exist.¹⁸⁴

Not all young adults with ASD experience an exacerbation of their difficulties when they are transitioning to adulthood. For some, outcomes (e.g. education, employment, independent living and social participation) in adulthood are more positive, for example with meaningful employment and independent living being achieved in adulthood. Farley¹⁸⁵ in a US study of 41 adults with average or near average cognitive abilities (mean age 32.5 years) highlighted the importance of community support and integration in increasing social participation. Kirby¹⁸⁶ in a systematic review of predictors of successful social outcomes in young adults with ASD, identified five conceptual categories: ‘personal characteristics’ (e.g. age, gender and race), ‘individual functioning’ (e.g. IQ, diagnosis/severity), ‘family context’ (e.g. household income, educational level of parents), ‘services’ (e.g. career counselling), and ‘other’ (e.g. general health). The review also identified varying levels of evidence for these predictors of successful outcome and highlighted a need for more high-quality research on outcomes for adults with ASD to inform practice, especially in relation to factors related to the family and services received. However, outcomes need to be defined and assessed in a more nuanced manner taking into account the preferences of individuals with ASD and their families, for instance in terms of what is achievable and preferable for each individual rather than simply comparing across population norms.¹⁸⁷

This paper uses data from a recently completed UK longitudinal study of young people with long term conditions (diabetes, cerebral palsy and ASD with additional mental health problems). We were able to review, over a 3-year period, the outcomes of the group of young people with ASD and additional MH problems as they were discharged from CAMHS. The aim of this secondary analysis was to identify those young people with ASD who transferred from CAMHS to AMHS, and to compare their levels of achievement and need with those who were discharged to primary care and those who remained in CAMHS beyond age 18 years. This analysis is intended to inform future practice, especially in respect to identifying how best to facilitate appropriate transition arrangements for this group of young people as they are discharged from CAMHS.

Methods

Young people aged 14-18 years, with a diagnosis of ASD who were accessing CAMHS for an additional mental health problem, were recruited to the Transition Longitudinal project (<http://research.ncl.ac.uk/transition/>) between October 2012 and October 2013. All were referred as in the average ability range, and able to complete questionnaires (with or without support). Young people were recruited from mental health clinical services in three different parts of England. The young people were visited once a year for 3 years (four visits in total) and asked to complete several questionnaires. Full details of the study protocol have previously been published⁶¹ and baseline characteristics of the sample.⁶²

The study received a favourable ethical opinion from Newcastle and North Tyneside 1 Research Ethics Committee. Numbers 12/NE/0059 and 12/NE/0284. All young people provided signed consent to join the study. For young people under sixteen years of age, the young people signed an assent form and a parent provided signed consent for their child to join the study.

Measures

The following measures were completed at each visit:

Sociodemographic Questionnaire: Using a bespoke questionnaire we collected data on gender, education and employment status, and socioeconomic status (postcodes used to calculate the ‘index of multiple deprivation’ (IMD, higher scores indicate more socioeconomic deprivation).⁶⁹

*Hospital Anxiety and Depression Scale (HADS)*⁸⁰: a 14-item questionnaire completed by the young people measures the severity of mental health problems with two subscales of *anxiety* and *depression*. Total scores can be categorised into ‘normal’ (0-7), ‘borderline abnormal’ (8-11) and ‘abnormal’ or clinical caseness (12-21). An initial validation study of this questionnaire has shown excellent psychometric properties in samples of older adolescents and young adults with ASD.⁸¹

*Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS)*⁷⁷: a 14-item, questionnaire (also completed by the young people), developed in the UK and valid in the age range 13 to 21 years that captures young people’s mental wellbeing. The scale had good internal consistency supporting the suitability of this measure for this group.

The Strengths and Difficulties Questionnaire (SDQ)^{188, 189} SDQ: was completed by both the young person and the parent.

*Social Responsiveness Scale*¹⁹⁰: This measure was completed by the parents and was used to confirm autism characteristics.

Information collated by the research assistants:

Information derived from clinical case notes: Before each of the follow-up visits the trained research assistants (RA) with the young people’s consent, accessed the clinical mental health case notes to record details of appointments including whether the appointment was attended, medication prescriptions given, and diagnoses. This information was used to determine a date of final appointment in children’s services (described as date of transfer).

Qualitative Data: At each visit the RAs made notes of contextual information about each young person, their family, and service provision (e.g. family issues, changes in school or service provider, comments about access to and lack of support or problems at school). Information was also recorded from clinical mental health case notes that was relevant to the process of transition, referrals made, and issues discussed during clinical appointments. The RAs recorded descriptions of difficulties and complexities for the young person, their family and relevant professionals together with positive successes and achievements for the young people.

Data Analysis

Quantitative Data Analysis: SPSS version 23 was used for data analysis. Descriptive statistics of education and employment status, age, gender, transfer location, age at transfer, medication use, additional mental health problem(s) and measures of mental health are presented. Logistic regression was used to identify predictors of transfer from CAMHS to either AMHS or discharge to primary care (family practitioner).

Qualitative Data Analysis: Framework analysis¹⁹¹ was used to consider all the available recorded contextual data for young people and their families. Authors 1 and 2 familiarised themselves with the data, noting initial emerging themes. Themes were informed by the authors' knowledge of the literature. A thematic framework was then developed and applied to the data. The data were presented as a table with each row representing a participant and each column representing a theme. This allowed each theme to be summarised and for exploration of patterns and associations in the data. A 10% sample was double sorted to ensure consistency and reliability. These themes were then refined into categories which are presented below. Any differences were discussed and resolved through consensus. The themes and categories were reviewed and finalised with the fifth author.

Mental Health Trajectories:

To help us understand further the interaction of the young people's self-reported mental health and their transition to adulthood over the 3-year study period, we reviewed the trajectory of the young people's HADS scores for those who completed HADS data on at least three of the four visits (n=87). The HADS is a measure of each young person's mental health status for the week prior to each research visit. Using the sequence of each young person's self-reported HADS scores, young people were grouped into three types of trajectories: those *doing well* with 'normal' HADS scores across all visits or showing improvement from abnormal or borderline abnormal scores to normal scores at the final visit; those with *continued moderate difficulty*, who continued to have borderline abnormal mental health problems over the visits or fluctuated between borderline and abnormal scores; and those who were *not doing well* where the young person reported continued abnormal HADS scores or had a decrease in scores over the study period ending with a score in the abnormal range. The trajectory of each young person was individually assessed by the first two authors and a consensus agreed.

Results

Baseline Demographics

In total, 118 young people with ASD and additional mental health problems were recruited and completed baseline measures (mean age: 16.1yrs, range: 14yrs-18.9yrs). Eighty-two (69.5%) of the sample were male, 36 (30.5%) female, and nearly all were white British (98.3%). At baseline the majority of young people were in full time education (either school or college; 93.2%). A small number of the young people had a part time job (6%) or did some volunteer work (2.6%).

All the young people had a diagnosis of ASD at recruitment and were accessing CAMHS for support with additional mental health problems. The mean total young person -reported SDQ score at baseline was 17.6 (SD = 6.1), parent reported SDQ was 22.8 (SD = 5.9), and the mean SRS score was 117.2 (SD = 29.7). SDQ scores of our sample were found to be significantly higher (indicating greater severity) than scores of a subset of young people aged 16 years with ASD from the UK Special Needs and Autism Project (SNAP) community sample.¹⁷⁴ The young people's median wellbeing score (WEMWBS) at baseline was 47 (IQR: 41–52), significantly below population norms¹⁹² and remained significantly below population norms at all visits. Out of the 118 young people recruited, 88 completed a final visit. As previously reported, there were no significant differences between those who remained in the study and those who withdrew from the study in terms of condition severity or socio-demographic factors.

Transfer Location

Of the 30 young people who withdrew from the study, information was available for five subjects on their transfer location and so were included in the analyses. For the 93 young people for whom transfer data was available, 20 young people were still accessing CAMHS, 48 had transferred to primary care, and 25 had transferred to AMHS. Table 16 compares the characteristics of the young people by transfer location.

Table 16: Characteristics of sample by transfer location

Transfer location	CAMHS	General practitioner	AMHS
	(final visit data)	(pre-transfer visit data)	
	N (%)	N (%)	N (%)
	20	48	25
Gender			
Male	16 (80)	31 (65)	16 (64)
Female	4 (20)	17 (35)	9 (36)
Age at visit before transfer			
Mean	17.7	17.4	18.2
Range	16.13 - 20.30	14.7 – 19.75	16.5 – 19.9
SD	0.89	0.89	0.69
WEMWBS ¹			
Mean (SD)	49.4 (7.47)	45.6 (8.00)	46.52 (10.17)
Range	28-58	29-60	27-70
IMD at baseline			
Mean (SD)	18.98 (11.36)	23.94 (18.133)	24.45 (18.74)
Range	2.46-38.82	2.17-80.51	3.72-71.83
Prescribed medication	16 (80)	27 (56)	20 (80)
Education and employment			
Full/Part Time Education	15 (75)	41 (85.4)	21 (84)
Employed	4 (20)	1 (2)	2 (8)
Not In Education Or Employment	1 (5)	6 (12.5)	2 (8)
Number of mental health problems			
1	8 (40)	27 (56)	15 (60)
≥2	12 (60)	16 (33)	10 (40)
Mental health problem			
ADHD/ADD	12 (60)	8 (16.7)	15 (60)
Mood ^a	2 (10)	18 (38)	7 (28)
Anxiety ^b	9 (45)	22 (46)	6 (24)
Odd/Challenging Behaviour ^c	2 (10)	5 (10)	1 (4)
Sleep disorders ^d	6 (30)	7 (15)	4 (16)
Other ^e	4 (20)	1 (2)	3 (12)
Self-harm	(5)1	2 (4)	5 (20)
HADS (Anxiety)			
<8	7 (35)	20 (42)	10 (40)
≥8	13 (65)	28 (58)	15 (60)
HADS (Depression)			
<8	18 (90)	39 (81)	17 (68)
≥8	2 (10)	9 (19)	8 (32)
Developmental disorder^f	3 (15)	5 (10)	5 (20)
Physical health problem^g	11 (55)	12 (25)	10 (40)

¹Significantly below population norms across all groups

^a Depression, low mood; ^b Anxiety, Obsessive Compulsive Disorder, phobia, social anxiety;

^c Oppositional Defiant Disorder, Conduct Disorder, challenging behaviour, behavioural problems, aggression, anger management problems; ^d Insomnia, requiring melatonin

Conversion disorder, psychosis (1 young person), chronic fatigue syndrome

^f Dyslexia, dyspraxia, dyscalculia, Developmental Coordination Disorder

^g asthma, epilepsy (1 young person), allergies, migraines, thyroid dysfunction

CAMHS Child and Adolescent Mental Health Services
AMHS Adult Mental Health Services

The logistic regression findings are presented in Table 17. Overall the model was significant in predicting transfer outcome, $\chi^2(7)=18.58$, $p=0.010$. Nagelkerke R^2 indicates that the model explains 32% of the variation in outcome. The odds of being transferred to adult services were significantly greater for those young people who had a diagnosis of ADHD (OR= 8.22 (95% CI=2.33-29.02) $p=0.001$) and young people who were prescribed medication for their mental health problem (OR=3.99 (95% CI=1.00-15.95), $p=0.05$).

Table 17: Logistic Regression for predictors of transfer location

Variable	N (%)	OR (95% CI)	Significance
	71		
Prescribed medication			
Yes	47 (66)	3.99 (1.00-15.95)	0.05
No	24 (34)		
Additional mental health problem			
ADHD	23 (32)	8.22 (2.33-29.02)	0.001
Not ADHD	48 (68)		
Number of mental health problems			
1	45 (63)	1.04 (0.31-3.43)	0.95
≥ 2	26 (37)		
HADS anxiety		1.06 (0.89-1.25)	0.53
HADS depression		1.03 (0.85-1.26)	0.75
WEMWBS		1.04 (0.94-1.15)	0.51
IMD score (baseline)		0.99 (0.96-1.03)	0.71

Qualitative Analysis

Framework analysis was used to explore the qualitative data using all available visits of the 118 young people who joined the study. Twenty-four themes were identified and then summarised into seven categories that described the young people's and their parents' experience of transition during their time in the study (see Figure 14).

Figure 14: Categories from framework analysis



The framework identified a number of themes related to the young people's mental health including their level of engagement with mental health services, engagement with medication and/or interventions, and times of crisis where their mental health problems resulted in emergency department attendance, self-harm or crisis team involvement. Other themes related to developmental and adolescent factors such as school transitions, seeking employment and managing social relationships, describing both successes in these areas as well as the difficulties experienced by some of the young people. How the young people experienced their ASD symptomology and how this impacted on developmental transitions and their transition from CAMHS was a theme of considerable significance for both young person and families. Some broader themes around family support and family health were raised, as well as the parents' concerns about the young person's social/emotional maturity and vulnerability as they dealt with the discharge from CAMHS and the wider agenda of transition of their child into adulthood.

Mental Health Trajectory

Using the sequence of each young person's self-reported HADS scores, young people were grouped into three types of trajectories: those *doing well* (N=23), those with *continued moderate difficulty* (N=29), and those who were *not doing well* (N=30). There were no significant differences in transfer outcome, age, baseline SRS scores, or additional mental health diagnoses between the three groups. However there were some differences between the groups in terms of WEMWBS, SDQ scores and gender (Table 18): the WEMWBS scores was significantly lower in the '*not doing well*' group compared to the other groups across all time points; those in the '*doing well*' group reported significantly lower baseline SDQ scores than the other two groups (add test and level of significance), and there were significantly more females in the '*not doing well*' group. Using the combination of the different data sources enabled appreciation of the experiences of the young people, their families and clinicians (see Table 18) across the three HADS groupings.

Table 18: Differences between HADS trajectory groups

	Doing well	Moderate difficulty	Not doing well	
	N (%)	N (%)	N (%)	
CAMHS	6 (26.1)	5 (17.2)	7 (23.3)	
Transfer location				
Primary care	10 (43.5)	15 (51.7)	16 (53.3)	$\chi^2(2)=0.53, p=0.77$
AMHS	7 (30.4)	9 (31)	7 (23.4)	
Gender				
Female	3 (13)	9 (31)	18 (60)	$\chi^2(2)=13.0, p=.002$
Male	20 (87)	20 (69)	12 (40)	
	Mean (SD)	Mean (SD)	Mean (SD)	
Young person SDQ total¹	14.17 (3.6)	19.49 (4.5)	20.38 (6.7)	$F(2,77)=10.3, p<0.001$
Parent SDQ total¹	22.09 (5.3)	22.45 (5.3)	22.23 (6.9)	$F(2,74)=0.02, p=0.98$
SRS scores¹	114.41 (19.7)	123.41 (27.9)	109.38 (31.8)	$F(2,77)=1.85, p=0.16$
WEMWBS²				
Visit 1	49.96 (7.8)	44.0 (8.2)	42.57 (9.0)	$F(2,79)=5.3, p=0.007$
Visit 2	52.27 (6.9)	45.25 (8.4)	41.89 (9.1)	$F(2,75)= 8.8, p<0.001$
Final visit	53.96 (8.1)	46.61 (7.6)	41.32 (10.3)	$F(2,76)=13.1, p<0.001$

¹ Higher scores reflect more difficulties on the SDQ and greater social impairment on the SRS

² Higher scores reflect better mental wellbeing

SDQ Strength and difficulties questionnaire

SRS Social responsiveness scale

WEMWBS Warwick Edinburgh Mental Wellbeing Scale

HADS 'doing well' group

Most young people were described in the clinical mental health case notes as well engaged with mental health services. They were said to be 'doing well' and/or coping well with their current treatment regime (with or without medication). There were very few reports about needing to access urgent care or incidents of self-harm or overdoses.

'Young person now uses Cognitive Behavioural Therapy (CBT) techniques on his own to manage his condition/anxiety/OCD symptoms when needed'

Notes suggested that individuals in this group were accessing a range of support services in addition to mental health services. These included school counsellors, social services and community ASD teams. Some young people described how they had decided not to attend an assessment in AMHS as their clinician discussed that they may not meet AMHS criteria.

The clinical records also indicated that the clinicians were considering some of the broader needs of young people. For example, there were comments about trying to encourage the young person to increase their independence in appointments and become more aware of their ASD, and how their diagnosis may be affecting them.

'Discussed...current romantic relationship: 'emotional distress tends to be focussed around his girlfriend, who was also a close family friend' - talked about how his Asperger's might affect his relationship'

Notes contained evidence that some young people were engaged in developmentally appropriate tasks. Some were beginning to be involved with romantic relationships, several were attending mainstream college following leaving school, but few had made the transition to university by the end of the study. Overall, in addition to positive references to levels of engagement with services, there appeared to be evidence of more stability in terms of education achievements and family life in this group compared to the other two groups. In summary, the data suggest that individuals in this group were learning to manage their mental health concerns, developing an awareness of the impact of their ASD and learning to negotiate, with support, some developmentally appropriate aspects of transition to adulthood.

HADS moderate difficulty group

For some young people, the clinical mental health case notes referred to problems with attendance and poor engagement with CAMHS over the three years of the study. In some cases these problems led to discharge from services. The pattern of the mental health needs appeared to fluctuate, with requests for urgent appointments, changes in types and doses of medication, and sudden events including self-harm attempts.

'Young person not doing so well at the moment'

There were also notes about changes in family circumstances, such as parents being ill (physically or mentally) or parents separating. These changing circumstances may well have contributed to some of the fluctuations young people experienced in their mental health.

As with the 'doing well' group, there were comments about young people not transferring to AMHS due to not meeting criteria or opting to not go for assessment. However, in this group there were also comments about families feeling unsupported as a consequence of either infrequent appointments or of being discharged from CAMHS.

'They only see someone once every 6 months or so now which parents have indicated that they don't feel is enough and dad especially would like more help with transitioning to adulthood and support with work etc. Currently see a different doctor every time they go so feel it is very impersonal.'

The young people were recorded as accessing a range of other community services, both in childhood and post 18 years in adult services- counsellors at school or through primary care, psychological wellbeing services and Improving Access to Psychological Therapies (IAPT) services (an adult community Cognitive Behaviour Therapy provision).

In terms of the other activities, there were comments from the parents of young people in this group with concerns about their child's independence skills (e.g. ability to leave home). Some of the young people had been in vulnerable situations (e.g. one young person had been led into messaging inappropriate images). Many of the young people had made the transition from school to college and some had hopes of applying for university. However, unlike the young people in the previous group, several of these young people had attended special needs schools and so through education services they had received additional support from, for example, occupational therapists and/or speech and language therapists during school hours. Some young people went on to experience considerable challenges as they transitioned to, and also in, their post-school education placements - for example those who had taken up a university placement often took some time to settle in and were accessing available support services.

'Young person is now at university. Had a few panic attacks to begin with but is doing ok. He has a counsellor at university.'

Others had experienced disruptions in their education provision, for example, being out of education for some time as a consequence of bullying or being expelled from a previous school. One young person also expressed feeling unsupported with job applications and requested help with interview skills.

HADS 'not doing well' group

The young people in this group experienced higher rates of crisis situations (such as episodes of self-harm or overdoses and suicide attempts) than young people in the other groups. Some had experienced episodes of inpatient hospital care while for others, police had been involved due to concerns about their risk-taking behaviour.

Concerns were also raised about poor attendance and compliance at health service appointments. Some young people refused treatment options or support and for some their level of disengagement led to premature discharge from CAMHS. Many young people and their families frequently reported a strong sense of feeling unsupported by services and described negative experiences with clinicians.

'He is now regularly seeing a Psychiatrist for talking therapy to help him deal with his anxiety. Mum feels this could have been avoided if he had received more help following child services rather than having a gap.'

Within this group it also appeared that their ASD was having a greater impact on their progress than the other two groups. There were several comments from the clinical records of the young people being given details of ASD teams to access for support around this. For example, some of the young people were accessing services/support for training in friendships, socialising and independence skills.

'Given literature from NAS [UK National Autistic Society] and list of books specific to ASD. Referral to Social Eyes service designed to help people with ASD to develop their social understanding and social skills.'

This group were also accessing more specialist services such as drug and alcohol support services or anger management teams. Discussions that had been had in appointments were recorded in the clinical notes about how illicit drug use would be interacting with their medication and mental health.

Although many young people were at school and college, there were comments about struggles to find appropriate placements for college or reports about time out from education. Others had been expelled or had dropped out of education due to difficulties. Encouragingly a couple of the young people had been able to obtain full-time work with the help of family members following dropping out of education.

'Young person was expelled from college so waiting to see if he can go back in the near future or September. He is now working full time with his dad.'

Discussion

The aim of this study was to identify predictors of transfer location and to understand the experience of transition in a sample of young people with ASD and additional mental health problems. In the three-year Transition Longitudinal study just over a third (35.3%) of the young people over 17 years transferred to AMHS and 64.7% transferred to primary care. The logistic regression analysis showed that only a diagnosis of ADHD and taking prescribed medication was a predictor of transfer location, explaining 32% of the variance. The qualitative analysis provided additional insights into potentially important individual, family and wider developmental and contextual themes that related to transfer location and provided valuable insights into young people's experience of transition.

The finding that an ADHD diagnosis, as well as whether the young person was receiving prescribed medication, predicted whether young people transfer into AMHS may reflect UK ADHD NICE guidelines (NG 87, NICE 2018). NG87 recommends that both diagnosis of ADHD and the initiation of drug treatment should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD, and that continued prescribing and monitoring of drug therapy may be performed by primary care physicians, under shared care arrangement with the specialist services¹⁸⁴. In an audit undertaken in the North West of the UK, only 15% of young people with a diagnosis of ADHD (from an eligible sample of 104 adolescents) were successfully referred and transferred to a specialist adult ADHD clinic, though it is unclear whether this sample included young people with coexisting ASD. Singh¹⁷⁹ also highlighted the problems for young people with neurodevelopmental disorders (both ADHD and /or ASD) achieving successful transfer to AMHS. Our findings seem to buck this trend. We are aware that within the mental health NHS organisations involved in the Transition Longitudinal Study, local arrangements for the management of young people and adults with ADHD were under review. For example, in one organisation a decision was made, during the course of the study, for CAMHS to take on the adult ADHD follow up clinics. It still remains unclear whether UK AMHS are adequately resourced to provide diagnostic and follow up clinics for adults with ADHD and additional co-occurring conditions including ASD and other behavioural and mental health problems. Certainly, within our sample, parents and young people commented that six monthly /yearly follow up medication clinic appointments did not meet the wider needs of young people coping with a broad range of concerns about mental health problems and other social and educational needs.

Interestingly, none of the other factors that we had identified as potential markers of severity or vulnerability (number of co-morbid problems, SES, HADS, wellbeing) predicted transfer to AMHS. Much has been written about the limited access to AMHS for young people with a range of mental health problems (ASD and additional mental health problems, other neurodevelopmental disorders (such as ADHD), emotional disorders and emerging personality disorders).^{179, 181} In UK the eligibility criteria for accepting a referral to an AMHS can vary but tends to be restricted to those suffering severe and enduring mental illness such as psychosis and severe depression. This may mean that some young people who reach the age of 18 years may find that, although their mental health problems do not suddenly change, they cannot access an ongoing mental health service.¹⁴ Of course, not all young people with mental health problems will either want or need to be transferred to AMHS. For some, discharge to primary care may be the appropriate pathway, especially if the young person is coping well with their ongoing mental health problems, adhering to treatment/medication and doing well at school/college. As was seen in the qualitative analysis, some of the young people and their families opted not to be referred to AMHS due to the likelihood of not meeting criteria, or due to no further clinical need. However, the qualitative analysis also identified a sub-set of young people where the pathway of discharge to primary care was not successful. These young people accessed crisis teams several times or received time-limited support in AMHS before being discharged again.

Further, for some young people and their families in this sample, engagement with services was a more longstanding problem. For these young people, if they had not engaged with CAMHS, this usually resulted in discharge to primary care - a finding consistent with the UK TRACK study.¹⁸⁰

Overall, the young people in our sample appeared to be doing reasonably well, with 67.5% in full time education (either school or college) at the end of the study. Under a third of our sample were in neither education nor employment. The analysis of the HADS trajectories also confirmed that some young people appeared to be doing well, managing their mental health, and able to engage successfully with services. These young people and their families also had not apparently experienced additional crises or life events. However, across all HADS groups, the majority of young people were experiencing episodes or continued levels of high anxiety. Thus, despite what appears as positive outcomes for young people (e.g. attending higher education), the HADS trajectories and qualitative data showed that the young people were struggling, particularly when faced with more challenging academic and social educational environments (such as university). Our data also highlight that females seem to be at increased risk of falling into the '*not doing well group*'. This finding needs further consideration in larger samples of able young people with ASD. However, it is in keeping with recent studies and the increased awareness of the social and emotional needs of females with ASD, and especially those of normal ability, who may struggle to understand their own mental health needs.^{193, 194}

How should we identify those young people (both male and female) that might be particularly at risk through transition? Our data suggest that engaging with young people, and using a regular self-report check such as the HADS (which the young people in this study were able to complete at each annual follow up visit), may help young people and the professionals supporting them to identify their own trajectory, the impact of individual and family life experiences, and any mental health needs that may be helping or hindering their personal goals and achievements.

The key themes emerging in the qualitative data included engagement, broader ASD social and emotional developmental needs, impact of family, and personal events which seem to adversely affect functioning. Consistent with previous research, positive influences on the young people's experience of transition seem to be the ability to participate socially, engage consistently and constructively with services, positive support including employment opportunities from family, and other community resources including education.¹⁸⁶

The qualitative data also revealed a common concern of 'unmet need' and/or 'lack of support' irrespective of whether the young person had been discharged to primary care or AMHS. These unmet needs were usually around broader aspects of functioning relevant to the young person's diagnosis of ASD, rather than just their mental health difficulties. These identified unmet needs reflect findings from other research where young people of normal intellectual ability with ASD can fall short of criteria for access to community learning disability or more specialist ASD services as well as mental health service.¹⁶⁹ Access to local community support around interpersonal support, advice and information especially if the services have expertise in working with young adults with ASD and their families, could help reduce this unmet need.¹⁹⁵

Strengths and Limitations

This study is a secondary analysis of data collected during the Transition Longitudinal study. The sample of young people with ASD and additional mental health problems is relatively small (93 in total), all were of normal ability and recruited from four mental health NHS clinical services across the UK. This means that the findings have limited generalizability when considering young people with ASD across the ability range. Further, although the qualitative data were consistently collected by the trained RAs from clinical mental health notes and during the interactions with young people and their families, the data were not primarily obtained for the purpose of this analysis. Therefore, some aspects of the young people's experience of transition over the three years of the study may not have been recorded. Finally, although the young people have been successfully followed up, the sample remains relatively young (aged 14-17 years at recruitment). Thus, although all young people were approaching or had experience of planning for or achieving discharge from CAMHS, 20 young people had not left CAMHS by the end of the study and we do not have follow up information for any individuals over the age of 21 years.

Conclusion

Despite the observations that the young people in this sample (all of whom had one or more mental health problems) consistently reported lower mental wellbeing than other young people of similar age and ability, two-thirds of the sample were in education or higher education by the end of the three year follow up period. For some young people, discharge from CAMHS was seen as a new beginning as they moved onto higher education opportunities, gained a growing understanding about how to manage their mental health difficulties and gradually acquired the adaptive life skills to address their developmental needs. For others, and perhaps especially for the females in the sample, ongoing mental health difficulties, social, emotional and relationship needs (particularly associated with ASD), and a feeling of lack of understanding and a perceived absence of professional understanding about their and their families' level of unmet need with regard to both mental health and local authority services, resulted in a negative experience of transition. In our sample, encouragingly, it was a relatively small number of individuals who had multiple negative experiences of services, struggled with engagement, felt unsupported, and presented with multiple crises over the study period. We propose that the use of a tool such as the HADS may be a useful adjunct for individuals and their supporting clinicians to identify patterns of functioning over time; the monitoring may help identify those young people especially at risk of negative outcomes and crisis presentations. Successful transfer to AMHS is one aspect of mental health support but these services currently vary according to local service design. Further, both AMHS and primary care may or may not include expertise in ASD. This study confirms the need to increase community practitioner clinical skills relevant to young people with ASD and additional mental health problems. Our findings also suggest the potential benefit of a more nuanced approach to identifying and prioritising the needs of those young people at greatest risk of poor outcomes. Clinicians and other professionals with specialist expertise could then support these young people and their families identify and prioritise their goals for timely community support before they are discharged from CAMHS. The longer-term impact of this prioritisation of resource use would need to be evaluated.

Appendix 6 Longitudinal study (qualitative)

In this appendix we set out the report of the qualitative work in WP 2.2, in which 13 young people purposefully sampled from the cohort in the longitudinal study (WP 2.1) are interviewed, along with family member(s) and health professional(s) involved in their care. At the end of the appendix is the interview schedule.

Report WP 2.2

WP 2.2 Addressing Objective 2: to identify the features of transitional healthcare that are effective and efficient

Recent reviews have explored the different aspects of transitional healthcare, focusing on the experiences of young people^{44,51} and parents.⁸³ This work shows how the process of healthcare transition disrupts the lives of young people and their families. Lugasi's⁵¹ review of 46 quantitative and qualitative studies, show how patients describe child services as 'a familiar and comfortable environment, and reported feelings of trust toward their health care providers'. As such, they can develop 'attachment' to child services and have problems to 'detach themselves'.¹⁹⁶ Narratives of certainty within child services and uncertainty about what to expect in adult services were confounded by direct or second-hand experiences of sub-optimal care from adult services. The issue of trust is identified, both trust in adult providers' abilities and knowledge to manage young people with their specific condition and trust in child service providers' reports on the competence of adult services. The review also highlights how transfer can be experienced as an 'abrupt event', through lack of knowledge and information about what to expect. Knowledge gained through joint clinics was therefore especially valued, as this

'reduced patients' fears and concerns about transition and provided them with an opportunity to create relationships with providers in [adult services], to get to know a familiar face before transfer, and improved transition outcomes'.⁵⁰

They argue that such meetings, ideally, over time rather than as a one off event, can help young people prepare for transition. Finally, they highlight, the role of shifting responsibilities, given young people's 'wish for independence'. At times, parents still offer support, but young people also report that parents will not always 'let them' enact such independence.

Lugasi⁵¹ draw on selected elements of Schumacher and Meleis¹⁹⁷ conceptual model of transition in a range of developmental, situational and health-illness transitions contexts. They highlight the need to focus on: positive meaning; managing expectations; increasing knowledge and skills to 'empower' young people; joint planning with young people; and facilitative environments, including such aspects as transition coordinator and young adult clinic. Fegran's⁴⁴ review, focuses on 18 qualitative, including many of the 21 qualitative studies reviewed by Lugasi⁵¹ and highlights four similar elements: facing changes in significant relationships; moving from familiar to unknown ward cultures; being prepared for transfer; and achieving responsibility. Again, we see the centrality of 'close relationships' that young people develop in child services and that prior experiences and knowledge is no longer relevant. Also, we again see a narrative of feeling 'unprepared' and so a 'need for guidance and support'. Finally, we see the same focus on developing, enabling and forcing 'movement to towards independence' and problems of 'parents letting go'.

In this way, these reviews, and many of the original studies, echo a core issue of transition, in whatever context, be it tied to the onset of a long term condition, so a transition from health to ill health, to changes in education, from secondary school to college or university.

At the individual level ... periods of transition are characterised by disconnectedness from the individual's current social context, a transient unfamiliarity with a new surrounding environment, the emergence of new needs that must be met, and the replacement of an existing set of expectations with new ones.¹⁹⁸

Transition is a disruption, or following,⁸⁹ a breach in taken-for-granted experiences, knowledge and expectations. It involves people having to adapt to a new set of circumstances, to learn from and develop new experiences, knowledge and expectations.

In much of this literature, the disruption of the healthcare, the movement from child to adult services is characterised by a narrative of the young person as moving from 'dependence' to 'independence'. The figure of the parent is seen as central in this process. Heath's review of 36 qualitative papers about parents' experiences and views on transition highlights the range of work they engage with. The review focus on how parents are central, especially mothers, in supporting the young person. They work to enable gradual 'independence-building' over time, supporting and enabling 'healthcare autonomy' to develop, at times engaging in a partnership approach, at other times 'stepping in to provide respite'. Such work impacts on them, echoing the young people's experience discussed above, in that they feel uncertain and anxious and at times reluctant 'to relinquish control' and this 'delayed the onset of young person autonomy'. Again, as with young people, they too go through a process of transition, from 'managerial role' to a new 'consultant role'.¹⁹⁹ Finally, where transition is sub-optimal we see the same focus on the loss of 'support, resources and trusted relationships'⁸³ that parents found available through child services.

Aims

To investigate young people's experiences of healthcare transition services.

- Explore young people's experiences of healthcare transition services over time
- Explore the experiences of healthcare transition service provision of lay people who are identified as significant in the young people's transition journey
- Explore the experiences of healthcare transition service provision of health professionals' who are identified as significant in the young people's transition journey
- Describe how healthcare transition services are operationalized in clinical encounters

Methods

A longitudinal multi-method qualitative study was conducted with young people. Young people were recruited from the longitudinal quantitative study (WP2.1). They were also asked to identify a lay person and a health professional significant to their healthcare experience; and a consultation that the researcher could observe.

Data collection took place between June 2013 and June 2016. The recruitment of young people was driven by criterion and theoretical sampling.⁸⁵ Young people (n=13) were aged 4-18 at the first interview. Family members (n=14) were identified by young people and included: ten mothers, three fathers/step-fathers and one brother. Health professionals (n=19) included seven paediatric consultants, five paediatric nurses/AHPs, three adult consultants and four adult nurses/AHPs.

The Interview Schedule is at the end of this report.

Thirteen young people were interviewed once, with four of them interviewed again at least eighteen months after first interview. The young people were interviewed on their own or with a relative if they wished. Fourteen family members were interviewed once, with eight of them twice, at least eighteen months after first interview. We also interviewed thirteen health professionals, nine from paediatric services and four from adult services. We undertook first interviews with 40 people (see Table 19). With thirty of these interviews, the young person had yet to transfer, with twelve, the young person had transferred. We also observed seven consultations, four whilst the young person was in paediatric services and three post-transfer in adult services. Twenty participants took part in interviews only, six in observations only and twenty took part in interviews and observations.

Table 19: Participants recruited for the study by condition, identity and method of data collection

		Diabetes	Cerebral palsy	ASD	Total
Participants for first interview	Young people	4	5	4	13
	Family member	4	6	4	14
	Health professionals	4	4	5	13
	Total	12	15	13	40
Participants involved in observations	Young People	3	2	2	7
	Family member	3	3	2	8
	Health professionals	6	3	2	11
	Total	12	8	6	26

Observations were recorded in contemporaneous field notes. Formal interviews were audio-recorded, transcribed, edited to ensure respondents anonymity and then analysed alongside anonymized field notes. All analysis was conducted according to the standard procedures of rigorous qualitative analysis.⁸⁶ We used procedures from first-generation grounded theory - coding, constant comparison, memoing⁸⁷ - and from analytic induction - deviant case analysis.⁸⁸ Data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored in subsequent ones. We undertook independent coding and cross checking, team data sessions and data triangulation (different times and persons) and between-method triangulation (interview, observation).

Analysis

All names below have been altered to ensure anonymity and maintain confidentiality.

As one parent outlined, the actual process of transfer from children's to adults' services, 'takes five minutes' (Angela, Family). However, crossing this organisational boundary takes practical, cognitive and emotional work, work that young people, family members and health professionals engage with, often over a long period of time. The young person has usually been in a specific child service for some time, often since early childhood. The family, especially the mother, have developed good working understandings of the best ways to support the management of the young person's specific health condition(s), and importantly, how to effectively navigate, manage and engage with the child health service system. The health professionals often have significant knowledge of the young person and their wider psychosocial context. Centrally, they have all worked to build relations of trust. The organisational process of transfer ends those relationships and calls the young people and their families' expectations, knowledge and practices into question.

All the services worked to support and effectively manage the range of transitions that the young person goes through, including the healthcare transition. They were aware of the implications of an ‘unsuccessful’ transition and how people can ‘drop off the system’ (Carlos, HP) or ‘disengage’ (Pete, HP). As one health professional noted

And I, I suppose that’s my biggest problem with, with transition is, is that I feel that I’m transitioning them to something that isn’t actually going to meet their needs if they’re vulnerable, or at risk, or not robust. And many young people aren’t. (Redgrave, HP)

Some health professionals felt that some young people were not always ‘robust’, not always ready to transfer when they reached a specific chronological. Given this context, they all had some kinds of formal or informal plans and procedures for transition and transfer that sought to prepare the young person and their family. In what follows, we will outline the practical experience of young people, families and health professionals, we will explore the informal and formal plans and procedures that were implemented within and across the services. This will be structured by focusing on each of the proposed beneficial features (PBF). Table 20 offers an overview of implementation issues.

Table 20: Summary of evidence for and determinants of implementation of the proposed beneficial features

Proposed beneficial feature	Evidence of implementation	Determinants of implementation
Age-banded clinic	Limited: only seen in diabetes services	Often not feasible due to logistics of managing appointments, spatial restrictions or low numbers of young people. In practice, situated alongside other adult clinics, with parent’s frightened by visibility of ill adults and health professionals aware of visibility ‘problem’. Young people report ‘not being fussed’.
Meet adult team before transfer	Variable: some services offer single joint meeting or shared appointments	Dependent on relations with adult team(s). In services that provide, meetings do not always happen or are effective. Problematic when low frequency of meetings, young person moving away (e.g. University), adult practitioner not person who will provide care, or general practitioner is missing (e.g. transfer to primary care).
Promotion of health self-efficacy	Variable: some services provided but in a very informal, ad hoc way.	Can occur in context of long term, trust-based, relationships with specific health professional. Minimal without continuity of personal, with low frequency of visits, and when not part of service culture.
Written transition plan	Very limited: one service offered formal plan.	One service had implemented as part of research project, but withdrew due to lack of resources and motivation to continue. Some practitioners resisted a written plan, as saw interaction is key over more forms and that such forms get forgotten or lost. Informal practices can lead to lack of awareness, knowledge and understanding of process.
Parents engaged appropriately	Extensive: all services report engaging parents.	Interdependence as service norm for some practitioners and so seek to enable appropriate involvement. Some see interdependence as demonstrating problematic attachment, and seek to minimise, often referring to legal issues around patient confidentiality.
Key worker	Variable: services may report designated key worker, but young people and parents often unaware.	In practice, most young people and families name ‘their’ de facto key worker – someone they trust, seen consistently, highly supportive and accessible. In practice, a parent – usually mother – takes this role.
Coordinated team	Variable: some services demonstrated aspects.	Largely dependent on service structures. Collaboration and coordination between team members can occur formally and informally.
Holistic life skills training	Very limited: few services provided elements albeit in a very informal, ad hoc way.	Some services had not considered, others had not considered it their responsibility. Education, social services, charities, and family were already providing this – or, if not, young people, parents and services felt they should be. All felt young people should be signposted to relevant services outside NHS.
Transition manager for clinical team	Very limited: one service reported recent introduction.	One service introduced, as realised need, but still developing remit for role. Many services would like to implement, but dependent on resources, managing workload and competing demands.

Age banded clinic: the organisation of groups or the organisation of clinical mind-sets?

Within our dataset, formalised age-banded clinics are only reported by young people attending diabetes services. We observed the appointments of two young people with diabetes, as they attended age-banded clinics in adult outpatients' wards. Neither of the young people reported this experience as being problematic, one outlining that she's 'not really fussed by that' (Ruth). However, both their parents and health professionals discussed a range of concerns. One parent Judy, described it as 'quite f- frightening I guess is the word', and Ralph (Family) describes it as 'not intimidating but' he thinks that the young people would be 'more comfortable' without seeing such older people. He later describes the ward environment as 'full of fat, old people'. Judy outlined similar concerns

It is a young adults' clinic, but you go and there's no other young people there. Whether they stagger them. You're sitting with people in wheelchairs, with amputees, the great, big older people that have obviously got type two. It's not a, a young clinic that you sit there and everyone's between 18 and 25. ... Everyone's attending other things. So there's amputees there because it's with podiatry. Erm, and then you get the, the lady that can't walk (Judy, Family)

Both parents are concerned about the negative possibilities of such visual interaction with older people with diabetes. The diabetes health professionals raised similar points

I think what we know is that it can be very off putting for young adults, say, for example, you know, if the waiting room is full of people with a very different demographic, you know, elderly, amputees or blind people, or whatever. Not that they shouldn't see those people, but I think, you know, it's partly it plays on their fears for what the future holds (Redgrave, HP)

Young people are seen by their parents and health professionals as needing protection from the issues they may face as adults with a long term health condition, while at the same time recognising that they should not hide the reality from them.

We see a similar narrative of the problems of visual interaction with accounts of parents of young people with other conditions. For example, Daisy, a parent, recounts their first visit to an adult service the whole atmosphere and everything was different to what he was used to. There was a young lad in the waiting room in a prison uniform who was obviously in a bit of a mood and was stomping about and clashing doors and swearing and what-have-you, it was a bit of a shock to the system from what he was used to (Daisy, Family)

However, the young person offers a more pragmatic narrative, that although he 'wasn't used to it' you 'just need to get on with it', that 'everyone's going to need help' (Darryl). In the child services that Darryl visited previously, such age-banded clinics, may occur, but not in any 'structured way', but rather a clinic list may, at times, have 'people of similar ages' (Delia, HP). One group within a service had historically offered age-banded clinics to young people attending specialist schooling and were beginning to expand the service. Another service reported that such an ad hoc, emergent, version occurred in some of the group sessions allied health professionals ran. In these groups sessions they have had increased benefits from recognising others with similar needs, feeling part of a group, that they're not isolated, that they're not alone and often it's generated friendships among them (Lucy, HP).

In this way, ideas around peer-support can be enacted in such group sessions. Albeit, we should note the caveat that group sessions often can be poorly attended by young people.

In very general terms all young people reported a preference for the 'idea' of appointments in outpatients wards that are set-up to support young people, over spaces that are designed to facilitate the play of babies and children. Some saw it as potentially offering an opportunity to interact with other young people, people that are 'On the same wavelength about things. So I think ... people can socialise better' (Fran). However, we should note that in practice - as reported by young people and as observed in clinic waiting rooms - very little interaction actually occurs between the young people. They are often only briefly in the waiting room, and, in some contexts, they move from room to room, seeing different health professionals throughout their time in outpatients. Some also felt that they could potentially also offer the opportunity for a more young person appropriate space - not one with a 'little kiddie area' (Fran) full of toys and not one, as experienced in some adult services, that are 'completely bare' (Charlie). Finally, some felt that such spaces could begin to enable other young people to feel quite comfortable cos they know I'm not the only one whose got a situation going on in my life, there are other people here, I'm not the only, I'm not weird it happens to loads of people (Sarah).

In this way, such visual interaction is seen as potentially working to normalise understanding of conditions, to offer a sense that young people are part of a broader community of young people like them.

In contrast, some young people - as well as families and health professionals - found the idea to be problematic. Some noted that it would create yet another transition, and so potentially create 'a lot more change' (Penelope). Others supported the idea of continuing with mixed spaces, in part so 'other kids' of different ages could see how people are 'getting on' (Lee). Similarly, a parent outlined that

I, I think it'd be much more useful for them to see, say, for example, a pregnant woman coming in [Int: Hmm] and glean information from that than just seeing people who are their own age group, either doing it badly or doing it well. ... It gives you an understanding of what the expectations are (Amy, Family)

In this way, some preferred the idea of mixed spaces – in terms of age - to normalise understanding of conditions and to outline potential future trajectories.

Irrespective of the different experiences of age-banded clinics, or different ideas about whether or not they may be desirable, young people all valued the quality of the clinical interactions within the clinic room over the physical (and visual) space of the waiting room. They want health professionals they can 'trust', that are 'nice ... helpful if I ask any advice' (Ruth) that they can build some kind of 'a rapport' with over time. They want an interaction where the health professional talks to them about issues that matter to them, and strikes the appropriate level of parental involvement. Where feasible, age-banded clinics are also seen by health professionals as useful

I think they work well and I think the reason that they work well is that it focuses your mind on adolescent issues. Erm focuses my mind I don't know whether it works well for the patients but it gets you into a mind-set of thinking about those sorts of things. Whereas if you're going from 18 months old to an 18 year old you sometimes not in the right zone. (Ardo, HP)

In this way, age-banded clinics focus the interactional order of clinical work so health professionals can invoke and sustain the right 'mind-set' to interact with young people as young people.

The idea of offering age-banded clinics – and, for some, running them alongside adult clinics - does appeal to some of the health professionals. However, in practice, they are often not seen as feasible.

it is quite a small waiting room which we, we've- we're trying to address [Okay]. But there's that many people going in and out, I don't know how you would manage it, to be honest. (Dee HP)

Questions about spatial restrictions within outpatients, alongside the distributed physical and organisational geography of services were raised. Relatedly, the organisational logistics of appointments – the practicalities of coordinating support staff, as well as young people and professionals was a concern. One service had historically offered them, but 'the logistics were hard' as they could not get 'sufficient numbers ... because they tend to trickle through at different periods' (Bow, HP). In some contexts and in some services the numbers of young people transitioning at the same period, or within a specific age-band, were relatively low and so coordinating them can be seen as unfeasible.

Meeting the adult team before transfer: first steps in new relations of trust?

In all the services we focused on, the young people moved to an adult service provider with a different set of health professionals that would be offering them care. Given these circumstances, meeting members of the adult team could be key for those that experienced it. When this did occur, it would generally take the form of a single face-to-face joint meeting between specific members of the adults' and children's teams alongside the young person and members of their family.

So what we aim to do, which doesn't always happen, is that, um, we'll have a joint appointment, um, prior to transferring them. So that they will come and see me and my adult colleague, um, so that I can introduce them and they know this new face [Int: Mmm] and that it's not someone completely unfamiliar for when they come (Redgrave, HP)

The young people could meet a single member of the team – often a consultant or nurse specialist – or a range of members of the team, including nurses and allied health professionals. In part, this was about establishing familiarity and trust, and feeling 'you're kind of delivering them into safe hands' (Delia, HP). Some services had a long history of offering this, sometimes this was formalised, and sometimes it was part of the unwritten norms of the culture of the service.

In services that ran young adult and adult clinics alongside one another, where these clinics were physically and temporally co-located, this could offer a range of opportunities for young people. They could become used to the physical and cultural geography of the service – in terms of location in the hospital and the layout, feel and routines of the clinic. They also could offer the young people the opportunity to get to know members of the outpatients' staff – 'they meet our clinic staff start doing their bloods, height and measurements and things' (Jewel, HP). This service also had plans to extend the number of opportunities for the young people to meet the adult team. In one service this co-location could mean a much more extended period of opportunities to meet the new staff

So here we, because we run it alongside the adult clinic, they can meet the adult team several times before they transfer and then we do a transfer appointment where it's either in our clinic or their clinic, er, we see them together. (Ardo, HP)

However, they go onto note that this ideal is not yet representative of other services in the region.

In [Local Town B] they tend to meet the adult doctor and nurse just once at that transfer appointment, er, and as I say in [Local Town A] it doesn't happen at the moment. (Ardo, HP)

And such inequity in access to opportunities to meet the adult team is present across our data set. In a few cases, allied health professionals from both adults' and children's services, may undertake a short series

of 'shared' appointments, and so handover for these specific aspects of the service may be more gradual and occur over time. Such meetings, however, fleeting, offered the potential for both symbolic and practical gains.

Prior to such meetings, child health professionals would introduce the idea of a joint meeting and seek agreement for them to take place. They would, often over time, also seek to explain the norms and expectations of adult services.

We alert young people to the way adult services are currently provided ... 'Unlike in [our service] where if you miss a few appointments we'll still keep trying to contact you, adult services will discharge you rather more promptly.' ... I really do feel we have to equip young people (Peters, HP)

Equipping young people with appropriate knowledge about the new service was central. However, what seen as key was enabling young people to actually meet those people whom would be providing them with care.

Young people had, in most cases, a long relationship with a particular service, and so built up, over time, relations of trust with health professionals they regularly saw.

Because I've had Fiona [HP] for years, and she's been absolutely brilliant like. Honestly she's helped us out and everything and she's always been there, if I've had any concerns, she's been a brilliant doctor. ... And I wish I could keep that, and I think it takes a lot to know your doctor, because obviously you trust them with your medical facts and what you do. (Fran)

As another young person noted, going to a new service means 'obviously, it's building relationships' (Brian). For those young people that experienced it, meeting members of the adult team was central to initiating new relationships with members of the adult service, ones that, over time, could develop into new relationship of trust. Charlie outlines his experience of a process he describes as 'nice':

Charlie Yeah, well I mean we did meet Crowley [HP] beforehand didn't we?

Cilla Yes.

Charlie But he was the only person we met beforehand but that was mainly because he wanted to meet me as well as us wanting to meet him. So that was quite nice, cos obviously then before I even went to my first appointment with him I knew his face, I knew a bit about him, he knew a little bit about me. So it wasn't like we went into the first appointment and it was like you had to find out about each other, you could still have a conversation, which was nice.

In such meetings, the young person could share something about themselves and begin to gain some sense of the adult practitioner, as well as the norms and expectations of the service they would be transferred to.

For parents, they enabled them to begin to make sense that their child was being transferred to (another) safe pair of hands. For adult health professionals, it also gave them a chance to 'get to know them'.

It's a one-hour appointment that we have [Int: Okay] with the joint session. So it just gives you chance to get to know them. ... They're gonna see somebody who's familiar (Pete, HP)

It also enables them to (re)establish ideas about the norms and expectations of the service, as well as answering any specific questions. Such an event helps young people and their parents to manage potential anxiety and fears and helps to offer more of a sense of certainty about the process.

However, not all services offered such a meeting with the adult team and even in those that did, the meeting did not always happen or were not always effective. In one service, it was seen as 'sufficient' to have a 'joint transition clinic' only once a year.

Our normal pathway for transition, erm, is that I do an annual transition clinic, with [adult consultant]. So I do that at [Location B]. But we invite in other young people, who are transitioning, simply because, you know, the bulk of them are at [Location B]. But it's sufficient just to have one, one clinic a year. So we've actually got one tomorrow morning, erm, a joint transition clinic. So usually, I would introduce the young person to [adult consultant] face-to-face, in the transition clinic (Carlos, HP)

However, if a young person was unavailable at that time, as 'for some people, it just isn't convenient', they would, therefore, miss out. And this was the case for Carl, whom did not attend the joint transition clinic, and whom felt 'abandoned' by the services. In Darryl's case, the 'handover' meeting, although scheduled, did not take place

Yeah there was supposed to be a handover but it never really came off. Em, Yeah. I think some in particular do sort of struggle with changes and routine and that kind of thing, so yeah it could help. ... I think that would have been really significant had it worked out. So at least we would have been prepared and if nothing else we had a sort of familiar face. (Daisy, Family).

Darryl, the young person, thought that such a meeting would have 'would have helped' and maybe offering 'even like a second meeting'. Such a meeting would have allowed him to 'sort of know where you're going rather than just feeling like you're being dropped into someone else's hands' (Darryl).

Those young people that move away for University are faced with a practical dilemma of whether to stay with their current services, transfer to adult services at the new location, or operate a more shared care model, involving primary and secondary care. Unless well managed and coordinated, they can also miss out on such meetings.

Organisational turbulence, be it in staff turnover or due to staff sickness, could also negatively impact on the process, meaning some young people lost out on the opportunity. Health professionals were aware of the often very practical problems that can emerge when trying to coordinate meetings with adult health professionals.

There are practical issues, such as, um, sometimes my adult clinic isn't there, so, um, we've got a joint appointment but they're not there so we can't see them. And sometimes they cancel or rebook and then they'll perhaps end up in an adult clinic without having had a joint appointment, in which case one of our paediatric specialist nurses will accompany them on that first appointment so that there is some sort of shared [Int: Yeah] information, um, and handover. (Redgrave, HP)

In such circumstances, the specialist nursing attending the clinic with the young person is not always seen as ideal. The consultant felt that the specialist nurses often did not always have such a long term relationship with the young person as they did and so did not always 'know' the patient as 'well'. In part this was due to this services having a large number of specialist nurses, and any one of them may be asked to attend, and as well in part, due to staff turnover.

In another service, joint transfer meetings only occurred between professionals and 'only ... for the really high risk cases' (Peter, HP) were the young person and family invited. However, part way during the fieldwork, this policy had changed to be open to all, although, again, they were aware 'it's not always possible' (Dee, HP). This new service was set up so that

In the last six months, they'll contact us to arrange an appointment. Erm, and then it, it's normally a joint transfer. ... it would be the patient, erm, normally the patient's relatives or next-of-kin comes [Int: Yeah], erm, and it would be the consultant from our team ... normally myself, and, and [another AHP] ... it's, it's just kind of closing one door and opening another, really. (Dee, HP)

In this way, the young person would meet different members of the team. This is important as we know that in some services the health professional actually meeting the young person in this first meeting was not the health professional they subsequently would routinely be seeing. We know that young people, at the very least, value being able to 'recognise one face, you're not sent into a room full on entirely new people' (Angela).

Finally, a missing figure, especially for those who will be transferred to primary care for all or part of their care, was the general practitioner. For example, one young person visited a range of services and, when he turned 16 his family were told that he was 'in the transition process'. In a consultation his mother outlined how

I did question, I said, like, 'If, once he does go into adult services what ha- what happens if he needs to see someone?' and they say, 'Oh, go to your GP.' (Beth, Family)

They had never visited the general practitioner in reference to his long-term condition. As they noted, at a later interview

Brian I couldn't even, I couldn't even name me GP to be honest.

Beth His GP, he sees a different GP every time he's there. Nobody knows him and knows him and knows his history.

Unfortunately, the general practitioner is often someone whom the young people had often had little interaction with over the years, yet is meant to be a central figure in coordinating their health care and access to health services.

Promotion of health self-efficacy: learning how to manage your health (services)?

Health services saw it as their role to help young people develop confidence in making sense of and managing their health condition. Such work is understood as 'kind of always a side-line of the work anyway' (Lucy, HP). For her, and others, this is 'quite often that is a big part of our role' and with her patients

it might be to work on anxiety, which it tends to be for me, but really part of that is feeling that you're not helpless and hopeless and that you can go forward and that you have got a lot to offer, and so definitely needs that input. (Lucy HP)

However, this was not formalised or based on a specific policy, but rather 'a sort of gradual process rather than a one off education session in a teenage year' (Ardo, HP). As such, supporting young people to develop confidence seemed to occur in an ad hoc way over time in consultations and other interactions with a range of health practitioners, including consultants, nurses, psychologists, physiotherapists, occupational health practitioners and speech and language practitioners. In practice, nurses and allied health professionals were often seen as more central to supporting and enabling this

informal work, in part as they may see young people more often, they spend more time with the young people, and at times the young people are felt to be more 'open' with them.

None of the services reported any form of structured, protocolled, approach to delivery. Such discussions may explicitly be created around specific devices or events. For example, one service used transition questionnaires that included

elements that ask, you know, 'do you organise your own appointments?' 'Do you organise', er, 'do you know how to pick up your prescriptions?' 'How would you', wh-'where would you go if you needed a-advice in an emergency, and your, your mum wasn't around?' [Int: Yeah] That sort of thing. So we, we ask about that, and obviously, if there are gaps in their knowledge, then we try and fill those gaps. But we don't provide them with any training. (Jones, HP)

In this way, in the space of a consultation, such questionnaires' may offer a very brief and focused 'teaching moment'. Another service had offered group sessions, organised meetings for young people to meet outside the space of the clinic, which were led by an allied health professional. These sessions included elements like 'problem solving' around disease management. However, they reported that such extra-clinic sessions often suffered from low levels of attendance. Finally, one service was seeking to transform what they had been doing 'informally for years' to ensure continuity in provision as the team grew. This was part of a broader peer review process, where they were seeking to look at 'What do we want them to know by the time they've been educated?' And then looking at the, sort of, that as the curriculum, and then 'how are we going to get to that point?' So starting with what it is we would actually like them to know and then how are we going to teach them that. So they're trying to put some sort of structure around it. And then how do you deliver that and then how do you check whether they actually know if afterwards. (Ardo, HP)

Their aim for was not to develop new questionnaires or develop checklists to ensure the young person has been talked to about a specific topic, but rather to create a more formalised and cross-team culture that ensures an awareness of and action around such issues.

Some of the young people and parents described receiving support in developing health self-efficacy: 'we did lots of different activities. It was never sort of formal' (Penelope). Some young people felt that, at times - 'obviously sometimes' (Sarah) - this was a focus of interactions with health professionals. For some, albeit through informal means, this was 'all the way through' (Amy, Family) their experience of the service. For young people and parents, a context of longer term, trust-based, relationships with specific health professionals seems key to enable them to develop such confidence in making sense of and managing their condition. Often, in discussing this topic, young people would refer to a specific member of their services team as central to offering such support.

However, some young people and family members felt they had not received any formal or informal support in this area. As one parent outlined, this was from her perspective absent, yet 'this is what he needs' (Leanne, Family). Another that

He hasn't really had any help like that. He has always had, like with Delia [HP] or someone, somebody to talk to. [Int: Yep] The usual checks, height, weight, that sort of thing to make sure that he is not having any kind of adverse reactions to any medications and that sort of thing but no a lot of it has either been down to us or him. (Daisy, Family)

A member of this young person's clinical team, echoes this absence, noting that such work is not always central to the care provided across their service: 'I don't think it is - it's - I don't think it necessarily is done; but I think it would be very helpful if it was.' (Delia, HP). Distribution of the work across teams and services is not always even. As noted above, often nurses and allied health professionals support this work. For some consultants, such work cannot always be taken on

I think I'm all for assuming responsibility ... I'd love to do that. But, um, we are so inundated with managing people. [Int: Yeah] that there is no chance to do that. And ideally that would, is work that was kind of, you know, primordial work (Peters, HP)

The lack of support for self-efficacy, was most marked when young people's appointments were infrequent and where staff and, or the services themselves, were in flux. However, the key work most young people need, alongside support making in sense of and managing their health condition, is in managing services post-transfer.

Going from Children's Services to Adult Services. There was no one really to talk to who told you what to do, it was just sort of, we've just picked up on it. (Charlie)

As young people are transferred to a new organisational and clinical environment with a new set of health professionals, norms and routines, the core focus they need is support and confidence in the practicalities of managing the adult healthcare system itself.

Written transition plan: gaining awareness of new norms and routines?

Plans about transition can be offered, experienced and valued in different ways. Several services stated that they had formal plans or procedures for transition and transfer of young people. However, in all but one service, health professionals reported that 'written transitions plan' were not used. In an

already bureaucratic culture, there was some scepticism about the place of such documents. As one practitioner noted 'I'd like to see patients and facilitate effective transitions, not be filling in plans' (Peters, HP). Another outlined that

I think unless it's been, sort of, discussed with the young person it's, sort of like, completely hopeless. ... It's, it's one of those things that people look at when it's written and then never again. And actually does anyone pay any attention to it? I don't think prof – health professionals do. And I don't think the young people do. So I'm sceptical about the utility of transition plans, um, I have to say. (Redgrave, HP)

Issues of time, resources and practicalities of fitting into on-going consultations were also seen as barriers. One service had implemented it as part of a research project, but then withdrawn it when that additional research resource was no longer available. However, two positioned them as an 'aspiration' (Brown, HP) or a 'target' (Delia, HP). For most health professionals, plans around transition were again seen as occurring over a series of consultations. Services also outlined that they then recorded such discussions in clinic letters. Discussions are

laid out in the kind of letters, which I write to the young person and their parent ... And transition is part of that, we don't have a separate piece of paper that's called transition, it's, it's everything weaved into their clinic letters (Carlos, HP)

Some patients reported experiencing plans about transition over time – 'It was more just something we talked about, there wasn't really anything written down' (Darryl). As we will outline below, such an informal approach was not always effective

Unsurprisingly, none of the young people were aware of ever having been offered any sort of 'written transitions plan' or access to 'health passports'. Sarah did remember discussing plans for specific aspects of her transfer in her recent consultation, but when asked about whether she received any type of written documents about any aspect of the process she noted that 'Hmm I don't think so but if I have I don't remember'. Another young person reported having 'got loads of transition plans' (Fran) centred on her move from school to college, but nothing from her health services. However, in one case, a written plan was reported, albeit that only the young person's mother was aware of it. As the topic was initiated in the interview, Jane, Jonah's mum said 'It's here somewhere' and then pulled a crumpled document – entitled a 'transition planner' – from under a large pile of other documents. Jane said to the interviewer that 'Jonah should have filled it in' and then turned to her son and said 'You've only had it about a year to fill in'. In all the other cases, none of the families of the young people had ever heard of such documents. Overall, the young people although less enthusiastic about the concept than family members. The young people were aware of some potential benefits, as well as problems, especially around their ability to 'lose' such documents. Family members and health professionals also shared this concern, health-related paper documents do and will get lost.

The lack of awareness did not only extend to such documents, but also about some aspects of the transition and transfer process itself. Albeit a more extreme case, a mother noted,

Well we have nothing at all to the extent that I don't even know when she goes over. I'm assuming it's eighteen but I don't know. (Amy, Family)

Another noted that 'anything would have been useful ... just to give us some direction' (Beryl, Family). In this case, the family had to actively arrange elements of the transfer of services themselves.

Remember at the time, I had to write to all of the individual services, and say, 'Ben is now 18. What do we do?' [Bob: Yeah] And a, a couple of them, I think physio being one of them, I had to chase up a couple of times, to just get letters back saying, 'Right, you just ring them.' And that was it, literally. So nobody even sort of came to see us, to say, 'Bye bye, this is where you go.' It was just literally nothing, and we had to write to everybody to say 'Ben is now 18. Can you point us in the right direction?' (Beryl, Family)

This service had 'no real formal processes ... or leaflet or anything like that' (Brown, HP) for transition. They discharge most patients from child services, but offer 'that safety net of the adolescent clinic to come to if and when they need it' (Brown, HP) – and these clinics are described as 'occasional'. Young people and their families have to then get themselves referred back into services. In such a context of a lack of awareness, families stressed the potential value of the concept behind such written plans for young people and, as well as them also receiving information about the process. For Paul, brother of Penelope, 'it seems pretty obvious really, like, that you would need something like that'. He notes that

There was literally no plan ... this letter was meant to be sent, this letter wasn't received ... she was just lost. She was just lost in that middle area. That, that, well obviously that transition ... Um, I think the most important thing is just clarity for the young person, for the parent, for the family ... as long as people say what they're going to do, and, you know, be organised and make sure that there is something in place (Paul, Family)

In this case, the young person and the family lacked basic information about the process, they were 'lost'. His sister also outlined the kind of very fundamental and basic information she felt she needed

Basically just knowing what's going to happen [Int: Mmm]. Knowing when it's going to happen. Knowing the process. They should tell you, not us chase them ... Instead of just leaving you in the dark. They should tell you all this. (Penelope)

In part, this lack of awareness was a product of a service in flux, with regular changes of staff – and regular changes in whom Penelope would see - and no specific person coordinating information to her about the transfer process. In Penelope's case, her family were very active in contacting services and seeking the appropriate information; they had sufficient cultural health capital to actively manage the situation.

Some young people, and their families, who had transferred felt unprepared and unsure about many aspects of the new service.

Connie None. We've had no word from nobody. Nothing, have we?

Carl No.

Connie It's like you've suddenly, you've reached that age and you're written off. ... So we've had no word from not one of them. And at the day we went to a meeting, must be two years, and basically they were all saying, 'Right, you're, you, you're moving onto now to adult services [Int: Mhm], you will hear from them in due course' and we've had nothing. Absolutely nothing.

In this case, the young person – Carl - and his family felt 'abandoned' after transfer. They were not, as far as they or a representative of child services whom we had also interviewed were concerned, transferred to primary care. They had visited adult services once, but since that point, had received no further contact, appointments or offers of support. They were unsure about what exactly to do or about whom to contact to effectively manage this situation. As such, they felt abandoned both by adults' and children's services.

It appears that such factors as informal practices and organisational turbulence can lead to a lack of awareness, knowledge and understanding of process. As noted above, young people are transferred to a new organisational and clinical environment with a new set of health professionals, norms and routines. They really need to be able to develop an adequate awareness of the transfer process itself and the people, norms and expectations of adult services.

Parents engaged appropriately: enabling interdependence?

At the heart of transition is an ambition to shift the work of managing health and health services from parents to the young person. Central to enabling such 'independence' is the support of family members, especially mothers (or if a mother was not present or able to play such a significant role, the person who takes on that role). However, in practice, this is not about a move from a discrete position of 'dependence' to 'independence', but rather about supporting and enabling the young person's autonomy, so a relational autonomy, where interdependence is central. As Fran noted, 'at the moment I think I like me mum coming to appointments with us, because I still think I need her guidance' (Fran). Family members, in particular, play a very significant role and contribute often invisible labour to the negotiation of the multitude of transitions the young person experiences, especially the healthcare transition.

They are the central mediators in young peoples' experiences of health and healthcare services. At different times, over the trajectory of transition, there is a fluidity to their involvement. They routinely act as key workers both within the clinic and home. Daryl, in conversation with his mother, positions the support he had in terms of his healthcare as 'from you and dad mostly'. Importantly, families provide the young person with some continuity of care and a point of reference and contact. In reference to his new appointments in adult services Charlie outlines what he would prefer.

I'd have rather mum was included cos I just come home and I'll tell mum everything anyway or I'll end up bringing her to the appointment so she's there anyway. But it's sort of all the letters just all of a sudden got sent to me and I'll open them and I'll be like 'Well, what's this? First I've heard about it' and mum will end up having to deal with it anyway, so if she's contacted as well, even if it's only for sort of the first year of it happening, until they know I'm a hundred per cent confident with what I'm going to be doing (Charlie)

Charlie positions his mother, as a central part of care. He seeks to actively involve her in his care, sharing information about the trajectory of consultations and other information coming from the service. He is clearly aware of her knowledge and abilities in supporting him and values this, especially at time when he is unsure about the practicalities of his care.

Family can also act as advocates for young people in negotiations with healthcare and other services. Ben's parents, Beryl and Billy are aware that some of the adult services Ben engages with do not want them to continue to be involved in his care. In reference to Ben's contact with social services about providing support for an aspect of his long term condition, she notes that

I'm not just being shoved to the side-lines so they can go and bully him like they do, or like they try and do when it comes to organising the things that they're currently making a mess of organising for him. Unless they think they can get away with it if I'm not there (Beryl, Family)

Most had experience, over the years, of ‘fighting to make sure he has the best of everything’ (Daisy, Family). Their experiences with services meant that

I’ve learnt over the years that I need to ask these questions because I never feel anything’s really offered, you always have to ask for the information rather than it being offered. (Cilla, Family)

All the families in this study would seek to be actively involved in obtaining access to the best care they could get for their young person. However, we did have reports of health professionals trying to work with unengaged parents, the ‘reality also is that we have lots and lots of families where parents, you know, just aren’t involved for love nor money. (Peters, HP).

Families can offer practical support in managing health and facilitating access to services, and cognitive support in terms of prompting or asking questions, doing research, providing information and checking understanding.

em my mum is my major leaning post for memory and all appointments and what’s been said and such ... If my mum didn’t know the answer the doctor would or if the doctor didn’t mum would (Sarah)

Other young people described family members enabling such distributed cognition. Family members were often the focus for the practical coordination of appointments, with many young people having to coordinate contacts with different services or organisations. Daryl’s mother took a very active role.

If I know it is an appointment and it’s addressed to him I will open it and then as soon as he shows his face downstairs or whatever I’ll say ‘this has come for you. Obviously I haven’t given it to you cos it’ll get lost somewhere in your bedroom. It’ll never be seen again so your appointments are here, we’ll get them marked up on the calendar’. At least everyone in the house knows what’s happening and when. (Daisy, Family)

Alongside such informational and coordinating work, they can also offer emotional support, providing reassurance, comfort and encouragement.

The young people and health professionals are very aware of the work of their families in supporting and enabling them. The young people recognise, request, and at times, require and celebrate this support. Penelope notes that her mother has ‘always just been involved ... um, she’s just always helped us with everything’. One of her professionals offers a related narrative

Her mother is really her champion. Uh, very creditable parenting style and ability. She knew when to back off and when to champion Penelope. ... She was pushed, but she wasn’t told where to go [Int: Yeah] by her mum, or where she needed to be. Wherever she was, that was celebrated, and yet masterfully pushed. (Peters, HP)

Family members are generally seen as enabling young people’s autonomy over restricting it. Practitioners are aware that often ‘they’re heavily reliant upon their parents still’ (Pete, HP).

However, parents can, at times, be seen as shifting between being understood as supportive and enabling to potentially over-invest. For example, a health professional describes Amy, Angela’s mother in the following ways

So we’re trying to give Angela a bit of independence but maintaining the support from her Mum who is very, very supportive. [Int: Yeah] Her parents are very supportive. They’ve had some erm bad experience of [long term condition] ... erm I think she will always find it hard to erm let go ... what we’ve tried to say to her is that actually the best way of avoiding that is to teach the girls how to look after themselves cos she’s not going to be around forever. ... I’m sure she finds it hard cos’ she’s that sort of mother who erm is very involved, and not all, all, parents are that supportive but she is. (Ardo, HP)

Parents are very aware of the potential to move from being cast as supportive to being understood as ‘very involved’. As with all young people with or without long term conditions, parents have to work to negotiate with the young person, and with themselves, about how best to enable and support moments of ‘independence’. For example, an interviewer’s question, about whether child services ever asked to see Daryl alone for part of a consultation triggered a new conversation between Daryl and his mother Daisy.

Daisy But you know, when we’re going to your appointments and things like that, if you ever feel that you just want to go on your own, I can always wait in the car you know?

Daryl I always want you to know what’s going on as well cos you know I have an awful memory.

Daisy Do you know, until you got talking there, it never occurred to me that me being there at every appointment could be too much, but yeah, of course it could, I mean, when I was his age the last thing I ever wanted was to go to the doctors or anything with my mother, I never wanted my mother there by my side.

Two years after the initial fieldwork with Darryl and his family, they then told us that Darryl now only attends appointments on his own. In this way, parents need to learn, over time, new ways to support and enable young people's autonomy.

Creating new routines, norms, and expectations evolves over time. Families and young people can experiment with new ways of being interdependent. Ruth and her father, Rod, had a very collaborative approach to her taking on more responsibility for managing her care as she got older.

For the last, erm, er, year, 18 months she's been taking on much more of it herself. ... I mean when we first started doing this, you know, she did six months of sort of [managing aspects of her long term condition] ... You know, not even six months, maybe just six weeks or something, and she said, 'I think I'm getting this all wrong.' You know, 'Can you help me out,' sort of thing [Int: Yeah]. And then we went back to what we were doing before and I [managed her care] and then, erm, er, and obviously she was there as well and then when she got more confident again with it, you know, then she went back to doing it herself, and she has done ever since, you know. (Rod, Family)

Clearly, this involves relations of trust, trusting that the young person will remember to undertake specific actions, or remember specific details, and trusting to them to know when to ask for additional support or information from their family or health professionals. Jack's mother, Judy talked about how her son was taking on responsibility for a new aspect of his care. Specific items needed to be ordered in advance. Jack was supposed to order enough for three months for his time away at university. Initially, Judy reported that she was not going to get involved but she then realised that he did not have enough.

Erm, and then I said, 'Are you sure you've got enough stuff?' He said, 'Yeah, yeah, I phoned it.' And I looked at it and I thought, 'You've got five boxes. This isn't gonna last you.' I phoned them up, found the number, phoned them up and so I said, 'I know, my son's 18, before you say anything, and he should be doing it himself.' And the woman's like, 'No, I've got a 19 year old.' She said, 'I know what you're talking about.' ((Laughter)) Erm, I said, 'He says he's ordered enough 'til Christmas,' and she says, 'No, he's ordered enough 'til October.' (Judy, Family)

Judy then collected the items and delivered them to her son at university. Judy's involvement, like other parents, is fluid, moving between wanting to be informed, to checking in with health care staff, to supporting Jack in making decisions about his health care - even when she disagrees with some of his choices - to encouraging him to lead an active, independent life. Such work at times, needs to be done with some delicacy, but often families can feel that they are being understood by the young people as doing different work: 'he probably thinks I'm nagging him but it's, it's just trying to encourage him' (Beth, Family).

In some services, or with some health professionals, or with some aspects of the healthcare system, such practices, especially in adult contexts, are seen as examples of 'attachment' or 'dependence' and therefore potentially problematic. Following the incident of Jack not having the specific items he needed to order in advance, Judy describes being told by one of her son's adult health professional's that 'You've got to step away'

The [health professional] is 'But leave him. He's got to sort it out himself.' But it's too late if he doesn't sort it out [Int: Yeah] and he hasn't got the item. ... I haven't been in for 12 months. I haven't been to any because it got-the, the [health professional] said, 'Back away,' It was like, 'Right, this year we're gonna back away. [Int: Yeah]. He's gotta build his confidence.' So I haven't been. I haven't been. (Judy, Family)

In Judy's case, they have decided to 'back away' and not go to any appointments, with the hope that her son will develop more (timely) awareness about self-care. They really want to support him in this process but also ask, 'why should he have to think about placing an order [Int: Yeah] when n- no one else his age has to think about that sort of thing?' (Judy, Family).

Some professionals see it as their role to shift the 'locus of control'.

we try to keep the parents out of [Int: Okay] the consultation but we do offer them, you know, if they want their parents to come in perhaps they could come in at the end of the, the consultation ... the sort of parental involved and the, the locus of control in these consultations very much shifts, erm, to the patient [Int: Okay, mm hm], the individual young person, erm, rather than the [service] team and, and the parent team. ... Erm, the people who often find it the hardest are the parents [Int: Yes] to go from that position of power come control, er, and they worry desperately about their children, which is understandable [Int: Mhm] ... And I think all parents ex- will experience that to a greater or lesser extent. ... (Jewel, HP)

This health professional seeks to give young people the ‘tools and the knowledge’ needed to enable them to ‘be empowered to make their own choices’ (Jewel, HP). However, in practice, families are always involved, albeit at times feeling they are forced to do this work in the background. Since moving to adult services, Charlie noted that his mother is not included in his care.

They seem to have left her out, like completely ... Yeah, rather than just doing it, actually saying ‘Do you want us to cut parents out completely or would you like them to still be involved?’ rather than just assuming. (Charlie)

However, as outlined above, Charlie still wants his mother to part of his care, he wants her to because for him, ‘having to deal with all of it, is a bit scary’. He still wants his mother ‘kept in the loop’ and in practice does this work himself.

Part of the narrative of (in)dependence, empowerment and attachment appears to be embedded in a broader narrative of legal independence. A child health professional talks about his own experience of his son’s care

the health practitioners won’t speak to me, or engage with me in any way whatsoever, even though he wants me to be involved. Erm, because he’s 18, and is deemed to be an adult [That’s...], so that is the way of the adult world, and it’s, erm, yeah, that’s, that’s, you know, they, they respect the individual’s confidentiality. (Carl, HP)

In this way, working with the family, around communicating issues about appointments of organising aspects of care can become problematic. We have various moments where part of a service will no longer communicate information to family members. For example, Ben’s family outline the problem.

Beryl: everybody’s sort of saying, ‘You’re an adult now, Ben, you’re an adult now, you’ve got to do this yourself.’ And everyone was saying, ‘You’ve got to do that yourself, you’ve got to ask for [service] yourself.’ So everything all of a sudden was lumped back on him, [Yeah] and people were starting to say they can’t speak, can’t speak to me. ‘We’ve got to speak to Ben.’ [Yeah] And he was, ‘I don’t want to speak to them. You just sort it.’

Bob They said, yeah.

Beryl And of course they wouldn’t speak to me, because they wanted to speak to him, as the adult.

Young people can, at times, be caught in a tension where (legal) independence is thrust upon them, whereas they have a preference for interdependence. Ben notes, in reference to his parents not being able to speak on his behalf that

I don’t know what to say. I’m not even old enough. I’m not experienced to blimmin’... I’m 19 years old. I’m looking out for other things. I don’t really know what to say to those kind of people (Ben)

Obviously, for these young people having a long term condition is only one of their identities, one they often want to minimize and only engage with at specific times, when it is necessary. Young people can feel, at times, confused about how to best manage doing being independent

I want to try and lead like a normal lifestyle. Like no one wants to ask for help really, you just want to do it and be independent. .. But it’s like, it’s confusing ‘cause at one point, I’m like, it’s like, ‘Oh ask for help’ and the next point it’s like, ‘Well you need to learn how to do it yourself’, so it’s like, which one do you do? (Brian)

Over the process of the interrelated transitions they face, be that stages of life, healthcare, education, they feel that they can receive conflicting messages about how best manage the rights and responsibilities that are embedded in these transitions.

Some services and health professionals, including those embedded in adult services, understand familial work of supporting and enabling, as demonstrating something like interdependence. Ben notes that one of his health professionals embodies this practice ‘He does the both, treats us like an adult but he’ll, he’ll also include me mam just in case I need her for anything’. (Ben). Similarly as Ruth notes, the doctors always said, you know, ‘You, you don’t have to have your dad here’ or, ‘You can have you dad here’ if he wasn’t there kind of thing [Int: Yeah]. And it, it was always more my dad’s decision than anything, you know, he would say, ‘Look, you know, you should try this on your own’ and I would go, ‘No, I don’t feel comfortable with that yet’ or ‘yes I would’. And the doctors would go along with it, you know, they’d be [Int: Yeah] supportive if he was there and supportive if he wasn’t kind of thing. (Ruth)

An adult health professional outlines, he is aware that with young people ‘they, they’re in charge of themselves in, in adult services, whereas sometimes they, they still need the guidance and the backup from the parental guidance. (Dee, HP). As such, some services can and do work to recognise, enable, support and accommodate interdependence where possible. One notes that, within their adult service that

the young people will pretty much always bring, erm, one of their parents or carer with them, yeah. Pretty, pretty much 99% of the time. Yeah [Int: Okay]. Erm, erm, as they get- even-well, even when they get older, they tend to bring partners [Int: Yeah] or, or relatives with them, yeah. (Pete, HP)

Some health professionals are aware that the involvement of others is normal, not dysfunctional. The 'parent team' is, at times, supported in shifting roles to a more 'partnership', 'shared care' or 'consulting' roles.

Key worker: enabling consistent, supportive, relations of trust?

Very few services reported offering a designated key worker. With those that did, the person the services named seemed to differ from the one the young person and family then went onto suggest. For example, one service outlined their practice

- Jones: So they, they have a named specialist nurse ... they should know who their named nurse is, and they all know how to get in touch with me, if they need to.
- Int: Okay, okay. So would you find they generally would get in touch with you, or they would get in touch with the diabetes nurses?
- Jones: Mostly with the nurses, and increasingly ... the nurses are actually getting in touch with them.

In this service, as with another, the official role is seen as tied to a nurse. When we asked the young person, he responded that person he would contact would be 'Jones normally' (Jack) and not a nurse. Jack's mother, Judy, offers a similar narrative.

Key worker you see, we don't even see the same nurse, even now ... see I always just phone Jones [HP], because he's the main person, you phone the nurses and they are all chopping and changing and they don't work every day ehm and one day 'oh I don't deal with [X], that's so and so she's on this day'

In practice, the young people and their families orientate to a specific health professional as their informal 'de facto' key worker due to such issues of consistency in relationship, knowledge and accessibility. As such, in nearly all the services, young people could identify someone whom they felt acted in the role of a key worker, albeit without a formal title or responsibility.

The core attributes around which define someone as an informal key worker for young people seems to centre on relations of trust. For example, when asked if she had one a young person responded that

I guess it's Redgrave [HP] I trust most out of the people, which I guess isn't really a nurse or anything. But he is the doctor who I trust most to talk to and that (Ruth)

Again, in this service, a nurse was an assigned key worker for Ruth. However, for Ruth and others, knowing someone over time and therefore being known by them is central. Someone whom 'knows me the most' (Fran) emerges from such consistency in relationships. The person also needs to be accessible and knowledgeable, often that means in terms of contactable via a specific number or replying to a call within a timely manner. A mother outlined how a specific allied health professional was the person she would always go to if she did not 'quite know who to contact' as they are the person that her son has 'seen the most' (Beth, Family). These informal key workers are often also positioned as someone whom is described as 'brilliant ... really helpful' (Daisy, Family). For example, Connie, Carl's mother, remembers someone in child service

- Connie I, actually yeah 'cause she was really good. ... So she was good, I mean I tell you what, that woman wants a medal [Int: Mm hm], she really does because she was so good not just at her job but she'd, you know, fit you in somewhere
- Int It's often the [allied health professional] who do, who do all of those things.
- Connie Aye, well there's not many, well honestly all the other ones you used to talk to, 'Yes, but there's naught we can do, goodbye.' You know, [Int: Yeah] and you'd think, 'But you're not saying which way, which route I've got to go.'

Post-transfer, the beginnings of such relationships of trust can be established. Charlie outlines that, the main person I've seen so far is Crowley [HP], he's sort of been really helpful, and he's even given me sort of a mobile contact for him and said 'if there's anything you ever need, just give me a call and ask me anything'. So that sort of made me a lot more comfortable with him and I literally will just give him a call or things like that, so that's sort of been helpful, but with everything else I'm still a little bit lost. (Charlie).

Charlie was in the process of transfer, with a few aspects of his care still situated in child services while most had transferred to adult services. As he notes, he is 'still a little bit lost'. Yet, the person he sees as most useful and accessible, emerges from his brief period of consistent interactions with a specific health professional whom has been 'really helpful' and made themselves easily accessible to Charlie. The centrality of relations of trust is most clear when they are absent. When asked this question about a key worker Ben and his mother, Beryl, responded

- Ben I thought that was what me mam was doing.
- Int Yeah, yeah.
- Beryl I think it's difficult, because I think, not sounding too defeatist, I think the damage has been done and we've just got no faith, well little to no faith, and little to no trust in them. Have we? [Int: Mm] I think they've, they've let us down so many times that we just, we don't trust them. Which is an awful thing to say if you're a health service, but speaking generally again I suppose, but I just don't think we trust them do we? We don't trust them to follow through what they say, they say that they'll do.

In this case the young person and family view of being offered sub-optimal care, in part stemmed from the lack of someone offering ‘consistent support’ (Beryl) in adult services and being an accessible source of knowledge and supportive over time. Ben had a large number of different people he would see and different services he would visit. The family members went onto outline the need for someone taking on the role of a key worker in one of their own interviews.

Bob Yeah, ‘cause they always fob you off onto somebody else when you ring up, ‘Oh, I don’t deal with that. You have to speak to this one.’ Speak to them and they go, ‘Speak...’ There’s no direct person you can deal with.

Beryl It’s passed round, mm. ...

Bob They should just have one person you can get in touch with and can sort it out for you. You know, one or two, not ten other people.

The service themselves noted that such support was absent, that it was only offered by ‘whoever’s working on at the time or with them at the time’ (Bow, HP). Whatever the context, whether services are seen as effective or not, mothers are often also understood as another informal key worker. As a health professional commented

She often said she can’t remember who her key worker is. She would call her Mum and her mum would then ring the ... nurses up the way er so I think at the moment Angela wouldn’t call one of our team, she’d call her Mum (Ardo, HP)

Mothers, or whomever takes on the primary carer role, are central to supporting the young person’s interaction with services. As such, they are the central consistent, trusted, knowledgeable resource for the young person. They then often liaise directly with someone whom they feel is a key worker within the service.

As noted above, very few services reported offering a formally designated key worker. Those that did were aware of a range of practical problems they could face. For example, staff turnover could mean that for some young people ‘the nurses change several times in the time’ (Ardo, HP) they are with the service. Another, when asked if they provide key workers ‘Uh, well yes and no’. They noted that:

We have a named key worker who, for every person under 19, who is one of the specialist nurses. But because there are [X] of them and they all work different hours there can’t be just one person they will always speak to [Int: Yeah]. So, um, and some of the nurses have embraced the key worker concept to different degrees. So [Nurse X] ... I mean he makes a real effort to work individually with patients of his, whereas some of the others, sort of, like to leave it as a, sort of, more generic role. (Redgrave, HP)

Clearly, this echoes the families’ narratives of problems of not being able to contact a specific person given the differing work schedules. It also highlights the awareness of different ways that staff can decide to enact such a formal role, some can ‘embrace ... the concept’, and others may not be so enthusiastic. A service outlined that

Well, we do in theory, erm [Int: Okay ((laughs))] and we – we should do. And I really, really, really feel, you know, that we’ve gotta have more attention given to proper key working. I feel that this is one of my regular beefs really. ... it’s also a problem that er, sometimes people get referred on to [Department X] [Int: Yeah] and then we see the [results] and then the key workers kind of – because they know that they’re going to be followed up regularly, the key worker kind of, goes out of the picture a bit but then, the other aspects aren’t properly addressed then. (Delia, HP)

As they note, again, the ‘theory’ is often not enacted in a coherent way. All the services are trying to attend to a large workload, with competing demands for their time and resources.

We’re really just um, ((laughs)), just about manage to get, um, haven’t quite got enough clinical staff to do what we’re doing, you know, but of course it’s a good idea. (Brown, HP)

For those services not providing a key worker, this is not about a lack of being ‘committed’ to such idea, but often more about ‘what they are resourced to do’ (Lucy, HP), what is practically possible given the constraints they work within.

Coordinated team: coordination and consistency?

Some services did try to formally coordinate appointments through offering a clinic where different members of a multi-disciplinary team attend, either in separate consulting rooms, or at time, with different members of the MDT in the same room.

it’s very flexible, yeah. I mean we, we, essentially we’ve got three pr-professionals there in three rooms, and, er, er, we’ve got two patients coming every half an hour. So there’s, there’s opportunity for, for – although, if we haven’t got the time for each of them to see every member of the team, there’s time for some of them to see more than one member of the team. (Jones, HP)

When this can be organised, this clearly enables young people to gain a range of support at single time point, to see ‘a selection of people’ (Amy, Family). In some services, this is ‘not a formal thing, but I try to arrange it that way. (Delia, HP). This is at times positioned as something services informally try to do ‘despite all the obstacles managers put in our place we still work as a multi-disciplinary team’ (Peters, HP).

For those young people whom have been attending such a service, they see this as the norm, as unremarkable. However, for some, when they experienced a large number of coordinated appointments this was remarkable

We've been up there sort of a good three quarters of a day cos I've had one appointment, then another appointment, so they've just all seem to have fallen on the same day (Charlie)

They would have preferred them spread over weeks, in part, as this impacted on college. For others, this was never an option, sometimes due to the service structure, or sometimes, as they see 'usually just the one person' (Sarah). Also, different services were at different stages of taking on such a model, some had historically not offered such a coordinated clinic. Some were not as coordinated in terms of information sharing between people or services – 'I know they didn't work as a team very well then, or you'd say one thing and people just didn't know (Judy, Family). Others were attempting to develop this aspect more.

However, at times, potential key figures are missing from these coordinated appointments. Within some services, psychological support can be available at the same time

Sometimes the psychologist comes as well but usually she's not at the clinic now because she's running her own clinics erm but there's an option to refer to the psychologist (Ardo, HP)

Often such psychological support is offered at separate appointments, at different times, often at different days. It was noted that some services have focused on getting good access to psychological support. However, for others, the psychological support was presented as noticeably absent 'we always talk about the fact that we don't have good access to clinical psychology' (Brown, HP). They noted that

It really, I mean that's a massive problem in paediatric services and services in transition services: being able to access psychological input, because the funding's just not there. Yeah, so you sort of beg, borrow and steal (Brown, HP)

Alongside this, physiotherapy and occupational therapy was seen as missing, as such services were already seen as 'under resourced' (Brown, HP). However, one offered a service that included a clinic with 'an OT or a physiotherapist in with the doctor as well, [Int: Okay] erm, and we can call a nurse in if nursing issues come up' (Bow, HP).

Such coordination can also be problematic given the range of services sometimes needed by young people. Going through transition and transfer can offer an additional layer of complexity. An interviewer tried to summarise the range of services one young person, Brian, was working with

Int: so, right, and so some of the people you see at the minute sit in paediatrics, some of them sit in adult care, [Brian: Yeah] some of them sit in adolescent care? Bit of pick 'n mix [Brian: Yeah], pick 'n mix healthcare ((Laughter)).

Distribution of services, especially across different organisational boundaries, can raise practical problems. The distribution can often mean a lack of communication between health professionals. As one family member noted, 'you find going from appointment to appointment you just keep repeating yourself don't you? They're asking the same questions at each appointment' (Cilla, Family). Another noted how

Well half your appointments wasted because you're going over the same old ground. ... Just getting the basics. [Int: Yeah] Instead of concentrating on why you're actually there. [Int: Yeah, yeah] People need, obviously you need a background to be able to treat somebody but you're wasting half your appointment [Int: Mm hm] going through the questions, whereas if they already know about it, they've been introduced to you [Int: Yeah] then you don't have to go over that. (Beth. Family)

Relatedly, such distribution can mean, potentially, a lack of coordination and consistency in information and advice that young people can receive. Even within services that offers an MDT within a single clinic, 'the bigger the team the harder it is to be consistent, and the harder it is to appear to be saying the same things.' (Redgrave, HP). A missing figure, especially for those who will be transferred to primary care for all or part of their care, was the general practitioner. As one service noted

But we do try to encourage, erm, sort of firming up the relationship with the GP [Int: Yes].

Because for many of these families, the GP hasn't played a very big part (Carlos, HP)

As noted above, the general practitioner is often someone whom the young people had often had little interaction with over the years, yet is meant to be a central figure in coordinating their health care and access to health services

Holistic life-skills training: another service's work?

Very few services within our data-set actually provided any form of holistic life-skill training. One did provide specific elements of Holistic life-skill training, often in the form of talks or group meetings.

So we normally do an education session in the summer holidays for university leavers. But we need to do more of that. Obviously those staying locally stay under us [Int: Yeah] for a bit longer. Um, and so it's an easier transition and their mums and dads help them do things and navigate, you know, how to change general practitioner and get your repeat prescriptions and things like that. But there are those practical skills they need to learn, actually, just how do you do things? And, um, so for jobs we do talk, if, you know, if they have specific career aspirations (Redgrave, HP)

This service provides some focused support around key issues – going to University, jobs and careers – they feel that the young people face. This service, and some of the others, were aware they could and needed to do more around such issues. One health professional was interested in extending their service to offer a broader range of support through a series of talks, albeit focused around ‘self-efficacy’, but including aspects around ‘managing money, erm, about jobs, about managing my time’ (Bow, HP)

Yeah. Well, it’s part of what we see as [core] which is trying to help people, [Int: Yeah] er, achieve [the] maximum [Int: Yeah, yeah] You know, and thinking of ... in terms of biopsychosocial. (Bow, HP)

Given the context of a focus on the broader young person, they were currently working on a longer term plan to introduce and implement a formalised Holistic life-skills training. A few parents also felt that such work was going in with health services, albeit in an informal way.

I think this team have, have been doing those kind of issues informally [Int: Yeah, yeah] i- but in a structured manner, in their heads already, without [young people] realising that they’ve gone ... Well, you see, they knew they were going to this. They were invited to attend this driving, [Int: Yeah] erm, seminar and so they met other teenagers the same - a couple of boys the same age as themselves there [Yeah] when they went. (Amy, Family)

Within this service, they had no formal courses or resources which they drew on to support such Holistic life-skills training. Instead, topics, like sex, may emerge or be prompted within the space of consultations. However, the focus appeared to be on the implications of the long-term condition and its potential impact on these topics, over a broader more holistic focus.

Health professionals were aware that such services could be offered and some felt it could be ‘really helpful’ (Lucy, HP) albeit given the caveats of more time and resources. However, they were aware that other non-health services are already offering this: ‘I think it would be something for another service. ... they can go to places like [Charity A] and that and, and they’ll do social skills there’ (Pete, HP). As such, this style of work is not always seen as a core responsibility.

I think it’s a bit over the top to be honest, you know, I think, but, you know, w- there are, there are aspects of what they need to do that’s a bit different to the next young person who doesn’t have [long-term condition], but that sort of stuff is the same for every [Int: Yeah] young person. (Jones, HP)

Holistic life skills are, given their nature, positioned as something that all young people need to acquire albeit that condition-specific issues will impact in specific ways on elements of their engagement with the world. Rendering this as something tied to health and health services per se can be seen as problematic.

No, I don’t think that should be part of ... health [Int: Yeah]. I think it’s more social services domain [Int: Okay]. That’s just my personal view point. (Peter, HP)

Clearly, there is an element of resistance from some professionals to realign the scope of their work in such a way. This is in part driven by the knowledge that other services the young people encounter are potentially offering such support already and may be better resourced and skilled to provide such training. However, as another health professional noted

I think it’s one of those, this is one of those areas that sort of falls between the agencies; so you could argue that that kind of input could be, erm, part of an education remit; part of a health remit; part of a, you know, social care remit (Delia, HP)

In this way, given the broad focus of such work, a range of service providers could, in theory, offer such support. However, in practice, only some young people are actively engaged with social and educational providers, from across the state, private and charitable sectors.

Echoing the health professionals, young people and families, were aware that such work was already going on through other providers. Some of this work occurred within the school or college environment. This was especially so when the young person was attending college courses tailored to offering such support around topics like ‘independent living’ or was involved in specialist schooling.

They had a little flat and it was a little flat where they would teach them how to budget money and day to day sort of living and how to cope and that sort of thing. I thought it was absolutely fantastic. But it came from the school. It came from nowhere else and it was never sort of kept up anywhere else and I really do think that helps to keep him on the right track but I suppose unless you are in a special school you don’t get that. (Daisy, Family)

Some young people also were provided with such training and support through groups, events or trips provided by the third sector: ‘well I’ve done sort of similar things but through maybe private charities, things like that’ (Charlie). Such charity run specialist groups, sometimes long term condition-specific, or more general, offered as part of their services elements of Holistic life-skills. In some cases, third-sector partners already had good links with the services.

It should be noted that, this work was also seen as something that families are already providing and should be central in. As one young person noted, when asked about such provision, the only person she has received support from is ‘My mam, it’s only me mam helps us with everything and all that sort of stuff.’ (Penelope). Again, echoing some health professionals, a family member also felt that such work should not be tied to health services

I think probably health departments, they’ve got enough to do really haven’t they? I think that should be down to the, you know, the, the individuals and their families. You know, to sort of sort out. I, I, I mean, I mean if there’s any advice there to be given, obviously, or, or asked for it might be handy. But, uh, but I really think, you know, health departments are for the health really aren’t they? (Ralph, Family)

The social institution of the family was often seen as a central resource – and note that all these young people had at least one family member closely involved in their healthcare. In this context, a core responsibility of health services was to signpost young people to relevant services outside of the NHS.

Beryl Um, yeah certainly signpost to, they’d probably dismiss it as not being their responsibility I would imagine, but

Bob I think they probably do a lot more things before they’d start doing this [Int: Okay], you know, they need to get other things put right [Int: Yeah] before they thing about [Int: Yeah] taking on more things they cannot do.

Beryl Yeah, I think so. ... I think that’s very fair point to raise [Int: Yeah], that they need, they need to do what they’re supposed to do best first and foremost [Int: Yeah] before they look at, at taking on more

For those families who felt aspects of the child or adult services were in some way sub-optimal, a focus into other domains of work, beyond a focus on supporting the core medical issues was clearly problematic.

Coordinator at managerial level: an absent idea(l)?

Only one service reported that they had introduced such a coordinator role as they realised the need. However, this was role was newly created

We have identified one of the nurses as taking a lead for transition and she’s the person who’s going to be looking at the pathway and the overall thing but they haven’t done anything much yet cos they’ve only been in post a month. So we we’ve sort of thought about having a person and erm but we haven’t got very far with what they’re actually doing in that post yet (Ardo, HP)

Other services were also aware of the opportunities that such a role could provide. One health professional noted that ‘I would like one. I think that’s a really important role’ (Redgrave, HP) and discussed a range of evidence they were aware of that demonstrates how it could benefit their service.

It was clearly seen as ‘useful’ (Bow, HP), and offering a range of potential benefits

Ideas about how to organise these clinics, you know, disseminating ideas, um, information sources – all that sort of thing and I mean, if all the various facets were all given the same message saying the same thing, directing to the same services then yeah, of course. That would be, that would possibly be the single most useful thing to do ... if somebody could kind of co-ordinate and pull together what, what is going on across the board, service wide, then that would make that sort of planning easier as well, I think. (Brown, HP)

Despite such enthusiasm, the practical realities of limited resources, managing increasing workloads and competing demands mean that such an ideal seems far from being implemented. For example, in one service, they noted that, they are a ‘relatively small area’, with few young people transferring, ‘So whether that’s enough to justify an individual’s work’ (Barbara, HP). In this way, such innovations will depend on such factors as clinician enthusiasm alongside, more external, policy drivers like developments in guidelines, tariffs and quality standards.

Strengths and Limitations

Conducting serial and triangulated interviews enabled us to confirm stories and capture evolving perspectives. Observing consultations enabled us to compare what people do, against what they said they did in these contexts. Whilst both the form and content of healthcare that is received may differ between the three exemplar groups, the organisation and experiences of the transition and transfer process showed many more similarities than differences.

The findings have face validity as they relate well to the findings in other WPs and other studies in the literature, especially how transition and transfer can be disorientating for young people and their families.^{44, 51, 83} This study strongly echoes work on how young people build relations of trust with health professionals and services,^{44, 51} especially where those relations are consistent and supportive,⁵⁸ as well as work on how the family, especially the mother, have built relations of trust with health professionals and services.⁸³

In its nature, qualitative work is in-depth but small-scale; a consequent strength being the richness of data and a weakness being the low number of case examples. We aimed to recruit fifteen families and achieved thirteen. We had difficulties in recruiting young people, with many seeing the breadth and depth of data-collection as an additional burden whilst already taking part in *WP 2.1*. Retention of young people for follow-up and/or post-transfer interviews was poor, so learning about the adult context was limited. We were unable to contact some young people and some of those we did contact declined follow-up interviews. They either withdrew from this aspect of the study, or suggested we speak to their parents or health professionals. Thus, our findings are valid in relation to the data we collected; however, it is possible we did not identify key messages that would have been relevant after transfer to adult services.

Additionally, all the young people had at least one family member closely involved in their healthcare. We therefore lack the perspective of young people with less input from families, including looked-after young people.

Discussion

Our work echoes the reviews of Lugasi, Fegran and Heath^{44, 51, 83} that transition and transfer is disorientating for young people and their families. The young person has usually been in a specific child health service for some time, generally since early childhood. They have, over time, built relations of trust with health professionals and services, especially where those relations are consistent and supportive.^{58, 144} They have, over time, learnt to make sense of how best to integrate the practical, cognitive and emotional work it takes to be a patient with a long term condition within a specific paediatric health service system. Similarly, the family, especially the mother, have built relations of trust with health professionals and services.⁸³ They have, over time learnt how best to support their child, how best to support the management of their child's health condition(s) and importantly, how to effectively navigate, manage and engage with the child health service system.

The process of transition breaches⁸⁹ the relations of trust. It breaches the relations of trust they have developed with others, with a range of health professionals, services and organisations. It also breaches the relations of trust they have developed with themselves. They no longer know what to practically do, how best to navigate consultations and services, whom best to contact. In this way, it breaches their taken-for-granted expectations, knowledge and relationships. The event of transfer is central to enacting this disruption for young people and their families.

Allen,^{58, 144} following and developing the work of Forbes,²⁰⁰ has focused on how continuity of care be effectively enabled, so as to reduce disruption for young people and so enact a 'smooth transition'.⁵⁸ They discuss seven different forms of continuity: relational, longitudinal continuity, managerial, cultural, informational, flexible, and developmental. Importantly, they note that

Relational and longitudinal continuities are the mechanisms central to transition because they also facilitate management and flexible continuity. They also provide a sense of safety at times of change, obviating the need for informational continuity interventions. Flexible and cultural continuities also emerge as important.⁵⁸

Relational and longitudinal continuities refer to an 'ongoing therapeutic relationship' and 'uninterrupted relationships with service providers over time'.¹⁴⁴ However as we saw above, for these young people and families, relational and longitudinal continuity are breached. In all the services we focused on, the young people moved to a separate adult service provider with a different set of health professionals offering them care. In such a context, Allen highlights that informational continuity – 'the provision of information in order that young people and their families are prepared for transition and understand the new arrangements for their care'¹⁴⁴ – can become central.

We have seen that systems, processes and practices that work to help people make sense of and minimise these disruptions are more likely to be effective for young people and their families. In Allen's^{58, 144} terms, informational continuity is a central resource through which effective transfer takes place within our data set. Quite simple and mundane practices, like being very clear about the processes in discussions and documents, are key, as is exploring how adults' and children's practices and procedures actually differ, exploring the new norms and routines. When there is informational discontinuity, young people and families can become lost, abandoned and feel there is no one to turn to. Similarly, organisational turbulence, through things like staff or services changes, prior to transfer, can lead to informational discontinuity and so create confusion and uncertainty. As young people are transferred to a new clinical and organisational environment with a new set of health professionals, norms and routines, the core focus they need is support and confidence in the practicalities of managing the adult healthcare system itself. We have also seen how, undertaking joint clinics and meetings with members of the adult team which the young person will actually be seeing, can be central. Following Allen,^{58, 144} this enables the possibility of the initial steps towards 'relational continuity'.

Finally, we have seen that systems, processes and practices that work to recognise, enable, support and accommodate interdependence and relational autonomy are more likely to be effective for young people and their families. Interestingly, in the reviews,^{44, 51, 83} and in nearly all the papers they worked with, the figure of the parent is cast as, albeit for good reasons, in some ways holding back the young person's move from dependence to independence. Allen's¹⁴⁶ work is a notable exception, in that they problematize the myth of independence, highlighting how 'the individualized focus of adult services does not reflect the realities of young people's lives, which are characterized by interdependencies'. As ethics of care work^{201, 202} has repeatedly outlined, interdependence, or rather 'relational autonomy', is a routine feature of everyday life. The involvement of others is normal, not dysfunctional, and for people in other age groups is largely accepted. Family members should be supported in shifting roles to a more 'partnership', 'shared care' or 'consulting' role.⁸³

May et al²⁰³ argue that, over time, patients with long term conditions, especially those with multiple morbidities, have increasing 'workloads', a burden of treatment. The everyday work of living with a long term condition includes work that is delegated from health professionals to patients. This includes managing and coordinating multiple appointments, treatment regimes, self-care and self-monitoring. This work disrupts everyday life. Through the process of transition, and especially the process of transfer, we are increasing that burden for young people and their families. Following May et al,²⁰³ we need to support and enable a minimally disruptive transition.

Conclusion

Transition and transfer is disorienting for young people and their families. It has practical, cognitive and emotional impacts. Importantly, it disrupts their often hard-earned knowledge of how best to navigate the child healthcare system effectively. Health professionals need to focus on helping young people and their families make sense of these disruptions. They can minimise them through actions like: being very clear about the process in discussions and documents; exploring how adults' and children's practices and procedures actually differ; undertaking joint clinics and meetings with members of the adult team the young person will actually be seeing; and including family members in the process. Transition is about supporting and enabling young people to become responsible for their own healthcare. However, family members remain crucially important in this process. The involvement of others is normal, not dysfunctional, and for people in other age groups is largely accepted. Family members should be supported to shift roles to be more 'partnership', 'shared care' or 'consulting'.

Interview schedule: Young person

Schedules for parents and health professional are similar – not reproduced here

Young Person Interview Schedule – Time 1

Note: The interview schedule is developmental. The questions will need to be tailored to the specific answers of each interviewee. The interview schedule given here is therefore a general topic guide for the one-to-one qualitative interviews.

Plan of interview

1. Introduction
2. About you
 - Education; Employment; Leisure/hobbies; Health/Mental Health
3. Proposed Beneficial Features/Things that might be part of your transition
4. Transition/discharge plan
5. Becoming an adult
6. Feedback

Setting

- Young people will choose setting – mainly their home, could be their school/workplace/college etc
- Time 1 interviews to take place in 2012/2013
- Newcastle University lone worker policies will be followed

Introduction

- Explain purpose of the study and this interview and that it is the first of two:
 - Won't affect the care you receive whether you take part or not
 - What you tell me will not be discussed with your health professionals/parents/carers or anyone else outside of the research team without your permission. (Unless you tell me that someone is hurting or harming you, in which case I will have to tell someone to make sure that you are safe)
 - We're looking at the experiences of young people with complex health needs as they move from child to adult health services
 - No right or wrong answers – not a test of your knowledge
- Consent – written.
- Explain interview recorded but details will be confidential I am not a clinician, but [appropriate clinician] who is involved in the study can speak with you or facilitate an appointment with your general practitioner
- Questions or concerns?

About you

Firstly can you tell me about yourself (things like how old you are and who you live with)?

Points they might cover:

- ❖ Age
- ❖ Current living arrangements
- ❖ With who?
- ❖ Plans to move?
- ❖ If yes – When?
- ❖ Where?
- ❖ Who with?

About your health/mental health care

Can you give me a brief description of your current health/mental health care (things like who you see and if they are helpful etc.)?

Have any plans been made about what might happen after you leave children's services?

Have you met anyone to talk about what might happen after you leave children's services?

Do you know if you will need to be followed up in adult services?

Have you talked to anyone about adult services and what might happen there?

Tell me about your current health/mental health appointments

Points they might discuss:

- ❖ Helping to make decisions about your care?
- ❖ Attending appointments (or part of your appointments) by yourself?

Do you think there is anything that could be changed about your health/mental health appointments to make them work better for you? (The things you like and the things you would like to improve)

Points they might discuss:

- ❖ Timing
- ❖ Location
- ❖ Professionals talking to you more
- ❖ Professionals talking to your parents more
- ❖ Language used

Education

Tell me about your education/school/college

- ❖ Where
- ❖ Subject(s) and level(s)
- ❖ Continue on to sixth form/college/university?
- ❖ Future studies?

Have you discussed education with your health/mental health professional(s)?

- ❖ If no – do you think this would be helpful?
- ❖ If yes – Tell me about it
- ❖ Helpful/useful to you?

Employment

Have you thought about what you might like to do for work/career?

- ❖ Specific career plans?
- ❖ How to do that

Have you had any support/advice about planning for your future career?

Points they might discuss:

- ❖ Who (Connexions/school careers advisor/transition employment support officer/similar)
- ❖ Tell me about this
- ❖ What did they say
- ❖ Helpful/useful to you?
- ❖ How could it be more helpful/useful to you?

Have you discussed this with your health/mental health professional?

- ❖ If yes – Tell me about it
- ❖ Was this helpful?
- ❖ How could it be more helpful/useful to you?

Leisure/hobbies

What do you like to do in your spare time?

Do you need any support with this/these?

Points they might discuss:

- ❖ Get any support?
- ❖ Tell me about your support
- ❖ Who
- ❖ Is it helpful/useful to you
- ❖ How could it be more helpful/useful to you

Have you discussed this with your health/mental health professional?

- ❖ If yes – Tell me about it
- ❖ Was this helpful/useful for you?
- ❖ How could it be more helpful/useful?

Proposed Beneficial Features/Things that might be part of your Transition

Here are some things that some people have said might be useful to help them move from children's health services to adult health/mental health services. You will have this list in your health contacts diary from the other research assistant who is working with you.

What would work for you, why, what would not work for you?

Go through each of the 11 features and find out if they have experienced them (in conjunction with health diary and information from clinical notes obtained from relevant local RAs) (See also Health Diary Piloting)

Things that might be part of your transition:

Number	Questions to think about
1	Was the clinic you attended separate from the children's clinic ; therefore just for young people or young adults?
2	Have you been introduced to people in the adult team who will take on your care in due course?
3a	Did anybody ask you formal questions or ask you to complete a questionnaire about whether you are a confident type of person . This does not mean how you appear to other people; rather whether inside you appreciate yourself, can deal calmly with difficulties or unexpected events etc
3b	Did anybody in the clinic team work with you to become more confident in looking after your health condition and your health generally?
4	Did anybody ask you formal questions or ask you to complete a questionnaire about whether you felt ready to move to adult services ?
5	Do you have any document completed by you and the clinic team with information about you and your condition; a document you can share with any new health staff you meet? This might be a health passport or a transition plan .
6	Did you think your parents were involved and consulted to the right amount about your healthcare?
7	Is there one person in the clinic or team working with you who you feel knows you well and is identified as your 'key' worker ?
8	Do you know if there is a person (a co-ordinator) whose job is to make sure services are well co-ordinated as you move from child to adult services (you may not know the individual personally)?
9	Did you think the doctor, nurses and other healthcare staff involved in your care work together as a team ?
10	Do you or your parents receive an 'individualised budget' ? This is a sum of money you or your parents receive to buy your health care which previously was provided free by the health service.
11	Did you receive from staff in the clinic any training such as watching a video or attending a course on preparing for your future? So it would cover such things as: <ul style="list-style-type: none"> • Planning for training or work or more education • Looking after your health • Making good and happy relationships • Looking after you finances

For each of those they have experienced:

Tell me about it

Potential prompts/areas they might discuss:

- ❖ What happened?
- ❖ What was discussed?
- ❖ What was done well?
- ❖ What could have been done better?
- ❖ What could have been done differently
- ❖ Do they think this was helpful?

If they do not think they have experienced them discuss the idea:

- ❖ Do they think it could be helpful/why

Ask them about any other ideas they have which might be helpful and use prompts if needed:

- ❖ Other ways to organise your health care
- ❖ Other training that might be useful to you

Transition/discharge plan

What do you think should be on a transition/discharge plan?

- ❖ Education
- ❖ Employment
- ❖ Leisure/hobbies/spare time
- ❖ Independent living skills
- ❖ Condition related needs
- ❖ Health/Mental health

Do/did you have a written transition/discharge plan?

If yes, tell me about it

Points they might discuss:

- ❖ helping to write it
- ❖ Anything extra should be on
- ❖ Anything should be taken off
- ❖ Do you have a copy?
- ❖ Was/is it helpful/useful to you?
- ❖ How could it have been more helpful/useful to you?

Who was involved?

Potential people involved:

- ❖ You
- ❖ Education
- ❖ Health
- ❖ social services
- ❖ parents/carers
- ❖ other family members
- ❖ friends
- ❖ Anyone else

What was on your plan?

Potential areas covered:

- ❖ Education
- ❖ Employment
- ❖ Leisure/hobbies/spare time
- ❖ Independent living skills
- ❖ Condition related needs
- ❖ Health/Mental health

If no do you think it would be/have been useful?

Becoming an adult

Do you feel like a 'grown up' or an 'adult'?

What do you think will make you feel like a 'grown up' or an 'adult'?

When do you think someone becomes a 'grown up' or an 'adult'?

Discuss, then show them the list adapted from Arnett²⁰⁴ and discuss whether or not they think each item contributes to being an adult. Can be simple yes/no.

Finally, we need to understand whether the kinds of questions we are asking actually relate to the issues that you think are important?

- Are we asking the right questions?
- Did these questions allow you to talk about what was important for you?
- Is there anything else you would like to tell me?

Thank you for taking part

Remind them that you will be contacting them about the arrangements for the diary exercise in 2-3 months' time.

Appendix 7 Discrete choice experiment and economic analysis

This appendix contains the questionnaire used in the DCE, followed by a draft paper that provides further details about the DCE questionnaire. Then there follows Report 2.3.2 Economic analysis.

Questionnaire

Preferences for a transition service

All information will be kept strictly confidential.

Dear Participant

We are interested in your views on the best way to organise NHS services for young people with long term health conditions. We want to hear from young people who are or will soon be making the transition from children's health services to adult health services.

You kindly agreed to participate in this study.

In this document, there is:

Section 1 This helps you to think about what the questionnaire will ask about

Section 2 This asks you about your current situation

Section 3 This is an example question

Section 4 This is the questionnaire itself

Please follow carefully the guidance about how to answer the questionnaire. There are no right or wrong answers; we are interested in your opinions. Don't spend too much time answering each question, as your first impression is likely to be the most accurate.

Please ask me if there is something you don't understand or find difficult to answer.

We will only use your answers for research purposes, and we will keep your answers private. No-one from outside the study team will see your answers, and you will not be identifiable when we report the results.

Thank you for taking the time to answer this questionnaire.

Yours sincerely, Jenni Hislop, on behalf of the Transition Collaborative Group

SECTION ONE

This section is to help you get used to the ideas we want to ask you about later on

Below are some aspects of transition that we want you to think about. Please read the descriptions and think about what you would prefer. We are not asking you to answer anything here; this comes later in Sections 2 and 4.

Appointment flexibility

Would you like the service to offer you an appointment:	<p>During office hours only</p> <p>The service is open from 9am to 5pm during weekdays only.</p>	OR	<p>During and outside office hours</p> <p>The service is open at various times throughout the week and may be able to offer you an appointment outside the hours of 9am to 5pm during weekdays.</p>
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Staff consistency

Would you like to see the same team of staff regularly?	<p>Yes</p> <p>You would like to see the same staff members on each of your visits to the service.</p>	OR	<p>No</p> <p>You don't mind seeing a team that is different from the team you saw at your previous appointment.</p>
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A key worker

Would you like to have a named 'key worker'?	<p>Yes</p> <p>You would like there to always be one staff member you know who takes responsibility for sorting out any problems regarding your healthcare.</p>	OR	<p>No</p> <p>You don't mind which staff member(s) take responsibility for sorting out any problems regarding your healthcare – it doesn't need to be done by one specific person.</p>
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Communication between staff members

Is it important to you that staff communicate well with each other to pass on relevant information about your care?	<p>Yes</p> <p>You would like information about your care to always be passed on to the right people straight away</p>	OR	<p>No</p> <p>You don't mind if information about your care isn't passed on to the right people straight away.</p>
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Parental/carer involvement

At your appointments, how do you think staff should involve your parents?	<p>Welcomed</p> <p>You would like staff at the service to welcome your parents' involvement in your treatment.</p>	OR	<p>Discouraged</p> <p>You would like staff at the service to discourage the involvement of your parents in your treatment as you get older.</p>
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My autonomy in decisions

When there are decisions to make about your care, what would you like to happen?	<p style="text-align: center;">My treatment is discussed but staff make the decisions</p> <p>You would like the staff talk to you about how your care could be managed, but then the staff decide on the best way forward.</p>	OR	<p style="text-align: center;">I am given choices and I make the decisions</p> <p>You would like the staff talk to you about how your care could be managed, but you will decide on the best way forward.</p>
--	---	-----------	--

Support

Would you like the service to offer extra support to help prepare you for everyday living with your condition in the future (e.g. for financial help, equipment, advice about life changes)?	<p style="text-align: center;">Yes</p> <p>You would like to be offered support to help prepare you for the future.</p>	OR	<p style="text-align: center;">No</p> <p>You would not like to be offered extra support to help prepare you for the future.</p>
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SECTION TWO: YOUR CURRENT SITUATION

We would like to know some details about the care that you currently receive. This will help us better understand the choices you make.

Please tick ONE box for each question.

Question 1

Do you currently attend a special health service for your condition?

- Yes
- No - I do not attend a special health service for my condition because there is no service available.
- No - I do not attend a special health service for my condition because I choose not to do so.

If you ticked 'Yes' to Question 1 please move on to Question 2. If you ticked either of the 'No' boxes, please just move on to Section Three on Page 6 now.

Question 2

When you visit the service, are appointments available outside of office hours (i.e. 9am to 5pm on weekdays)?

- Yes.
- No.

Question 3

When you visit the service, do you usually see the same team of people that you've met before?

- Yes, I usually see the same team of people I've met before on each of my visits to the service.
- No, the team people are usually different.

Question 4

When you attend the service, how do staff involve your parent(s)/carer(s) in your treatment?

- Staff welcome the involvement of my parent(s)/carer(s) in my treatment.
- Staff discourage the involvement of my parent(s)/carer(s) in my treatment.

Question 5

When you talk with staff at the service about your treatment, how are decisions made?

- Staff discuss my treatment with me but make the decisions on my behalf.
- Staff give me with choices about my treatment but expect me to make the decisions.

Question 6

Thinking about support for your condition (e.g. financial support, getting new equipment, advice on coping etc.), is help with this provided by the service you attend?

- Yes, the service provides extra support to help me prepare for everyday living with my condition in the future.
- No, the service does not provide extra support to help me prepare for everyday living with my condition in the future.

SECTION THREE: AN EXAMPLE QUESTION

Here is an example of a question. We want you to imagine that you have the choice to attend either of two transition services for your condition. These services are described in the box below. We want you to choose which service you think would be best for you if you had to choose between those two services and there was no other option available for you. We then want you to think about which situation would be best if you could choose either of the two transition services described, or your current situation in real life.

If you have already moved to the adult service in real life, just imagine you get to do it all again and choose the option that you would prefer.

For each question we ask you to select the **best** for you by putting a **tick** in the appropriate box.

Figure 15 Example DCE question

	Care at Service A	Care at Service B	
Appointment flexibility: The service offers appointments:	During and outside of office hours	During office hours only	
Staff consistency The staff I see at the service are:	Usually same staff members that I've met before but I do not have a key worker	Not usually the same staff members I've met before but I do have a key-worker	
Staff communication Information about my care always seems to get passed on to the right person who can help me	Yes	No	
Parental involvement My parents' involvement is:	Welcomed	Discouraged	
My autonomy When it comes to decisions about my care:	My treatment is discussed but staff make the decisions	I am given choices and I make the decisions	
Support: The clinic provides extra support to help me prepare for everyday life with my condition in future	Yes	No	
Which service do you think is better? (please tick <i>one</i> box)	Service A <input checked="" type="checkbox"/>	Service B <input type="checkbox"/>	
Which service would you choose? (please tick <i>one</i> box)	Service A <input checked="" type="checkbox"/>	Service B <input type="checkbox"/>	My current situation <input type="checkbox"/>

In this example, the participant has ticked 'Service A' for both parts of the question. This shows that the participant prefers what happens in Service A to what would be available in Service B, and that the participant prefers what happens in Service A to what would be available in both Service B or the service they currently receive in in their life.

SECTION 4: THE ACTUAL QUESTIONNAIRE

The questionnaire sets out eight questions with the layout of the example question on the previous page.

The response options varied with each question. The full questionnaire is available on request.

DCE Report

A discrete choice experiment of the service preferences of young people with long-term conditions as they transition from paediatric to adult care.

Jenni Hislop, Hannah Merrick, Jeremy Parr, Allan Colver, Luke Vale

Introduction

Young people with long-term conditions diagnosed during childhood face the prospect of having their health care transferred, at some point, from paediatric services to adult health services. This process of transfer occurs within a wider ‘purposeful, planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents and young adults with chronic medical and physical conditions as they move from child-centred to adult-oriented health care systems’ known as ‘transition’.⁵ It is known that this period of transition can be difficult for young people, and that this can lead to poorer long-term health, social and educational outcomes.^{17, 18, 205, 206} By developing a full understanding of young people’s preferences for services during this time, it may be possible to minimise withdrawal from or reduced uptake of health services during transition, thereby preventing future health risks associated with this. The Transition Research Programme⁶¹ aimed to establish how successful transition can be facilitated in the United Kingdom to improve health and social outcomes. Part of the work involved a longitudinal study of young people at four time points during their transition (baseline and follow-up at one, two and three years respectively). This paper reports one component of this longitudinal study which sought to quantify young people’s preferences for health services using a discrete choice experiment (DCE).

Methods

A sample of young people was drawn from the third annual visit (or fourth visit if they did not attend the third visit) of a longitudinal cohort study to identify which features of transitional healthcare are effective and efficient.⁶¹ These young people were aged 14-18 at the time of the baseline visit and had been in receipt of specialist paediatric services at that time point, for one of three conditions; autistic spectrum disorder (with an additional mental health need), cerebral palsy or diabetes. DCEs are well-established methodology in health economics.²⁰⁷ DCEs describe a service in terms of a number of characteristics, or ‘attributes’ (e.g. the flexibility of appointments, parental involvement). The extent to which an individual values an intervention is expected to depend upon the ‘level’ these attributes take (e.g. can appointments be made outside office hours or not; is parental involvement encouraged or not). In other words, DCEs explore relative preferences for the different ways services can be organised where the services are defined by differing levels of their attributes.⁹³ The design and conduct of the DCE involved four steps:

Step 1: Identification of attributes and levels

Attributes and levels of the DCE were informed by a Q-sort⁵¹ From this work, the transition issues that young people had strong opinions about (regardless of their viewpoint) were selected for further consideration as attributes for the DCE and were discussed with ‘United Progression’ (UP) a young people’s group convened specifically for the Transition Research Programme.²⁰⁸ Other information was drawn from the findings from the literature about important features of transition.⁹⁴ Refinements on content and layout of the DCE were undertaken in conjunction with the members of the Transition Research Programme’s Collaborative Group and the UP young people’s group. The chosen attributes and levels are shown in Table 21.

Table 21: Description of the attributes and levels used in the DCE

Attribute	Number of levels	Description
Flexibility	2	0 = Does not offer appointments outside of office hours 1 = Offer appointments outside of office hours
Staff at appointments	4	0 = Do not see the same staff at my appointments and do not have a key worker 1 = Do not see the same staff at my appointments but have a keyworker 2 = See the same staff at my appointments but do not have a key worker 3 = See the same staff at my appointments and have a keyworker
Staff communication	2	0 = Yes 1 = No
Parental involvement	2	0 = Discouraged 1 = Welcomed 'if I want it'
Decisions about care	2	0 = Staff discuss my care but make the decisions 1 = Staff give me choices but expect me to make the decisions
Extra support	2	0 = No 1 = Yes

Step 2: Experimental design

The number of attributes and levels described in Table 21 gives 128 possible combinations. Therefore, statistical approaches were used to reduce the number of scenarios to be more manageable. N-gene software was used to identify the most statistically efficient number of questions to ask. The resulting d-efficient design contained twenty-four discrete choice questions. The number of questions was further reduced by 'blocking' the design into three groups, so that each respondent in each block was asked to complete eight questions (thereby reducing response burden). Young people were also asked to answer questions about the current care they received in terms of the attributes and levels used in the DCE.

In each choice question respondents were presented with two hypothetical ways the service might be organised. Respondents were asked to consider whether they would prefer either of these two hypothetical options or their own care. Details of the service the respondent was receiving were collected in a separate part of the questionnaire. Figure 16 gives an example of a choice question.

Figure 16: Illustrative example of a choice question presented in the DCE

We want you to imagine that you have care of the type at Clinic A or Clinic B.

We then want you to choose which would be best for you between those two imaginary situations and your current situation.

If you have already moved to the adult service in real life, just imagine you get to do it all again and choose the option that you would prefer.

For each question we ask you to select the **best** by putting a **tick** in the appropriate box. Please tick just **one** box for every question. Here is an example question:

	Care at Clinic A	Care at Clinic B	My current care
Appointment flexibility The service offers appointments:	During and outside of office hours	During office hours only	
Staff at my appointments The staff I see at the service are:	Usually same staff members that I've met before but I do not have a key worker	Not usually the same staff members I've met before but I do have a key-worker	
Staff communication Information about my care always seems to get passed on to the right person who can help me	Yes	No	
Parental involvement My parents' involvement is:	Welcomed	Discouraged	
Decisions about my care When it comes to decisions about my care:	My treatment is discussed but staff make the decisions	I am given choices and I make the decisions	
Support The clinic provides extra support to help me prepare for everyday life with my condition	Yes	No	
I would choose (please tick <i>one</i> box)	Clinic A <input checked="" type="checkbox"/>	Clinic B <input type="checkbox"/>	My current care <input type="checkbox"/>

In this example, the participant has ticked 'Clinic A'. This shows that the participant prefers what happens in Clinic A to what would be available in Clinic B or their current care.

Refinements on content and layout of the questionnaire developed following discussion and feedback with the UP group. Further advice was provided by members of the Transition Research Programme's Collaborative Group on how best to help facilitate completion by the programme's longitudinal cohort with autistic spectrum disorder (ASD).

Step 3: Data collection

Following completion of the design work for the DCE and receipt of ethics approval the DCE was completed during visit 3 or 4 of the longitudinal study.⁶¹ The paper-based DCE was administered in a face to face setting by researchers, trained to facilitate completion of this particular DCE. To further minimise non-response, a range of additional tools were created to aid completion (Table 22). The final DCE questionnaire therefore contained five parts: the reference guide describing each of the attributes, questions about the service they currently received, the discrete choice experiment questions, the ranking exercise and an office-use only section allowing the researcher to document use of additional tools.

Table 22: Description of tools developed to aid completion of the DCE

Additional tool	Description
Attribute ticking	For each attribute, if the respondent was struggling to choose they were permitted to tick, for each attribute within the question, their preferred alternative.
Current practice grid	Paper grid showing respondent's own levels of 'current care' being received. The grid can then be placed alongside the two hypothetical alternatives in each question to readily show how the respondents own care corresponds to each alternative.
Scenario grid	Empty paper grid version of the hypothetical alternatives. The researcher made up the grid using cut-out pieces of paper printed with the levels for each attribute. They could then move the pieces of paper as the respondent progressed from one question to the next, to show that each question was different to the previous one.
Skip to ranking exercise	If the respondent was struggling, the researcher had the option of asking them if they would prefer to skip to the ranking exercise and omit the remaining choice questions.
Tear off reference guide	The first section of the DCE questionnaire described each of the attributes and what they meant. If the respondent was struggling to recall what these meant at any point during the DCE, this reference guide could be torn out of the DCE questionnaire so that the respondent could re-read these definitions without having to turn pages back and forth.
Researcher prompting	If the researcher was concerned that the respondent was struggling, or not considering the options before answering, they could ask the respondent to articulate their thinking behind their choice. This would enable the researcher to either verify that they respondent understood the exercise, or help facilitate completion using any of the other tools if the respondent was struggling.

Step 4: Data analysis and interpretation

Data were analysed within a random utility model framework using logistic regression techniques to predict the value that young people placed on the different attributes and levels of the DCE. DCE analysis can provide estimates of the predicted uptake of the service. This can illustrate the relative importance of attributes and their associated level – the more an attribute is preferred by young people, then the higher the predicted uptake.

Results

Response rates and participants characteristics

Of the 375 participants who commenced the longitudinal study, by the time of the DCE 101 participants had left the study or could not be contacted. Of the remaining 274 participants, 247 had completed at least one DCE question (238 completed it at visit 3 and 9 completed it during visit 4). Of those completing the questionnaire it was fully completed by 223 participants and partially completed by 24 participants. All data collected between September 2014 and December 2016. Demographic details for study participants are provided in Table 23.

Table 23: Characteristics of participants

Characteristic	Responders (Partial and complete)	Non-responders (Did not complete any DCE question)	Total
Total sample	247	27	274
Gender: Female	109	8	117
Gender: Male	138	19	157
Mean (SD) age at time of data collection	17.92(1.28)	18.11 (1.53)	17.94 (1.31)
Condition: ASD	71	16	87
Condition: Cerebral palsy	71	4	75
Condition: Diabetes	105	7	112
Block: A	76	13	89
Block: B	90	6	96
Block: C	81	7	88
Block: Missing	0	1	1
Additional tools used: Y	85	12	97
Additional tools used: N	162	7	169
Additional tools used: Missing	0	8	8
Attends specialist service: Y	196	13	209
Attends specialist service: N	50	6	56
Attends specialist service: Missing	1	8	9
Transfer status at time of data collection: Transferred	162	18	180
Transfer status at time of data collection: Not transferred	85	8	93
Transfer status: Missing	0	1	1

In terms of these characteristics there were no statistically significant (0.05 level) differences, except that compared to participants with diabetes, young people with ASD were less likely to be respondents ($p < 0.001$). Also when comparing complete and partial responders (data not shown), partial responders were less likely to be attending a service ($p = 0.0032$).

With respect to the ranking exercise complete rankings data were available from 259 respondents, including 16 of the 27 who did not complete the DCE, and 243 of those who did. Whilst not formally tested there appeared to a high priority given to 'Decisions about care' whilst 'Extra support' is consistently given a low priority (Table 24). Although not shown in Table 24 those with ASD and those who had not yet transferred, may prioritise flexible clinics compared with those with other long-term conditions. Those with ASD, those with cerebral palsy may give less priority to which staff they see at their appointments compared to those with diabetes. Likewise those with ASD and those with cerebral palsy. Compared to those who had transferred those who had transferred also may give less priority to who they see at their appointment and to staff communication.

Table 24: Result of ranking exercise

	Respondents	Median (IQR)	Mean (SD)	Estimated rank based on scores
Flexibility of clinics	260	5 (3)	3.4 (1.7)	4
Staff coordination	260	3 (2)	3.3 (1.6)	3
Staff communication	261	3 (2)	3.1 (1.4)	2
Parental involvement	260	4 (3)	4.0 (1.7)	6
Decisions about care	261	2 (3)	2.6 (1.5)	1
Extra support	259	4 (3)	3.8 (1.7)	5

Results of DCE

Table 25 reports the result of the DCE analysis. There were 43 respondents who always chose their current care and 60 who never chose it. Those not currently receiving a service were significantly less likely to choose current care ($p < 0.001$).

In the analysis the attributes levels are compared to the situation where the attribute is absent. For example, the base level for flexibility of clinics attributes is that clinics are only available during office hours. As this table shows all the attributes including the alternative specific constant, which shows an underlying preference for current care are statistically significant.

Table 25: Summary results of the discrete choice experiment

	Coefficient (95% CI)	Standard error of coefficient	Exponential of coefficient	z	p-value
Alternative specific constant for current care option	0.23 (0.10-0.37)	0.07	1.26	3.33	<0.001
Appointments available: during & outside office hours	0.38 (0.33-0.51)	0.07	1.46	5.75	<0.001
Sees same staff: No & keyworker: Yes	0.29 (0.06-0.54)	0.13	1.34	2.33	0.002
Sees same staff: Yes & keyworker: No	0.78 (0.57-0.98)	0.11	2.18	7.39	<0.001
Sees same staff: Yes & keyworker: Yes	0.67 (0.48-0.86)	0.10	1.96	7	<0.001
Staff communication: Good	0.97 (0.84-1.11)	0.07	2.63	13.47	<0.001
Parental involvement welcomed	0.92 (0.78-1.07)	0.08	2.52	12.27	<0.001
Young person given choices and they make the decisions	0.83 (0.70-0.96)	0.07	2.29	12.54	<0.001
Extra support: Available	0.60 (0.48-0.73)	0.06	1.83	9.5	<0.001

The model results reported in Table 25 do not take into account respondent characteristics. Doing this showed that preferring current care itself (ASC) more pronounced amongst men than women and less pronounced among those who had transferred compared with those yet to transfer. Those with ASD compared with those with cerebral palsy had less pronounced preferences for parental involvement and for being the ones to make decisions about their treatment. Appointment flexibility was the only attribute no longer statistically significant once demographics were taken into consideration, but men had a significantly more pronounced preference for out-of-hours clinics than women, and less pronounced preference for making decisions about treatment.

Table 26 shows that in a service where none of the attributes were present the uptake of the service would be 78% (95% CI: 75% to 81%). This is as would be expected given the chronic nature of the young people's conditions. So as an example, adding a new service with flexible appointments would result in predicted uptake by young people of 81% (95% CI: 78% to 84%).

Table 26: Predicted probabilities of uptake of services as attributes are added

Attribute	Probability of uptake	Lower 95% CI	Upper 95% CI
Current service (none of the attributes)	0.78	0.75	0.81
New service with flexible appointments	0.81	0.78	0.84
New service with a keyworker	0.79	0.74	0.85
New service seeing the same staff at each appointment	0.90	0.85	0.94
New service seeing the same staff and having a keyworker	0.88	0.84	0.92
New service with good staff communication	0.93	0.91	0.95
New service with parental involvement	0.93	0.90	0.95
New service offering young people decisions about treatment	0.91	0.88	0.93
New service offering extra support to young people for their future	0.86	0.83	0.89

Comparison of Ranking and DCE results

Using the results of the DCE it is possible to indicate the relative importance respondents gave to each attribute (Table 27). The initial model showed that staff communication was on the most important attribute and use of a keyworker the least. However once we controlled for demographic characteristics and condition, decisions about care was the attribute shown to be most important to young people and clinic flexibility was least important. A direct comparison with the ranking exercise was only possible when the attribute around which staff the young person saw at an appointment (which has 4 levels – see Table 27) was collapsed into a 2 level.

Table 27: The relative importance respondents gave to each attribute

Attribute	Initial model	With interactions	Initial model	With interactions	Ranking exercise
Flexibility of clinics	7	8	6	6	4
Keyworker only	8	7	5*	5*	3
Same staff only	4	4			
Both same staff and keyworker	5	6			
Staff communication	1	3	1	3	2
Parental involvement	2	2	2	2	6
Decisions about care	3	1	3	1	1
Extra support	6	5	4	4	5

*staff attribute averaged to compare with ranking exercise

When comparing the DCE results and the ranking exercise it is clear that young people have consistent and well-formed preferences around how much they value making decisions about their care and staff having good communication with each other. This is consistent with the model findings, once we have accounted for demographics. However, the most striking differences between the DCE and ranking are that young people may consciously underestimate the importance they place on parental involvement in their care, and over-estimate the value of having clinics with flexible hours.

Discussion

The purpose of the DCE was to explore the importance that young people with complex health needs place on different ways their care can be organised. It was anticipated at the outset that some of the young people may struggle with this completing the DCE because it is considered demanding and it does require that respondents choose between different hypothetical ways a service can be organised. It was for this reason a number of aids to help the young people complete the task were devised and that a simpler ranking of the attributes and levels was also used.

Of those young people who had not withdrawn from the longitudinal study (n=274) over 90% were able to complete at least one DCE question. Those participants with ASD were more likely to be non-responders to the DCE but a significant proportion of those with ASD were able to complete the DCE and ranking exercise.

The results of the DCE suggest that the features of care a priori considered potentially important to young people were found to be valued with the exception of flexibility of appointments. As might be expected preference for the way care was currently provided was strong and this preference was more pronounced amongst young men than young women. It was also stronger for those who had not transferred.

Most young people (and especially women) least valued being able to have appointments outside of office hours. Clinics that welcomed parental involvement were highly valued by the young people, but this appeared more important in the DCE results than the ranking exercise. This may indicate that young people might underestimate how important this involvement is to them and the DCE by presenting a more complex set of choices allows this to be teased out. The young people also placed a high value on clinics in which: information is passed on to the right person. Young people also valued when staff give them choices and allowed them to make decisions about their care; and that those staff provide extra support to help young people prepare for everyday life with their condition in future. Notably, young people valued seeing the same staff at each clinic appointment more than having a keyworker.

Strengths and limitations

A major strength of the DCE was that it was embedded within a rigorous longitudinal study. Within this study extensive and exhaustive efforts were made to recruit, engage and retain a large cohort of young people throughout a period of major change in their lives. Whilst potentially framing the responses, the various aids to completing the DCE were arrived at using the study team's considerable experience of working with these groups and following advice and piloting with the young people themselves. The aids to completion of the DCE might have infringed strict DCE methodology but they enabled young people, with a wide range of confidence, intellectual ability and flexibility of thinking, to complete it. Indeed the use of aids has been advocated.⁹⁷⁻⁹⁹

The results of the DCE suggest that the condition itself was not of central importance in preferences, this is not to say that the condition the young person had did not have an effect. The number of withdrawals and dropouts from the longitudinal study limited the ability to detect differences in preferences when they existed. A DCE can be demanding to complete. Whilst most young people were able to respond, proportionately fewer with ASD responded.

It is possible that these young people may have different preferences to those that did complete the DCE. Furthermore, it is possible that the DCE failed to accurately capture the preferences of those young people who did complete the DCE. For this latter issue some reassurance was provided by the broad similarities between the DCE findings and the ranking exercise. The advantage of the DCE over the ranking exercise was that the DCE provided an indication of the relative importance of each attribute.

As a methodological approach DCEs are widely accepted and are a tool preferred by many organisations. For example, they form the basis of eliciting EQ-5D-5L population tariffs throughout the world⁹⁵ and Center for Devices and Radiological Health, part of the Federal Food and Drug Administration have stated that DCEs are a suitable method for eliciting patient preferences.⁹⁶

The approach adopted is consistent with best practice with respect to design and conduct of the DCE. With respect to analysis, a fixed-effects modelling assumed respondents were consistent in their choices over time. Whilst the approaches adopted are not incorrect, more sophisticated econometric modelling approaches could be used to explore heterogeneity and whether participants considered only a subset of attributes when choosing among alternatives. This might help explain why an appreciable proportion of respondents always chose current care. Further interrogation of the data set might help but there is a limit to how complex an analysis can be within the confines of the sample size.

Conclusions

These findings from the DCE may help those tasked with designing services in deciding how services might be redesigned. The study has shown that all the different aspects of organising a service are wanted, except flexibility in clinic appointments. Most young people prefer clinics where staff give them choices and allow them to make decisions about their care. They also place a high value on clinics where staff communication is good and information about them always seems to get passed on to the right person. Young people may also underestimate how much they would like clinics that welcome parental involvement. Young people generally liked their current care although this was less marked for those who had made the transfer to adult services.

Draft paper

Report WP 2.3.2 Economic analysis

1. Introduction

This appendix focuses on the economic analysis conducted as part of the second work package. The main quantitative empirical part of the second work package is a four year longitudinal study of young people with diabetes, cerebral palsy or autistic spectrum disorder (ASD), who are aged 14-18 at baseline. These people are followed up three times, on a roughly annual basis, after being recruited at baseline. During each of these visits, the young people complete a battery of outcome measures. There are three sets of outcome measures that are most relevant to the economic component of the work:

- 1) The EQ-5D-Y. This is a generic health status measure developed for completion of people aged between 7+ and is an adaptation of the EQ-5D measure which is primarily aimed at adults. Since the programme has started the EQ-5D has been validated for people aged 12+. We have continued to you the EQ-5D-Y to remain consistent and the main difference between the two versions is how the EQ-5D-Y describes one aspect of daily living. Within the cohort study the EQ-5D-Y is completed at baseline and each of the 3 subsequent visits.
- 2) Health and social service contacts. At each visit a form was completed, describing the nature, type and number of contacts is collected. The young person also kept a diary of all the contacts they had had with the NHS since their previous visit. Further, data was obtained from the young person's medical notes and this was reviewed prior to the young person's visit. The resulting data (called the 'Final Account of Consultations) provides details of the use of services for each young person over the follow-up visit.
- 3) Stated preference exercise. The young people complete once during the third or fourth visit (depending upon whether they met the third scheduled visit) a discrete choice experiment (DCE) questionnaire.

These data were also collected to inform a proposed economic evaluation model. The design conduct and analysis of the discrete choice experiment are covered earlier in this appendix. We now cover: (1) the longitudinal data quality of life data; (2) the longitudinal cost data; and (3) the proposed economic model.

2. Methods

2.1. Longitudinal data analysis

The analysis of the 'economic' data as part of the longitudinal cohort followed similar principles to those used for the statistical analysis of outcome data reported for WP2.1. The dependent variables are health related quality of life as measured by the EQ-5D-Y and costs.

2.1.1 EQ-5D-Y

As noted already the EQ-5D-Y was collected 4 times within the longitudinal data set. The responses to the EQ-5D-Y were considered in two ways. First EQ-5D-Y data were converted into a utility score using the value set for adults.¹⁰³ Second they were summed with equal weighting to each of the five component questions. In this simple scoring system each of the five domains of the EQ-5D-Y was given equal weighting, and each level of each domain was scored 1, 2, or 3 depending on severity. This meant that each individual's response to the EQ-5D-Y could be scored between 5 and 15. This is defined hereafter as the sumscore. Lower scores by domain and sumscore indicate better health related quality of life.

These two approaches were adopted because there are known difficulties with applying the adult EQ-5D value set to the EQ-5D-Y, which does not have its own value set. However, it should also be noted that the study population was, on average, aged 16 or over at baseline and the adult EQ-5D questionnaire can be used with such a population. So, while the EuroQol Foundation note the EQ-5D-Y is a separate instrument, we expect that most of our study population would have been able to complete the adult version and, had they done so, it would be possible to apply utility values to such results without question.

Coupled with data on the young person's last date in paediatrics (considered the date of transfer), and also the visit (two, three or four) by which the young person had transferred, we calculated two definitions for their average pre- and post-transfer utility and their average pre- and post-transfer sumscore.

The plan was to assess the impact of the proposed beneficial features as well as demographic features of condition (diabetes, cerebral palsy or ASD), age at baseline, gender and transfer status (child services, adult services or general practice) using generalised linear modelling (GLM). This approach was adopted because of the highly skewed nature of sumscore, utility data. To conduct GLM fitting we utilised STATA and additional 'glmdiag' code [<http://www.uphs.upenn.edu/dgimhsr/stat-cstanal.htm>; accessed August 2017] and methods described by Glick and colleagues [<http://www.uphs.upenn.edu/dgimhsr/documents/acadh1th.glick.061008.pdf> accessed August 2017].

For utilities, there were no appropriate distributions (from either Gaussian, Inverse Gaussian, Gamma or Poisson) combined with tried link functions (cube root, square root, reciprocal, identity, log, squared, cubed) that could successfully model results. For sumscore the inverse Gaussian distribution with a log link and the gamma distribution with a log link were also considered plausible. Nevertheless, results from these analyses did not appear robust.

As a consequence an exploratory analysis estimating the median scores when a specific proposed beneficial feature was present were estimated.

2.1.2 *NHS, social service and costs to young people and their families*

The use of services all elicited as part of the longitudinal study were used in the estimation of costs. The costs data were then used as dependent variables in a set of regression analyses similar to those outlined above for the EQ-5D-Y data.

The perspective for the estimation of costs is the NHS and personal social services. Thus, it covers use of primary and secondary NHS care services, personal and social services and out-of-pocket expenses for the costs of accessing care (time and travel).

NHS and personal social service costs

Use of NHS, personal and social services based upon each young person's Final Account of Consultations obtained at each visit. A unit cost was assigned to each item of resource use. These unit costs were sought from standard data sources such as the Unit Costs of Care for, for example, general practitioner visits.

The unit cost of medications was taken from the British National Formulary (BNF) and unit cost of inpatient and/or day case stays was derived from NHS reference costs. As insulin prescriptions were not consistently mentioned in the data, these were costed separately according to existing literature sources^{209, 210} inflated to the current price year (2016) and whether or not the young person was documented as receiving an insulin pump in the Final Account notes. Visits that were cancelled in advance did not incur costs, but those where either the respondent or the staff member did not attend, incurred 50% of the cost of a typical visit of that type.

Once all documented resource use items received a unit cost, data were combined with information on each participant's transfer status to calculate average pre- and post-transfer costs across all participants.

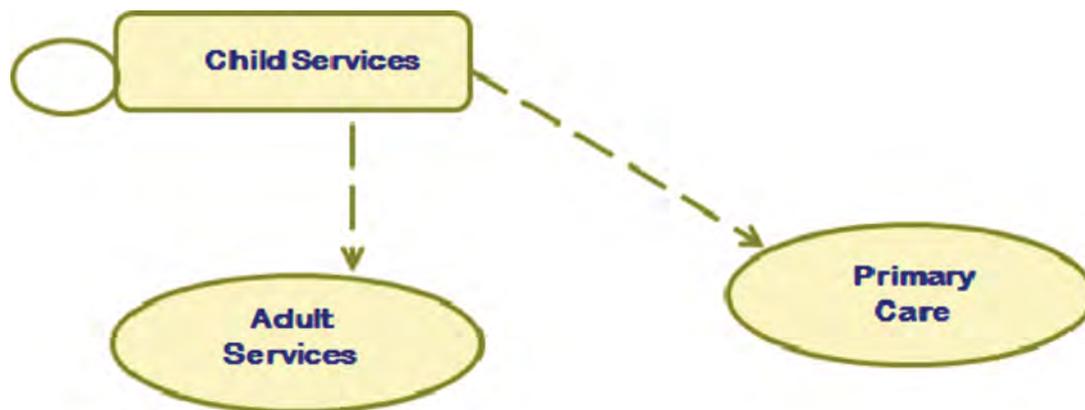
The plan was to assess the impact on cost of the proposed beneficial features as well as demographic features of condition (diabetes, cerebral palsy or ASD), age at baseline, gender and transfer status (child services, adult services or general practice) using generalised linear modelling (GLM). A similar problem to that described above was encountered and hence an exploratory analysis estimating the median scores when a specific proposed beneficial feature was present were estimated.

2.2. **Economic evaluation modelling**

The purpose of the economic modelling was to compare the costs and effects of alternative hypothetical ways (termed interventions in the economic model) of delivering care during transition. The different transitions interventions were to be defined in terms of the presence or absence of the potential beneficial features. Data on the impact of the potential beneficial features was to come from the longitudinal analysis described in WPs 2.1 and 2.2. A model such as this however has limited value unless it is plausible that the potentially beneficial features could influence costs and effects. Therefore, its conduct was conditional on the findings of WPs 2.1 and 2.2.

Figure 17 gives the structure of the model. In the model all young people start in child services and are aged 14 years old and are followed for 10 years; the time over which a young person would be expected to be undergoing transition. The model considers a hypothetical cohort of 1,000 young people. Each year they have a probability of transferring out of child services and being discharged into primary care or moving into adults services. If in any given year they do not make the transfer then they remain in child services indicated by the ellipse connected to the Child Services state. In each state an annual cost, utility or sumscore value was assigned. The values used for this were derived from the work conducted under WPs 2.1 and 2.2. By combining these values with the chance of being in a state in give year it was possible to estimate cumulative costs, cumulative utilities (which because they are estimated over time provide an estimate of quality adjusted life years – QALYs) and sumscore.

Figure 17: Structure of the economics model



The chance of being in a given state in a given year was given by the rate of transfer. The rate of transfer was calculated by considering the number of people who transferred from child services each year, and the ratio of transferred young people who were transferred to adult services compared with PRIMARY CARE services. This decline in the proportion of young people in child services is modelled by the exponential distribution whereby $y = n(e^{-0.498t})$, where n is the baseline sample size and t is the number of years since baseline. Of those who transfer, approximately 55% go to adult services, with the remainder of those who transferred going to primary care.

The cumulative effects were estimated for hypothetical transition services. The first of these was a service that did not contain any of the proposed beneficial features. Alternative services were defined in terms of the presence of a single proposed beneficial features, thus there was an alternative service defined for each of the nine proposed beneficial features.

The difference in cost and QALYs and sumscore between each alternative service and a service containing no proposed beneficial features. These data were then used to estimate the extra cost required to produce one more unit of effect – the incremental cost-effectiveness ratio (ICER). All costs are presented in terms of a common price year (2016) and all costs and consequences are discounted at 3.5%.

(Discounting is used because the when a cost and benefit occurs is believed to be important. It reflects the fact that costs and benefits that occur in the future are given less weight than costs and benefits that occur now. 'This time preference' for when costs and benefits might occur is captured by the use of a discount rate, which reduces the importance of future costs and benefit in an analysis.)

The presence or absence of the proposed beneficial features was elicited in two ways. A form was completed each year by the research associate from data in the medical notes. It consisted of details of clinic visits, professionals in attendance, medical tests undertaken and whether PBFs had been experienced. This was called the 'Final Account of Consultations'. Following the home visits with further discussion of appointments and PBFs and completion with the young person of a questionnaire, it became clear that the Final Account was incomplete for some young people. Therefore analysis was also undertaken with data combined from both sources.

2.3. Balance sheet analysis

The results of the model were combined with finding from other areas of the report in a balance sheet analysis. In this analysis we have presented those outcomes that could favour a hypothetical transition intervention compared to a situation where there is no support during the transition from child to adult services. The approach can incorporate quantitative data such as that produced from the statistical analysis of the longitudinal study, evidence from the broader literature and evidence from the other work conducted within the programme.

3. Results

3.1. Longitudinal data analysis

3.1.1. EQ-5D results

Of the 375 participants in the Transition Research Programme, 66 left the study. EQ-5D-Y data were available for 373 respondents at baseline, and 244 respondents by visit 4.

Summary response data for the EQ-5D-Y

For each of the five domains, the minimum and maximum scores were the extremes of the 3-levels (1 and 3 respectively, and the median score was consistently 1, meaning that for every domain at every time point, at least half the respondents reported 'no problems'. The number and proportion of respondents responding at each of the three levels for each of the five domains is provided in Table 28. For most domains the proportion of respondents report some or lots of problems (scores 2 and 3) increase over time. The mean score also suggest that health may have declined over time (score look to have increased on average for all domains except self-care).

Table 28: Responses by each of the domains of the EQ-5D-Y over the follow-up

		Scoring 1		Scoring 2		Scoring 3		Missing		Mean Score	SD
		n	%	n	%	n	%	n	%		
Mobility	Baseline	298	79.5%	63	16.8%	12	3.2%	2	0.5%	1.23	0.49
	Visit 2	239	63.7%	59	15.7%	6	1.6%	71	18.9%	1.23	0.47
	Visit 3	190	50.7%	52	13.9%	14	3.7%	119	31.7%	1.31	0.57
	Visit 4	189	50.4%	44	11.7%	11	2.9%	131	34.9%	1.27	0.54
Self-care	Baseline	311	82.9%	50	13.3%	12	3.2%	2	0.5%	1.20	0.47
	Visit 2	258	68.8%	35	9.3%	11	2.9%	71	18.9%	1.19	0.47
	Visit 3	214	57.1%	30	8.0%	11	2.9%	120	32.0%	1.20	0.50
	Visit 4	204	54.4%	30	8.0%	10	2.7%	131	34.9%	1.20	0.50
Usual Activities	Baseline	273	72.8%	96	25.6%	4	1.1%	2	0.5%	1.28	0.47
	Visit 2	226	60.3%	73	19.5%	5	1.3%	71	18.9%	1.27	0.48
	Visit 3	163	43.5%	90	24.0%	3	0.8%	119	31.7%	1.38	0.51
	Visit 4	170	45.3%	70	18.7%	4	1.1%	131	34.9%	1.32	0.50
Pain	Baseline	245	65.3%	122	32.5%	6	1.6%	2	0.5%	1.36	0.51
	Visit 2	200	53.3%	95	25.3%	9	2.4%	71	18.9%	1.37	0.54
	Visit 3	163	43.5%	88	23.5%	5	1.3%	119	31.7%	1.38	0.53
	Visit 4	154	41.1%	78	20.8%	12	3.2%	131	34.9%	1.42	0.59
Anxiety	Baseline	236	62.9%	117	31.2%	20	5.3%	2	0.5%	1.42	0.59
	Visit 2	177	47.2%	106	28.3%	21	5.6%	71	18.9%	1.49	0.62
	Visit 3	142	37.9%	95	25.3%	19	5.1%	119	31.7%	1.52	0.63
	Visit 4	125	33.3%	102	27.2%	17	4.5%	131	34.9%	1.56	0.62

The variations in EQ-5D-Y responses by the three conditions is reported in Table 29. As this table show that young people with diabetes consistently experienced fewest problems in any domain. Those with cerebral palsy were more likely to experience problems in the mobility and self-care domains than young people with diabetes or ASD. The proportion of respondents with ASD reporting problems in the anxiety domain was consistently higher than for the other two conditions. As these differences were present at baseline, they may simply reflect the nature of the conditions under consideration.

Table 29: Summary of EQ-5D-Y responses by condition

Dimension	Time point	% experiencing problems (score 2 or 3) including missing			% experiencing problems (score 2 or 3) excluding missing		
		ASD	CP	Diabetes	ASD	CP	Diabetes
Mobility	Baseline	16.1%	47.7%	3.3%	16.2%	48.1%	3.3%
	Visit 2	11.9%	40.2%	5.3%	15.4%	50.6%	6.3%
	Visit 3	14.4%	43.0%	2.0%	20.5%	63.0%	3.0%
	Visit 4	10.2%	36.4%	2.7%	15.8%	56.5%	4.0%
Self-care	Baseline	15.3%	40.2%	0.7%	15.4%	40.6%	0.7%
	Visit 2	8.5%	31.8%	1.3%	11.0%	40.0%	1.6%
	Visit 3	11.9%	24.3%	0.7%	16.9%	35.6%	1.0%
	Visit 4	10.2%	26.2%	0.0%	15.8%	40.6%	0.0%
Usual activities	Baseline	36.4%	37.4%	11.3%	36.8%	37.7%	11.3%
	Visit 2	24.6%	29.0%	12.0%	31.9%	36.5%	14.1%
	Visit 3	35.6%	32.7%	10.7%	50.6%	47.9%	16.0%
	Visit 4	26.3%	25.2%	10.7%	40.8%	39.1%	16.2%
Pain	Baseline	38.1%	51.4%	18.7%	38.5%	51.9%	18.7%
	Visit 2	27.1%	42.1%	18.0%	35.2%	52.9%	21.1%
	Visit 3	29.7%	37.4%	12.0%	42.2%	54.8%	18.0%
	Visit 4	25.4%	34.6%	15.3%	39.5%	53.6%	23.2%
Anxiety	Baseline	65.3%	28.0%	20.0%	65.8%	28.3%	20.0%
	Visit 2	50.8%	29.9%	23.3%	65.9%	37.6%	27.3%
	Visit 3	46.6%	27.1%	20.0%	66.3%	39.7%	30.0%
	Visit 4	46.6%	27.1%	23.3%	72.4%	42.0%	35.4%

ASD = Autism spectrum disorder; CP = cerebral palsy

EQ-5D Sumscore

The higher the sumscore the worse health is reported to be. The median sum score for all participants across all time points was 6 (IQR: 2.8), which indicates at least half of participants did not experience 'no problems' across all domains (a score of 5 is required). Average sumscores were not associated with gender, nor were pre or post transfer scores. In addition, there were significant differences in both sumscores by condition, as diabetes participants had significantly lower scores (i.e. better health) ($p < 0.001$) at all time points (Table 30).

EQ-5D-Y Utilities

The median utility score across all participants was 0.83 (IQR: 0.304). Average utility scores were not associated with gender nor were pre or post transfer scores. However, among those who transferred, scores were significantly higher (Wilcoxon Signed Rank test 7465.5, $p < 0.001$) for those doing so to adult services (median 0.86, IQR: 0.37) compared to Primary Care services (median 0.78, IQR: 0.38). As was found for the sumscore participants with diabetes had a higher significantly higher scores ($p < 0.001$) at all time points (Table 30).

Table 30: Summary Sumscore and Utility score by condition pre- and post-transfer

	All (IQR)	ASD (IQR)	Cerebral palsy (IQR)	Diabetes (IQR)
n	301	96	83	122
Median sum score	6 (2.79)	7 (2)	7 (2.98)	5.2 (1)
Median utility score	0.83 (0.30)	0.75 (0.27)	0.70 (0.43)	0.94 (0.14)
<hr/>				
n	269	86	70	113
Median pre-transfer sumscore	6 (2)	7 (2)	7 (3)	5 (1)
Median pre-transfer utility score	0.85 (0.27)	0.75 (0.26)	0.72 (0.43)	0.95 (0.13)
<hr/>				
n	230	68	66	96
Median post-transfer sumscore	6 (3)	7 (2)	7 (2.75)	5 (1)
Median post transfer utility score	0.82 (0.29)	0.76 (0.24)	0.70 (0.33)	0.95 (0.16)

IQR = Interquartile range; ASD = Autism spectrum disorder

3.1.2 Use of services and costs

Use of services overall and by condition

The number of participants providing data was 286 at visit 2, 249 at visit 3 and 216 at visit 4, representing 76.2%, 66.4% and 57.6% of the total sample respectively. The young people in the sample recorded a total of 8383 visits over the course of the follow-up. Of these 7755 (92.5%) occurred, with others either being cancelled in advance or without sufficient prior notification (i.e. 'did-not-attend' or 'DNA'd'). Corresponding to the fall in the sample contributing data the number of visits occurring at each time point declined from 3293 (42.5% of all visits) at visit 2, to 2476 (31.9% of all visits) at visit 3 and 1986 visits (25.6% of all visits) at visit 4.

The average number of visits experienced by the participants declined from a median of 7 (IQR 8) at visit 2, to a median of 6 (IQR 9) at visit 3 and 4 (IQR 9) at visit 4. The median number of visits across the whole duration of follow-up was 19 (IQR 20), but this varied depending on condition, ranging from 14 (IQR: 27.8) for those with cerebral palsy to 23 visits for those with diabetes (IQR: 13.8). Those participants with ASD had a median of 16 visits (IQR: 23).

Over time, the median number of visits, among participants who experienced visits over the time period decreased for those with cerebral palsy and diabetes (from 7 and 8 at visit 2 respectively to 5 and 7 at visit 4), whereas for those with ASD the median number of visits increased from 5 to 6 over the same time period. If we include those who had no visits here, this trend is lost (cerebral palsy goes from 6.5 to 1 and Diabetes goes from 8 to 6, ASD goes from 4 to 3). The composition of visits also varied in terms of venue and staffing, both across time and for each of the three conditions (Table 31).

As Table 31 illustrates for those with ASD, visits were typically held in community/high street venues (this includes CAMHS) or home/school visits. Whereas for those with cerebral palsy visits typically took place at either home/school or outpatient clinics. Over half of contacts for those with diabetes took place in outpatient settings at each visit, and the majority of 'other' types of contact were comprised of telephone conversations with clinicians.

Table 32 illustrates the type of staff seen and as this table shows there was a very small number of multidisciplinary contacts. Compared to participants with diabetes, participants with ASD and cerebral palsy were less likely to have multidisciplinary visits, although the proportion of visits that were multi-disciplinary for those with ASD increased over time, whereas for those with diabetes they decreased. The proportion of visits involving doctors increased over time for those with diabetes, whereas it declined for those with ASD. Visits involving other care providers (typically social care staff or volunteers working with the young person) increased in those with ASD as did nursing visits, whereas the latter decreased for those with diabetes.

Table 31: Percentage of all health care contacts by provider and by condition

	% of all visits of this type at visit 2	% of all visits of this type at visit 3	% of all visits of this type at visit 4
All			
Community	17.5%	16.8%	12.6%
Primary care	7.0%	8.9%	12.5%
Home visit	34.5%	29.7%	26.0%
Inpatients (elective)	0.6%	0.6%	0.6%
Inpatients (emergency)	0.9%	1.2%	1.3%
Outpatients	30.2%	33.9%	39.1%
Other	9.5%	8.8%	7.9%
ASD			
Community	53.1%	29.2%	22.3%
Primary care	5.6%	11.2%	17.6%
Home visit	25.7%	43.9%	41.7%
Inpatients (elective)	0.0%	0.1%	0.3%
Inpatients (emergency)	0.3%	1.5%	1.4%
Outpatients	3.4%	7.7%	10.4%
Other	11.8%	6.4%	6.3%
Cerebral palsy			
Community	6.5%	17.4%	15.5%
Primary care	4.5%	4.0%	4.7%
Home visit	63.1%	46.8%	39.9%
Inpatients (elective)	0.5%	0.8%	1.1%
Inpatients (emergency)	1.0%	0.5%	0.9%
Outpatients	23.6%	28.9%	34.8%
Other	0.8%	1.5%	3.0%
Diabetes			
Community	2.0%	4.5%	1.8%
Primary care	10.6%	10.4%	14.3%
Home visit	10.5%	3.8%	1.3%
Inpatients (elective)	1.1%	0.9%	0.6%
Inpatients (emergency)	1.4%	1.5%	1.6%
Outpatients	57.8%	62.4%	67.2%
Other	16.5%	16.6%	13.1%

ASD = autism spectrum disorder

Table 32: Descriptive statistics on use of health services

All	From baseline to visit 2	From visit 2 to visit 3	From visit 3 to visit 4
% healthcare contacts with doctor(s) present	31.9%	33.4%	32.6%
% healthcare contacts with nurse(s) present	28.3%	26.4%	26.1%
% healthcare contacts with AHP*(s) present	38.2%	34.2%	28.6%
% healthcare contacts with others present	16.4%	18.8%	24.7%
% of healthcare contacts: multidisciplinary	13.1%	13.0%	11.5%
Diabetes			
	Visit 2	Visit 3	Visit 4
% healthcare contacts with doctor(s) present	39.4%	41.6%	43.6%
% healthcare contacts with nurse(s) present	66.3%	56.6%	51.7%
% healthcare contacts with AHP(s) present	29.2%	29.7%	29.2%
% healthcare contacts with others present	2.1%	1.9%	1.7%
% of healthcare contacts : multidisciplinary	32.0%	29.2%	24.4%
Cerebral palsy			
	Visit 2	Visit 3	Visit 4
% healthcare contacts with doctor(s) present	18.6%	23.1%	20.1%
% healthcare contacts with nurse(s) present	3.8%	2.6%	2.9%
% healthcare contacts with AHP(s) present	56.6%	36.5%	41.2%
% healthcare contacts with others present	23.4%	39.5%	38.0%
% of healthcare contacts: multidisciplinary	2.6%	2.0%	2.7%
Autism spectrum disorder			
	Visit 2	Visit 3	Visit 4
% healthcare contacts with doctor(s) present	40.6%	32.9%	31.3%
% healthcare contacts with nurse(s) present	13.0%	12.9%	18.0%
% healthcare contacts with AHP(s) present	23.9%	37.1%	16.1%
% healthcare contacts with others present	25.4%	20.6%	39.0%
% of healthcare contacts: multidisciplinary	3.0%	4.4%	4.6%
*AHP Allied Health Professional			

Combining data from Table 31 with unit cost data allowed a cost of care for each young person to be estimated. Data were available on 301 young people (78.6%). The overall median cost per participant was £4954 (IQR: £6103). Diabetes was the most costly condition, and cerebral palsy was the least costly although there was considerable variation between individuals. The difference between the cost of those with diabetes and those with ASD was statistically significant ($p < 0.001$). The difference in pre and post transfer costs was not statistically significant at the 0.05 level although there was a trend both overall and by each condition (Table 33).

Table 33: Estimated median costs, by condition both overall and pre and post transfer

	All (IQR)	ASD (IQR)	Cerebral palsy (IQR)	Diabetes (IQR)
N	301	96	77	125
Median total costs	£4954 (£6103)	£2351 (£4211)	£2394 (£5606)	£7003 (£3667)
Median total costs per annum	£2307 (£2705)	£1659. (£2573)	£1447 (£2725)	£2915 (£2422)
N	279	88	67	121
Median pre-transfer costs	£2420 (£4506)	£1694 (£2454)	£1370 (£4215)	£4434 (£5136)
Median pre-transfer costs per annum	£1673 (£2242)	£915 (£1277)	£949 (£1974)	£2410 (£1587)
N	194	56	48	87
Median post-transfer costs	£2080 (£3470)	£1262 (£2540)	£1395 (£3015)	£3114 (£3440)
Median post-transfer costs per annum	£1371 (£1862)	£645 (£1883)	£707. (£1673)	£1849 (£1193)

Presence of proposed beneficial features

The presence or absence of the proposed beneficial features was elicited in two ways.

A form was completed each year by the research associate from data in the medical notes. It consisted of details of clinic visits, professionals in attendance, medical tests undertaken and whether PBFs had been experienced. This was called the 'Final Account of Consultations'. Following the home visits with further discussion of appointments and PBFs and completion with the young person of a questionnaire, it became clear that the Final Account was incomplete for some young people. Therefore analysis is also undertaken with data combined from both sources.

Sensitivity analyses were carried using these alternative definitions.

Details regarding the nine criteria used to define the amount of PBF required to be 'satisfactory' is defined elsewhere. When this was applied to the data, the following numbers of young people met the criteria for receiving each PBF – Table 34. This has been shown by the two data sources. These young people did not always also have available cost data, but where they did have cost data this is reported in Table 34 in parenthesis.

3.2 Economic evaluation model

Using the data reported above in the proposed economic model an attempt was made to estimate the impact of the proposed beneficial features on sumscores, utility score, QALYs and costs. The model sought to reflect the fact that the young person's place of care would change over time as they leave child services. On leaving child services the young person would be either receive care in primary care or secondary care.

Table 35 shows the input parameters for costs, utilities and sumscore. The data reported in Table 35 are point estimates and whilst there may be apparent trend in the data it is important to remember that confidence intervals around these values would be very wide. Therefore, for the purposes of making decisions about care their quality would be judged as low. However, when interpreted with other findings they may help highlight areas for further research.

Table 34: Number of young people experiencing the proposed beneficial features when experience is captured in different ways

	All (for whom cost data are available)	Child services (for whom cost data are available)	Transferred to adults services (for whom cost data are available)	Transferred to primary care (for whom cost data are available)	Left study
As captured from Final Account					
No PBFs	35 (33)	9 (9)	11 (11)	15 (13)	0
Meet adult team before transfer	66 (60)	3 (3)	57 (52)	5 (5)	1
Age-banded clinic	141 (129)	25 (25)	108 (97)	8 (7)	0
Holistic life-skills training	128 (114)	29 (29)	80 (73)	18 (12)	1
Key worker	58 (50)	12 (12)	37 (32)	9 (6)	0
Transition manager for clinical team	23 (21)	3 (3)	17 (16)	2 (2)	1
Appropriate parent involvement	11 (11)	3 (3)	8 (8)	0 (0)	0
Promotion of health self-efficacy	30 (27)	4 (4)	26 (23)	0 (0)	0
Coordinated team	95 (84)	27 (27)	53 (48)	14 (9)	1
Transition plan	26 (24)	5 (5)	20 (19)	0 (0)	1
All PBFs	0 (0)	0 (0)	0 (0)	0 (0)	0
As captured from both sources (face-to-face contacts and Final Account)					
No PBFs	7 (7)	1 (1)	2 (2)	4 (4)	0
Meet adult team before transfer	121 (108)	12 (12)	91 (84)	15 (12)	3
Age-banded clinic	163 (142)	26 (26)	119 (107)	13 (9)	5
Holistic life-skills training	149 (129)	31 (31)	91 (83)	23 (15)	4
Key worker	78 (66)	17 (17)	54 (45)	7 (4)	0
Transition manager for clinical team	70 (61)	13 (13)	45 (44)	7 (4)	5
Appropriate parent involvement	121 (108)	18 (18)	73 (69)	30 (21)	0
Promotion of health self-efficacy	100 (90)	19 (19)	70 (63)	11 (8)	0
Coordinated team	195 (170)	45 (45)	122 (111)	21 (14)	7
Transition plan	56 (50)	9 (9)	41 (39)	2 (2)	4
All PBFs	1 (1)	1 (1)	0 (0)	0 (0)	0

Table 35: Costs, utilities and sumscore data Cost

Costs												
State	PBFs captured from final account						PBFs captured from final account and face-to-face					
	Child services		Transferred adult services		Transferred primary care		Child services		Transferred adult services		Transferred primary care	
	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR
No PBFs	816	1,162	800	1,247	662	831	658	-	1,245	1,027	199	336
Meet adult team before transfer	2,915	1,554	1,823	1,222	845	699	3,188	1,793	1,761	1,213	754	1,043
Age-banded clinic	2,915	1,837	1,894	1,263	2,325	764	2,477	1,576	1,735	1,347	2,325	976
Holistic life-skills training	2,456	2,328	1,708	1,609	569	2,114	2,616	2,254	1,677	1,666	504	2,206
Key worker	3,233	2,727	1,546	1,356	2,431	1,519	2,497	2,179	1,600	1,376	731	1,087
Transition manager	2,616	4,777	1,644	2,963	5,114	2,576	2,616	1,527	1,510	1,738	1,623	3,292
Appropriate parent involvement	NA	1,373	NA	2,447	NA	NA	2,400	2,760	1,487	1,929	566	669
Promotion of health self-efficacy	NA	1,616	NA	1,232	NA	NA	2,794	1,892	1,600	1,362	401	1,267
Coordinated team	2,915	2,712	1,350	1,626	853	2,002	2,725	1,633	1,677	1,498	1,040	1,933
Transition plan	NA	1,258	NA	2,026	NA	NA	3,391	1,258	1,894	1,817	1,136	582
All PBFs	NA	NA	NA	NA	NA	NA	NA	-	NA	NA	NA	NA

Table 35: Costs, utilities and sumscore data Utilities

Utility scores												
State	PBFs captured from final account						PBFs captured from final account and face-to-face					
	Child services		Transferred adult services		Transferred primary care		Child services		Transferred adult services		Transferred primary care	
	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR
No PBFs	0.90	0.19	0.66	0.47	0.80	0.26	0.90	0.00	0.41	0.34	0.87	0.18
Meet adult team before transfer	0.36	0.44	0.98	0.17	0.83	0.09	0.82	0.45	0.92	0.22	0.80	0.23
Age-banded clinic	0.88	0.16	0.91	0.22	0.64	0.32	0.87	0.15	0.91	0.24	0.61	0.19
Holistic life-skills training	0.83	0.40	0.89	0.26	0.81	0.12	0.83	0.35	0.88	0.30	0.81	0.12
Key worker	0.87	0.19	0.92	0.21	0.82	0.12	0.86	0.22	0.92	0.24	0.82	0.17
Transition manager	0.73	0.28	0.77	0.42	0.92	0.06	0.83	0.44	0.81	0.26	0.73	0.53
Appropriate parent involvement	NA	0.30	NA	0.28	NA	NA	0.79	0.45	0.85	0.33	0.78	0.20
Promotion of health self-efficacy	NA	0.06	NA	0.18	NA	NA	0.87	0.18	0.91	0.19	0.80	0.22
Coordinated team	0.87	0.52	0.82	0.28	0.68	0.30	0.86	0.22	0.90	0.25	0.68	0.29
Transition plan	NA	0.12	NA	0.15	NA	NA	0.88	0.51	0.85	0.22	0.75	0.07
All PBFs	NA	NA	NA	NA	NA	NA	NA	0.00	NA	NA	NA	NA

Table 35: Costs, utilities and sumscore data Sumscores

Sumscores												
State	PBFs captured from final account						PBFs captured from final account and face-to-face					
	Child services		Transferred adult services		Transferred primary care		Child services		Transferred adult services		Transferred primary care	
	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR
No PBFs	6.00	2	8.00	3	7.00	2	6.00	0	9.50	2.5	6.00	0.5
Meet adult team before transfer	10.00	2.5	5.00	1	6.50	1.25	6.00	4	6.00	2	7.00	2
Age-banded clinic	6.00	1.5	6.00	2	8.00	1.75	6.00	1	6.00	2	8.00	1
Holistic life-skills training	6.00	2	6.00	2	6.50	1	6.00	2	6.00	2	6.50	1
Key worker	6.00	1	6.00	1.5	7.00	1	6.00	2	5.00	2	7.00	1
Transition manager	7.00	2	7.00	3	5.50	0.5	6.00	3	6.00	2	7.00	2.75
Appropriate parent involvement	NA	1.5	NA	2	NA	NA	6.50	3	6.00	3	7.00	2
Promotion of health self-efficacy	NA	0.25	NA	1	NA	NA	6.00	1.5	6.00	2	7.00	2
Coordinated team	6.00	4	6.00	3	8.00	2	6.00	2	6.00	2	7.50	2
Transition plan	NA	1	NA	2	NA	NA	6.00	4	6.00	2	7.00	1
All PBFs	NA	NA	NA	NA	NA	NA	NA	0	NA	NA	NA	NA

Using these data within the economic model described in Section 2.2 and modelling over a 10 year time horizon it is possible to estimate how costs, sumscore and QALYs vary by presence or absence of proposed beneficial feature. This analysis considers each proposed beneficial feature separately and given the limited data available as reported in Table 34 should be considered as exploratory only. Given the exploratory nature probabilistic sensitivity analysis has not been conducted as there is considerable imprecision in result. The results are best considered as either illustrative of the approach take or hypothesis generating about possible proposed beneficial features to consider when developing an intervention to improve transition.

Table 36 shows estimated costs, effects (sumscore and QALY) and Table 37 the incremental cost-effectiveness for the comparison of a service incorporating each proposed beneficial feature alone a service where no features were present. All outcomes are discounted (each at 3.5%) It was not possible to compare individual PBFs against a situation where all PBFs were provided, as only one young person experienced all PBFs in the study. As the presence of the proposed beneficial features is based on reports during face to face contacts a sensitivity analysis has been performed using these data.

The data reported in Tables 36 and 37 illustrate that the results are sensitive to the methods used to define whether a proposed beneficial feature was present. In general there were more reports of the PBFs being present. The higher the incremental cost-effectiveness ratio the less likely an intervention would be considered value for money.

In relative terms there were several PBFs that seemed to perform better regardless of whether the definition of 'satisfactory' PBF exposure is based on final account or face-to-face data. These were the provision of holistic care; having a key worker, and, (where the sample was sufficient to quantify it) promotion of health self-efficacy.

Meeting the adult team was sensitive to the source of data and was considerably better when estimates were based on face to face data. Having a written transition plan was one of the poorer performing proposed beneficial features as was having a Transition manager for clinical team.

Table 36: Estimated costs and effects for each intervention

PBFs captured from Final Account of Consultations			
	Mean costs of strategy over model time horizon	Mean QALYs for strategy over time horizon	Mean sumscore for strategy over model time horizon
No PBFs	£6552	6.65	8
Meet adult team before transfer	£15,726	6.48	8
Age-banded clinic	£20,018	7.02	8
Holistic life-skills training	£13,406	7.28	7
Key worker	£19,922	7.53	7
Transition manager	£26,134	6.96	8
Appropriate parent involvement	NA	NA	NA
Promotion of health self-efficacy	NA	NA	NA
Coordinated team	£14,116	6.80	8
Transition plan	NA	NA	NA
All PBFs	NA	NA	NA
PBFs captured using responses to Final Account and face to face questionnaire			
No PBFs	6415	6.02	9
Meet adult team before transfer	15,941	7.36	7
Age-banded clinic	18,396	6.93	8
Holistic life-skills training	13,519	7.28	7
Key worker	13,592	7.51	7
Transition manager	16,042	6.78	7
Appropriate parent involvement	12,912	6.94	8
Promotion of health self-efficacy	13,644	7.43	7
Coordinated team	15,268	7.05	8
Transition plan	18,523	7.09	7
All PBFs	NA	NA	NA

Table 37: Incremental cost effectiveness

Cost per QALY gained		
	ICER using PBFs captured from final account	ICER using PBFs captured from final account and face to face questionnaire
Meet adult team before transfer	Dominated*	7121
Age-banded clinic	36,487	13,176
Holistic life-skills training	10,991	5618
Key worker	15,259	4811
Transition manager	64,359	12,592
Appropriate parent involvement	NA	7070
Promotion of health self-efficacy	NA	5127
Coordinated team	52,100	8596
Transition plan	NA	11,259
Cost per 1 unit change in sumscore		
Meet adult team before transfer	15,092	7011
Age-banded clinic	22,693	12,662
Holistic life-skills training	5692	4563
Key worker	13,363	3878
Transition manager	23,364	7114
Appropriate parent involvement	NA	5345
Promotion of health self-efficacy	NA	5341
Coordinated team	12,746	7700
Transition plan	NA	8947

* PBF on average more costly and less effective. Therefore it is dominated by a service without that PBF

ICER Incremental cost effectiveness ratio

QALY Quality adjusted life year

PBF Proposed beneficial feature

3.3 Balance sheet

Taking the data from the all the economic analyses and elsewhere within the programme a balance sheet summarising the pros and cons of developing a service which has some of the proposed beneficial features compared to a service without these features can be developed (Table 38). The purpose of Table 38 is to inform a decision about whether the cost of implementing a new service would be offset by any reductions in cost in the future and improvements in health.

The development and implementation of a service containing one or more proposed beneficial features would incur a cost, the magnitude of that cost will be determined by how that proposed beneficial feature is delivered. The limited data available from the economic model suggests that the implementation of a new service will increase the use of NHS services at least over a 10 year time horizon for a young person aged 14 entering a 'transition' service but there are no obvious harms to the young person of any of the proposed beneficial features.

The question for the decision-maker is whether the development of a flexible service capable of meeting the changing needs of young people, allowing appropriate parental involvement, promoting self-efficacy and more general independence of the young person would be worth these extra costs given that they may increase engagement with health services and prevent deterioration/exacerbation in health in the long-term.

Table 38: Pros and cons of a transition service containing some of the proposed beneficial features

Favours service containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the proposed beneficial features in the prospective study.	Favours service not containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the proposed beneficial features in the prospective study.	Source
	Avoided the currently unknown costs of providing beneficial features. Costs of some may be modest e.g. a 'written transition plan' whilst others are substantial e.g. adoption of a multi-disciplinary team.	Costs not estimated
A service should be flexible enough to meet the need of individuals – one size does not fit all and needs may change over time. Service needs to consider the condition, the stage of development, and the young person's personality.		Q-sort (WP 1.3) and DCE (WP 2.3.1)
	High predicted uptake of a service with no proposed beneficial features (78%; 95% CI 75-81)	DCE (WP 2.3.1)
Predicted uptake of a service higher when the service included parent involvement; a service where the same staff are seen at each clinic appointment; where the young receive good communication and are offered the opportunity to make decisions. - Increasing engagement may help prevent deterioration in the young person's condition over time	From the DCE a strong preference for current care; no strong preference for a 'key worker' or flexibility of appointments	DCE (WP 2.3.1) Anticipated impact not measured in study
'Appropriate parent involvement', 'Promotion of health self-efficacy', 'Meeting the adult team' improved outcomes.		Analysis of longitudinal data (WP 2.1)
Estimated additional benefit to health service of adopting any of the above features, except care by a co-ordinated team	Estimated additional cost to health services of adopting any of the proposed beneficial features	Economic model analysis (WP 2.3.2)
Longer term model cautiously suggests 'holistic life-skills training'; 'having a key worker', and 'promotion of health self-efficacy' might be value for money.	Longer term model cautiously suggests that a 'transition manager for clinical team', 'age-banded clinic' or 'meeting the adult team before transfer' might not be value for money'.	Economic model analysis (WP 2.3.2)
No evidence of a difference		
Lack of clarity over what was meant by a health passport, which might be valued but rarely used		Works conducted by UP (WP 1.2)
During transition, no evidence of any effect on outcomes of 'having a transition plan', 'attending an age-banded clinic', 'being cared for by a coordinated team'; 'being part of a service with a transition manager for clinical team'; 'having access to holistic life-skills training'		Analysis of longitudinal data (WP 2.1)
Over the duration of the longitudinal study, no evidence of any effect on costs or health related quality of life of 'having a transition plan', 'attending an age-banded clinic', 'being cared for by a co-ordinated team'; 'being part of a service with a Transition manager for clinical team'; 'having access to holistic life-skills training'.		Analysis of costs and EQ-5D data in the economic analysis (WP 2.3.2)

4 Limitations and strengths

Loss to follow-up may have led to biased estimates if those lost to follow-up differed systematically from those who were not. For this reason, we did not conduct an analysis of completers only (i.e. those for whom data at all four time points was available). On the factors for which we had data, there was no selective attrition except for a suggestion in those with cerebral palsy that more socio-economically deprived young people were likely to drop out.

A second concern was whether the HRQoL instrument was sufficiently sensitive to capture an influence of PBFs. The study was not powered on the EQ-5D-Y but rather on the outcomes used in *WP 2.1*. We did have sufficient power to identify clinically significant changes in the EQ-5D-Y but, for analysis by condition, sample size meant that some real effects of difference may not have been detectable. In relation to the PBFs, power was limited if a feature was often absent.

Alternatively, the HRQoL instrument might have been sufficiently sensitive but follow-up time was too short to capture any influence of PBFs.

The DCE suggested that experiencing some of the PBFs might increase young people's engagement with health services, which in turn might alleviate longer term harms (and costs) due to inadequate healthcare. The economic evaluation was exploratory and only compared services with individual PBFs to a service with no PBFs. Therefore, no probabilistic sensitivity analysis was conducted as is normally recommended for health technology assessment type economic evaluations and a quantified estimate of the effect associated with various combinations of PBFs was not possible. Therefore the economic conclusions should be interpreted with care.

It was necessary to annuitise the cost data for participants to compare with the EQ-5D-Y data. Thus, certain costs for participants for items mentioned occasionally but likely to apply over the course of the study were calculated as a daily rate following aggregation of the visit data. For example, as insulin prescriptions were not consistently reported in the data, these were costed separately according to existing literature and then inflated to the current price year. We think this made best use of the available data and is unlikely to have distorted the results.

The data collected on outcomes, costs and health service use were complex to interpret because there was loss to follow up, differing healthcare transfer arrangements and the intervals between the annual visits by the research assistants were not always one year (young people have a lot going on in their lives and often visits had to be rescheduled). Strict econometric modelling, despite considerable efforts, proved intractable to undertake. A less robust exploratory analysis was adopted. This drew out some key implications and generated a balance sheet. This was not wholly in concordance with some conclusions from other parts of the Programme, but triangulation of findings allowed key consistent conclusions and implications to be identified and reported.

Appendix 8 Introduction of developmentally appropriate health care

In this appendix we present a draft of a paper submitted for publication.

Report WP 3.1 Introduction of Developmentally Appropriate Healthcare

Normalising Developmentally Appropriate Healthcare for young people in hospitals: commitment, practice and inequity

Introduction

Adolescent health is a neglected yet pressing global issue²¹¹ affecting the largest generation in human history.²¹² Internationally, and in the UK, there is now increasing recognition of the importance of providing quality healthcare for the specific biopsychosocial needs of adolescents and young adults. One key challenge to addressing and researching this issue is the variable status of adolescent medicine across countries. Within the UK adolescent medicine is not a recognised medical speciality. Youth-friendly health care¹⁰⁴ has been promoted as a way to enable improvement of health services for young people. This concept has been used to underpin quality of care¹⁰⁵ and policy^{94, 213} frameworks. However, as highlighted by the World Health Organisation (WHO), there is the need to move from the ad hoc provision of adolescent-friendly projects and services into adolescent-responsive health systems that can respond to the priority health and development needs of all young people.¹⁰⁶ Health care needs to respond to adolescents' and young adults' changing developmental needs. This provision needs to be consistent and universal, provided across all areas of the health care system. Such youth-responsive health systems need to focus on how health care professionals engage and communicate with young people in the consultation through to how services are planned, organised, delivered and commissioned. Developmentally appropriate healthcare (DAH) for young people^{3, 4} is one concept that could underpin a youth-responsive health systems.

DAH has been described as a key principle underpinning the practice of adolescent medicine.²¹⁴ It is about making health care work for young people by recognising their changing developmental needs and the role of health care in addressing and supporting these through adolescence and young adulthood. It focuses on biopsychosocial development rather than chronological age. Each young person will make this journey to adulthood in a way that is unique to them and young people's development does not have a fixed time frame attached to it. Many of these developmental milestones will be met after reaching the legal age of adulthood.

DAH services with particular reference to adolescents and young adults have been reported nationally and internationally as a key mechanism to improve health outcomes for young people²¹² and national guidance in the UK now specifically refers to the need for provision of DAH for young people.¹⁴ Alongside this, the increasing knowledge surrounding adolescents' and young adults' development²¹⁵ offers unprecedented opportunities for service improvement. Existing approaches that draw on the concept of youth-friendly health care need to be reframed and extended. DAH offers an opportunity to transform traditional models of healthcare delivery, to create youth-responsive health systems. However, in spite of the existing evidence base and guidance, sub-optimal provision of health care for adolescents and young adults continues.^{106, 212}

There has been a range of ways that the concept of DAH has been operationalized in the medical literature.³ We have shown that clinicians and managers directly involved in the provision of health care for adolescents and young adults in three UK hospitals have different ways of making sense of the concept.⁴ In this paper, we focus on the normalization¹⁰⁹ of DAH for young people within three UK hospitals. We explore the ways that people and services attempted to implement a more youth-responsive healthcare delivery.

Methods

Initially a scoping review¹⁰⁷ was conducted to explore the use and meanings attributed to the concept of DAH for young people. Articles were subjected to manifest and latent content analysis¹⁰⁸ in order to identify preliminary patterns and to explore the core ideas attached to concept.

A qualitative multi-site ethnographic study was then conducted across three hospitals in England: a district general hospital, a paediatric tertiary hospital and an adult tertiary hospital. Health professionals (HP) were recruited through six medical and surgical specialties chosen to represent the heterogeneous services found in UK National Health Service hospitals: Diabetes; Emergency Care; General Paediatrics; Outpatients; Rheumatology; and Trauma and Orthopaedics. In addition, some HP were recruited during the course of the study through other specialties (Endocrinology, Cardiology, Oncology and Respiratory), departments (Chaplaincy, Psychology, Radiology, and Youth Work) and settings (training sessions). Managers (MA) were recruited at each site when their roles were relevant to the provision of services for young people in paediatrics and/or adult care.

The Interview guide is at the end of this report.

Data collection took place over three phases, between June 2013 and January 2015. Recruitment was initially mediated through gatekeepers, then a mixture of snowball, criterion and theoretical sampling was used to recruit further staff. 192 participants were recruited. Approximately 1600 hours of non-participant observations were conducted, alongside 65 formal qualitative interviews (See Table 39). Observations were recorded in contemporaneous field notes. Formal interviews were audio-recorded, transcribed, edited to ensure respondents anonymity and then analysed alongside anonymised field notes.

Table 39: Participants recruited for the study by site, type of staff and method of data collection

		District general hospital	Paediatric tertiary hospital	Adult tertiary hospital	Total
Participants observed	Health professionals	65	27	11	103
	Managers	57	0	15	72
	Total	122	27	26	175
Participants interviewed	Health professionals	13	18	10	41
	Managers	13	6	5	24
	Total	26	24	15	65
Overall participants	Health professionals	78	45	21	144
	Managers	70	6	20	96
	Total	148	51	41	240
Number of participants who were both interviewed and observed		39	5	4	48
Total number of participants		109	46	37	192

All analysis was conducted according to the standard procedures of rigorous qualitative analysis.⁸⁶ We used procedures from first-generation grounded theory - coding, constant comparison, memoing⁸⁷ - and from analytic induction, deviant case analysis.⁸⁸ Data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored in subsequent ones. We undertook independent coding and cross checking, team data sessions and member validation with some of the participants in the fieldwork. The analysis was theoretically-informed by Normalization Process Theory.¹⁰⁹

Findings

Diverse values and commitment

As we have outlined elsewhere,⁴ there was a wide variety of definitions of DAH across clinical and managerial staff in all the sites. Some did not recognise it as a concept, for some it made little sense and for others it was difficult to conceptualise, it is 'a bit amorphous'. Many focused more on the need to create a more age appropriate environment, in terms of the physical space, the visual and material culture of waiting room and wards (e.g. age appropriate leaflets and computer games). Others, especially those who did some work with young people, often discussed 'the medical bit plus all the extras', outlining a wide array of features, including aspects like developmentally appropriate communication, norms around confidentiality and a more holistic focus. As one manager noted:

the young people have told us that, um, we need, they're not bothered about where they are seen so, as in, what the building's look like or what the clinic room looks like. They want to make sure that they see somebody who's interested and who knows what their disease is like, but also has an awareness of all the other stuff that's going on when they're 16 to 18, as in their, the, sort of, the physiological bit of just being a normal teenager and what happens.
(MA, General)

This manager's view is intimately informed by working closely with and listening to the experience of young people. At this site, there were a variety of ways in which young people were involved in the provision of services for other young people as well as research. Recruitment of young people was often done through various channels within the hospital, for instance via the posters and leaflets which adorn the walls. Centrally, involvement at this hospital was considered to be part of patient experience, and it was mentioned that young people were involved in doing things such as helping to design books about the patients' journey, as well as sitting in on governance meetings and helping with the training of staff. In this way, young people's experiences were a central resource in helping to shape their understanding of appropriate service provision.

Alongside the different understandings of the purpose of DAH, there were conflicting views on the value and worth of enacting it across the organisations. The numbers of young people accessing health services were often portrayed as quite small, so in organisational terms they can become 'just below the radar'. In contrast to older, and especially elderly, patients, they were also positioned to often be 'very rarely unwell'. For some, this raised questions about whether a focus on young people is legitimate.

the trouble that we still have is that it's seen as a paediatric problem. It's not recognised as an adult medical issue, uh, because it's a small number I think. ... [for example] when you've got 10, at most, per year coming through with complex health problems. Why do they have to set up a separate service for them? Or why do they have to change the way that they work? Um ... because they don't come into contact with them that, very often (HP, General)

In this way, the 'small number' argument, in both paediatric and adult contexts, led some to question whether they, or others, should be adjusting their practices or offering distinct, more tailored, services. Relatedly, there are always competing demands for resources, time and expertise.

It's small enough [numbers] that if you don't, if you don't buy into it, there's plenty to be getting on with the other 90%. And everybody's jobs are so frantic that you could easily do a very good job with that 90% who are 25, 26 plus. You wouldn't be short of things to do, do you see what I mean? So, you could actually ignore these young people completely.

(MA, Adult)

Individuals can, at times, choose not to buy into such work. Questions of legitimacy and buy-in, or rather, enrolment, are central to individual, team and organisational change.

In part, this lack of capacity and willingness seems to be compounded by the liminal status of young people within the organisational and professional culture of the UK healthcare system: 'adults don't really want them because they are too young and the paediatricians don't really want them because they are too old' (HP, General). Adolescent medicine is not a distinct profession, 'still considered as somewhat of an add-on'. Albeit with the exception of charity-supported oncology wards, adolescent only wards, or spaces within wards, were rare and often temporary affairs subject to dissolution given competing demands across all three sites. This is also reflected in management terms.

there isn't a designated clinical lead for adolescents or a designated board member for adolescence. ... you know, who's flying the flag high up for adolescents? I don't know.

(MA, Paediatric)

None of the sites had a senior clinical or management lead for young people. However, across all the sites we did observe a complex network of adolescent minded practitioners. We frequently either meet with, or heard about, people acting as adolescent or young people 'enthusiasts', or 'champions', within specific clinical or management teams in either a formal or informal capacity. In this way, specific services and practices were organised around the care of young people. However, relying on the enthusiasm and willingness of specific individuals can become problematic.

several people have left, who have been very senior members and very adolescent minded and have been replaced by either rotational posts or part-time posts, so that continuity within our team and the wealth of expertise has been impacted on significantly. (HP, Paediatric).

In this way, a focus on champions raises key questions for people about the sustainability of services for young people over time.

Across all three sites, we found a variety of definitions of DAH, alongside conflicting views on the value and worth of enacting youth orientated care across the organisations. For some, a focus on young people is questioned, given the contexts of small numbers and competing demands. Such a view is compounded by the liminal status of young people, given the lack of professional and managerial roles focusing solely on young people. Across all the sites, young people's champions, be they working in a formal or informal capacity, were key in getting people involved in the care of young people. However, people were aware of the practical problem of relying on key individuals. For them, it should be 'about consistency of approach, not a person', about developing local cultures of good practice within and across teams and clinical spaces, that can withstand changes in specific personnel.

Informal cultures of good practice

As one manager, with clinical experience outlined

'Transitions, probably, um, suggest a process where Developmentally Appropriate Healthcare suggests a philosophy' (MA, General).

Across all three sites, we observed local cultures – in teams, clinics, wards and meetings - where they attempted to enact both a set of processes and philosophy of care towards young people. They were driven by an awareness of how approaching young people in a different way can mean that they 'might take the right messages away, might not end up neglecting their health needs, damaging themselves' (MA, General). For these professionals working with young people required a specific mind-set and skill-set.

At its simplest level this often involved the ability of the professional, or professional across an MDT, to communicate effectively, listening carefully to young people about their health needs and asking them questions, often tied to the dimension of the HEEADSSS assessment tool,²¹⁶ about their broader social situation in order to determine how these fitted together. It was an approach that centred on going beyond strict medical issues or focusing solely on chronological age, to consider a range of psychosocial issues impacting the young person given their stage of development. As such, care is contextualised with a wide variety of information surrounding the patient's life, including educational, vocational, social, and friendship and family issues, exploring the normal 'risks' a young person faces. Such information is used by teams to generate an appropriate context for effective communication or to organise consultations in a particular way, including appropriate health education and support for self-management.

Providing an appropriate service for young people is often a deeply rooted value for these individuals and groups. The 'You're Welcome Quality Criteria'⁹⁴ were generally well known, including core issues such confidentiality and consent, joined-up working, transition and accessibility. So, for example, some schedule some of the clinics to start in the afternoon and extend them into the evening to enable young adults to arrange their appointments to suit their college or work schedule. Within the context of adult care, DNA was a prevalent issue in some of the clinics. Ways of dealing with this seemed to vary from clinic to clinic and across organisations, as policies regarding DNA may vary. However, we were told about what was referred to as, 'a softer approach to the DNAs'

The Trust ruling of one strike and you're out, we don't adhere to, so we will give them multiple attempts to come into clinic ... since as we don't actually put them as a DNA, because they just booked in [the consultants] calendar but we don't actually book it on the system so they don't officially come as a DNA ... So I'll make informal appointments with the young people and then, when they arrive we book them into clinic, so that way they don't DNA (HP, Adult).

Working creatively with the existing norms, rules and resources was typical of individuals and groups that had bought into the idea that young people need to be recognized as group with specific needs and approaches.

What we observed across all the organisations was 'lots of great pockets of work' as some specialties, teams, people or spaces seemed to offer very strong young person orientated care. However, not all people or services felt it relevant to make 'special arrangements', but choose instead to treat them like 'an ordinary patient'. Alongside this, the uneven distribution of resources within and across specialties can create inequities of care.

There are ... areas in the hospital who, because they have more funding or they're funded in a different way, they might have a youth worker because it's part of their team and just for their team. They might have a psychologist who is just part of their team, social worker. ... it very much depends on what speciality you're unfortunate to fall into, depending on what illness you've got as to what service you then get. ... So, if you were a liver patient, you've got access to more services that if you were a medical patient. That's not appropriate. ... We should be offering the same service to everybody that comes through the doors. (HP, Paediatric)

However, resources are not the only source of inequities. In part the inequities in skills and experience across the organisations seem to be self-sustaining within organisations. Centrally, those with an interest, the 'enthusiasts', are embedded in an informal network of care.

we've now got a group of interested people across the Trust. So if a young person comes to me and they've got a, a joint problem, but they've also got a bowel problem, I know which bowel consultant and which bowel nurse will be the most appropriate to send them to, which chest doctor, which chest nurse will be the appropriate. Um, so we've got a good group of people across the Trust that we can actually send these youngsters to who've got more awareness of the issues that they could have (HP, General)

In this way, an informal knowledge economy of young person friendly practitioners and practices exists within the organisations. These are networks of trust. These referrals help to create, sustain and reinforce the network over time. This practice also exists across organisations, as practitioners, especially in terms of the transfer of young people to adult services, will seek to refer the young person to specific organisations, clinical teams or individuals over others – as this early field note illustrates:

they refer to known doctors from this or that hospital as being more 'appropriate' or 'adolescent friendly' for the patient being discussed, it's as if they are able to assess the suitability of a professional based on some not evident informal knowledge that I am not aware of at this point. (Paediatric)

Adolescent-minded practitioners refer to other adolescent-minded practitioners – in this way, they work to actively avoid referring young people to those less adolescent minded practitioners. As such these people then gain less practical experience with managing these patients, and so less chance to reappraise their values and commitment to working with young people in new ways, as well as to develop the right mix of skills.

We also see an informal network in terms of spaces, as well as, people. At each site, at least one specific ward was known to offer more young person friendly care. They are seen as repositories of key knowledge and skills, able to manage the potentially unruly, undisciplined, teenage other.

We were getting so much inquiries regarding adolescents from the other wards, even just for the basics. So, they would ring us and say, 'We can't get them out of bed in the morning'. You know, 'they just want to stay in bed all the time and they don't want to interact with anything'. So we would say, 'Well then you have to be stern, you know, you have to tell them, 'This is the plan,' you have to do a contract with them and agree with them that if they get over this time, then they can do this at this time' (HP, Paediatrics).

Such wards were not only required to offer basic advice to teams on other wards, but were also called onto to manage more complex issues. For example, when a young patient was self-cutting, the ward staff panicked and sought to move the patient to the more youth-friendly, or rather youth-experienced, ward.

instead of sort of accepting that everybody has these patients throughout the hospital because this is just another component of young people's care, they are not just a regular like thing, they've got other parts to them as well and about holistic approach. There was quite a bit of panic and, 'This patient needs to get off our ward immediately,' (HP, Paediatrics)

The immediate reaction was to move the teenager. It is not only that 'just different wards have a different tolerance', but rather that different wards and teams, develop, over time, different young-person orientated understandings and different sense of what is legitimate work, as well as young-person friendly skills, competencies and routines.

in some situations, we've had patients on our general wards where the parent has wanted to stay. And we, my nurses, would find that very strange. But actually, in oncology, that would not be strange at all. Because ... [they] would be used to that, even a patient could be 22, 23 and still may want their mum. But they're not exposed to that in the main wards because they only see bits of the journey as well. (HP, Adult)

Centrally, exposure to working with young people was a central resource to enable them to become seen as just another young patient, over a set of unknown and unexpected concerns. Exposure offers a chance to adjust expectations and develop new skills.

Across all three sites, local networks of people, teams and spaces, work to enact services tailored to the specific needs of young people. They work to integrate biological, psychological, social and vocational issues across MDT and offer specific services and spaces for young people. Developmental assessment is used to inform aspects of service delivery and they seek to offer appropriate and timely health education and support for self-management. However, in all the sites, such DAH is unevenly distributed. Some people or services feel no 'special arrangements' are required. Some services are perceived as being overly- or under-invested. In this way, inequities of care for young people exist within each organisation. Informal networks of trust existed within each site, where certain people, teams or spaces were understood as having the right skill-mix, or mind-set, or access to resources, to work effectively with young people. As a young person moves through an organisation, the preference is to direct them to those people and spaces that are known to have an interest in young people. Albeit for good clinical reasons, this can mean that some of the inequities in skills and practical experience across the organisations can be self-sustaining. A lack of meaningful exposure to the care of young people, can also mean a lack of a chance to reappraise values and reconfigure practices.

(In)formal cultures of training

Within each of the organisations there were different ways in which the young people enthusiasts or champions met and supported each other collectively. They took the form of both formal and informal groups. Essentially, these groups were a collective effort to promote initiatives to raise awareness across the organisations, create change, offer support and, importantly, learn from each other outwith their team, area or specialty.

'I have nothing in writing in my job plan that says I specialise in young people. ... The training that I've had is training that I have thought that I need. Nobody said, 'If you want to be a young adult person, you need to go on this'. It's just something that I became aware of through organisations or talking to people. So, it's all quite ad-hoc rather than really, really planned. And it's just really by hearsay and talking to people and networking throughout [this organisation] over many years.' (HP, Paediatrics)

Without any formalised professional routes available to people, the local, regional and national special interests groups became a central resource in supporting young people focused training across the organisations. Training in how to communicate effectively and around the needs of young people was seen to be an important component of effectively delivering DAH as well as an important driver to raise awareness and create change across the organisations.

In two of the sites, the only initiatives involving training around young people that we were aware of originated from their respective special interest groups in the form of yearly organised study days. At one of these sites, there was a policy initiative explicitly around transition, yet no specific training had been organised. It is worth noting that, focusing on young people in relation to transition means a focus on young people with long-term conditions, over a broader focus on the experience of all young people that enter the organisation. At the other, development of a formal policy was said to be 'not a priority for the trust'.

Priorities are the front door, A&E, CDU, waiting times and, it's those things that they are being judged on.

Interviewer: Why do you think this is not a priority at all?

Just because they've got bigger fish to fry ... I mean if you sat them down individually and talk about it they would be very, they are, very supportive. But it's not a priority for the [organization] because of all the other things by which they are measured. And young people's care isn't on that list. (MA, Adult)

In the current context of the factors that drive organisational change at this site, creating further engagement and buy-in from senior management was not seen as a practical solution to enable change. As such, issues about the care of young people remained focused in the informal, organisation-wide group, of young people's champions. As we discovered during our fieldwork, not everyone interested in the care of young people in that organisation was aware of the existence and work of that group.

Even within the group, they were often surprised by the number and range of young person-orientated initiatives that were occurring within the organisation.

However, at one site we did observe specific training around the topic of DAH being planned and delivered. A DAH strategy emerged as the result of the work of a number of key people who sat on a transition strategy group. The group comprised of managers, clinicians and allied healthcare professionals who meet every couple of months and who all had a particular interest in the healthcare of young people and transition. There was strong cross over between managerial and clinical levels and they worked to actively foster communication and create connections across services in order to highlight the issue. In this way, the ideas emerged from the local special interest group, but centrally the dissemination was targeted well beyond the special interest group. Part of this involved looking where change was currently occurring within the organisation and 'where the energy within the Trust at the moment is', alongside the broader national, governmental, agendas on young people's health, in order to harness that momentum and get people involved.

Training at this site was very much linked to the development of a DAH strategy and consisted of 'delivering key messages' from various government policy initiatives, especially the 'You're Welcome Criteria'.⁹⁴ It was positioned both in management meetings and in training sessions as 'just ... good holistic healthcare'.

The focus of the strategy, and concomitant training, was on organisational level factors (e.g. staff appraisal includes training goals around young people; provision of age-banded clinics) clinic and consultation level factors (e.g. signpost sexual health, drug and alcohol services; copying letters to young people) and training and awareness factors (e.g. adolescent development; confidentiality). This programme of training had senior management support, albeit initially from within child health, alongside access to resources. Using money to 'back fill' was seen as a key component in the success of the roll-out of training, as without this, departments would not only be unwilling but also unable to release staff for training. For example, some training sessions, were focused on raising awareness of basic issues.

Last year we did, um, we did ten days, so ten individual day sessions for training in adolescent, basic adolescent health. Basically to increase awareness across the [organisation] so as to make sure it wasn't just the, the chronic illness patients that were being looked at ... but it was the patients coming through A&E, coming through X-ray. And so we had members of staff from all over the [organisation] came on these training days. So it could've been a radiographer taking an X-ray, um, it could've been a nurse in theatre, it could've been a, a nurse in, um, A&E, just to get them aware of what a young person's needs are and why they're different to being an adult [HP, General].

In this way, central norms and practices of good, everyday care for young people were distributed well beyond the local existing networks of people, teams and spaces of young people's champions. The initiative emerged from, and depended on, their enthusiasm and expertise. The network of trust of young person friendly practitioners was then supported by key actors within wider management. This led to an on-going programme that sought to make the young people's healthcare visible across the organization, to begin to get to people to reappraise values and commitment.

Discussion

Our findings reveal the everyday working practices of something like a discipline of adolescent medicine-in-action without a formal professional or organisational status as a 'Discipline'. Across each organisation a complex distributed network of young people minded practitioners understood the potential value and worth of practices and services for young people, such as DAH. These were people committed to working with and for young people, to enacting adolescent medicine, to enacting DAH, within consultations, clinics and wards. Within and across organisations, an informal knowledge economy of young people friendly practitioners, practices and spaces exists. People have a preference for referring to other young people friendly practitioners or spaces, to others within the networks of trust. Such referrals help to create, sustain and reinforce the network over time. Such networks also support and provide, through formal and informal means, the training and development around young people's health.

In this way the concept of DAH is being normalised as networks of people within each hospital make sense, buy-into, enact and reflect on and adapt it. Clearly, the enactment of DAH is fluid - both present and not, both excellent and not - within and across professional, organisational, ward and team boundaries. It is largely sustained and (re)enacted by a distributed network of informal ties, knowledge and practices. However, the very definition of DAH, its organisational and policy relevance and its resource and spatial allocation, are contested issues within and across hospital settings. To move beyond normalisation of DAH for a few, to normalisation for an organisation, we need to move beyond the informal cultures of training and good practice. At one site, providing a trust-wide strategy and training on organisational, team, clinic and consultation level factors as well as training and awareness factors offered such an opportunity. It relied on buy-in and formal support from senior managers in both adults' and children's services to initiate and sustain it over time. The WHO recommendations to achieve adolescent-responsive health systems,¹⁰⁶ highlight the centrality of service delivery and workforce capacity issues to achieve successful integration and consistency of health services for all young people within and across organisations and levels of care.

There is also a need for strong and clear guidelines, strategies and policies on the practical implementation of DAH. At the end of the fieldwork, guidance appeared in the UK around the need to implement DAH in relation to transitional healthcare.¹⁴ However, such a focus on transition and transfer has important limitations. Currently, the guidelines are concerned with young people with long term conditions whose care is planned at the clinic and team levels within a specific speciality. However, not all young people attending hospital services will have a long term condition. Some will follow acute, emergency or surgical pathways. Young people with long term conditions will often experience care in various settings within an organisation, whether that be as an in-patient, out-patient, day-case or in other departments such as radiology, pharmacy or investigation suites. As we saw, normalisation of DAH for a few, introduces inequities. The potential normalisation of DAH around transition and transfer may reduce some inequities, but may sustain inequities in the access and provision of DAH care across an organisation.

Limitations

The selection of ethnographic methodology is a major strength of the study as it facilitated the immersion of the researchers into the organizational culture of each hospital, enabling them to observe and examine the process and practices in context. A limitation was that only three sites in two UK regions were studied. However, a significant number of staff participated and a wide range of settings were encompassed including outpatient, inpatient and emergency care. Furthermore, although the hospitals involved had a history of championing research and innovative service provision for young people, this did not include a defined adolescent medicine service and participating areas and/or specialties were at different stages of familiarisation with providing DAH, thus providing the study with breadth and depth of experience. We think, therefore, that we captured a broad range of relevant views but it is likely that not all were covered. Similar work in a comparator group of hospitals who did not have the same history would be of interest. Other limitations, such as the UK scope of the study and the hospital-based (non-community) sampling of professionals, should be addressed in future research.

Conclusion

Currently there are a wide variety of definitions of DAH within the literature and across clinical and managerial staff. There are conflicting views on the value and worth of DAH. Youth-friendly practitioners and managers, be they working in a formal or informal capacity, are initially key to raising the profile DAH. To move beyond pockets of good practice to services responsive to young people buy-in and formal support from senior managers in both adults' and children's services is central. Providing a trust-wide strategy and training on organisational, team, clinic and consultation level factors is key.

WP 3.1 Interview schedule: clinician manager

Interviews

Implementation of Developmentally Appropriate Healthcare in an Organisation (IDAHO)

Note: The interview schedule is developmental. The questions will be developed from the findings of the observations. The questions will need to be tailored to the specific answers of each interviewee. The interview schedule given here is therefore a general topic guide for the one-to-one qualitative interviews.

Plan of interview

Setting

Staff member will choose setting – mainly hospital room

Introduction

Explain purpose of the study and this interview and that it is the first of two or three.

Explain interview recorded but details will be confidential.

Explore any questions or concerns?

About you

Can you just explain what your role is?

How long have you been working in this role?

What where you doing prior to this?

Definitions

The WHO defines ‘young people’ as those aged 10 to 24 years old, ‘youth’ as those aged 15-24 and adolescents as those aged 10 to 19

What types of distinctions do you make?

How would you define ‘developmentally appropriate services’?

And specifically in relation to young people?

What do you think are the key aspects of developmentally appropriate services for young people?

How would you define Transition?

What do you feel are the key aspects for a successful transition?

Trusts wide issues

Do you feel that the Trust as a whole is particularly young people friendly?

Are young people are priority for the trust?

Are you aware of any Trust wide strategies promoting developmentally health care for young people?

Where did you first hear about them?

Have you heard of the ‘Trust Transition Strategy’?

Has this been discussed in your governance meetings?

Your service

Roughly what percentage of your service provision (in patient /clinic) do young people make up?

Those aged 10–19?

Those aged 16-24?

Do you feel that the in your service is particularly young people friendly?

Are young people are priority for your service?

Is there a ‘young person’s champion’ in the speciality?

Are they formally recognised (i.e. in job description/within Trust?)

Or are they only internally recognised?

Does your service offer specific services for young people?

What are they?

Which of these focus on transition?

How developmentally appropriate do you think they are?

Are you considering developing them?

In what ways?

What’s been successful/unsuccessful?

What do you feel are the key barriers?

What are the key drivers?

Are staff supportive?

What steps have been taken to introduce/further develop services in line with the Trust Transition Strategy?

What's been successful/unsuccessful?

What do you feel are the key barriers?

What are the key drivers?

Do you think the roll out of developmentally appropriate services should be a priority for your service?

What priority should be given to those focused on transition?

Are you aware of the Department of Health 'You're Welcome' accreditation and are you considering using this?

Feedback

Have you had concerns / complaints / compliments about your services for young people?

From young people themselves?

What issues did they raise?

How were they managed?

Did any change happen as a result of this?

Are young people involved in the design and evaluation of your services?

What issues did they raise?

What impact have they had on your service provision?

Training and support

Have your staff had any specific training/CPD about working with young people (as distinct from the care of children)?

How useful did you find it?

Is training ongoing?

What, if any, further training do you feel they need?

Have your staff undertaken the Trust in house awareness raising programme on the needs of adolescents?

How useful did they find it?

Do you know if they apply it in their day-to-day practice?

Finally, we need to understand whether the kinds of questions we are asking actually relate to the issues that you think are important?

Are we asking the right questions?

Did these questions allow you to talk about what was important for you?

Is there anything else you would like to tell me?

Thank you for taking part

Remind them that you will be contacting them about the arrangements for a follow-up interview at some point in the future.

Appendix 9 Commissioning

Report WP 3.2

Authors: Maniatopoulos G, McCafferty S, Bate A, Vale L, Colver A, Kolehmainen N.

BACKGROUND

Work package (WP) 3.2 aimed to contribute to the third objective of the Transition programme by investigating how transitional healthcare should be commissioned.

‘Commissioning’ is the process by which public services are organised and contracted to meet population needs. Commissioners follow a generally cyclical process of: assessment of population needs, setting priorities, developing strategies in line with objective outcomes, procuring services and measuring outcomes.¹¹⁰ The commissioning landscape for health and social care has recently been subject to substantial change. Specifically, changes in policy set out in the Health and Social Care Act which came into force April 2013 and resulted from the White Paper ‘Equity and Excellence: Liberating the NHS’.²¹⁷ Under the reformed system, the NHS Commissioning Board (now called NHS England) was established within the Department of Health to provide national leadership for commissioning healthcare, to allocate budgets to clinical commissioning groups and to commission specialist services (with the abolition of incumbent PCT commissioners and SHAs).²¹⁸

Commissioning has a pivotal role in ensuring the successful transition of young people with CHN from child-centred to adult-oriented healthcare systems. The need for better discharge of this role was highlighted in the Kennedy report,¹² recommendation 32 which stated: ‘Ensuring a smooth transfer between adults’ and children’s services should be a priority for local commissioners’. Further, the Green Paper²⁰⁶ highlighted the importance of successful transitional healthcare and proposed that PRIMARY CARE Consortia and Health and Wellbeing Boards should be supported in their commissioning for young people with disability. Further the complexity of transitional healthcare overall, due to its multidisciplinary, interagency nature, is a particular challenge for NHS Trusts, even when the organisation has the strategic will and resources to develop services. User-friendly, effective and efficient health and social care protocols may have little impact on health outcomes of the young people with long term conditions if the service providers are unable to implement the protocols and/or services in other agencies are absent or inadequate. The Government’s proposal that more public health and social care service commissioning should be undertaken by Local Authorities is a significant opportunity to ensure services for more comprehensive transitional healthcare are not commissioned in isolation from services in other sectors.

NHS England's Draft Research and Development Strategy 2013-2018 has as its first Objective 'To identify and prioritise commissioning health services research topics and co-ordinate this work with the Department of Health, NIHR,'¹¹¹ Research is needed to explore and understand the challenges of commissioning for transitional healthcare, and identify successful commissioning practice and guidance within the context of a restructured combined health and social care service.

AIMS AND OBJECTIVES

Aims:

1. To explore and understand the challenges of commissioning for transitional healthcare, focussing on the explicit and implicit organisational structures, processes and relationships which drive commissioning decisions around transition.
2. To explore and understand what constitutes successful commissioning practice for transitional healthcare and identify lessons to inform guidance on commissioning for transition across the NHS, including CCG's; Local Authorities and Health and Wellbeing Boards.

These Aims were addressed in two stages:

Stage 1: Literature review

Stage 2: Semi-structured in-depth interviews with key stakeholders

Stage 3: Case studies

STAGE 1: Literature review of academic, peer-reviewed papers

A systematic review of academic, peer-reviewed literature relevant to commissioning for transition was conducted. The core bibliographic databases used were: Medline (1996 -), Web of Knowledge (WOK) (1996 -) and Scopus (1996 -). A structured search strategy was formulated using controlled search terms, including free text terms and MESH headings were available. Given the complexity and ambiguity of the terms ‘commissioning’ and ‘transition’, all alternative terms were used in order to be as thorough as possible. Search terms (Box 4) were applied across databases. To ensure that the literature review remained up to date, searches were conducted regularly over the duration of the review from September 2013 to July 2014. The identified papers were reviewed using explicit exclusion criteria (Box 5).

Box 4. Academic literature search

Commissioning search terms

“Delivery of Health Care” OR [(Contract Services OR Contract* OR Commission* OR fund* OR purchase* OR budget* OR plan* OR provide* OR manage* OR procurement* OR assess*NEAR/1needs) AND healthcare]

Transition search terms

Transition to Adult Care OR Health Transition OR transition* OR continuity* OR pathway OR "service mapping" OR transfer*

AND healthcare AND (‘to adult OR ‘from paediatric’) AND (young person* OR young adult* OR adolescent* OR youth OR child*)

Box 5. Academic literature exclusion criteria

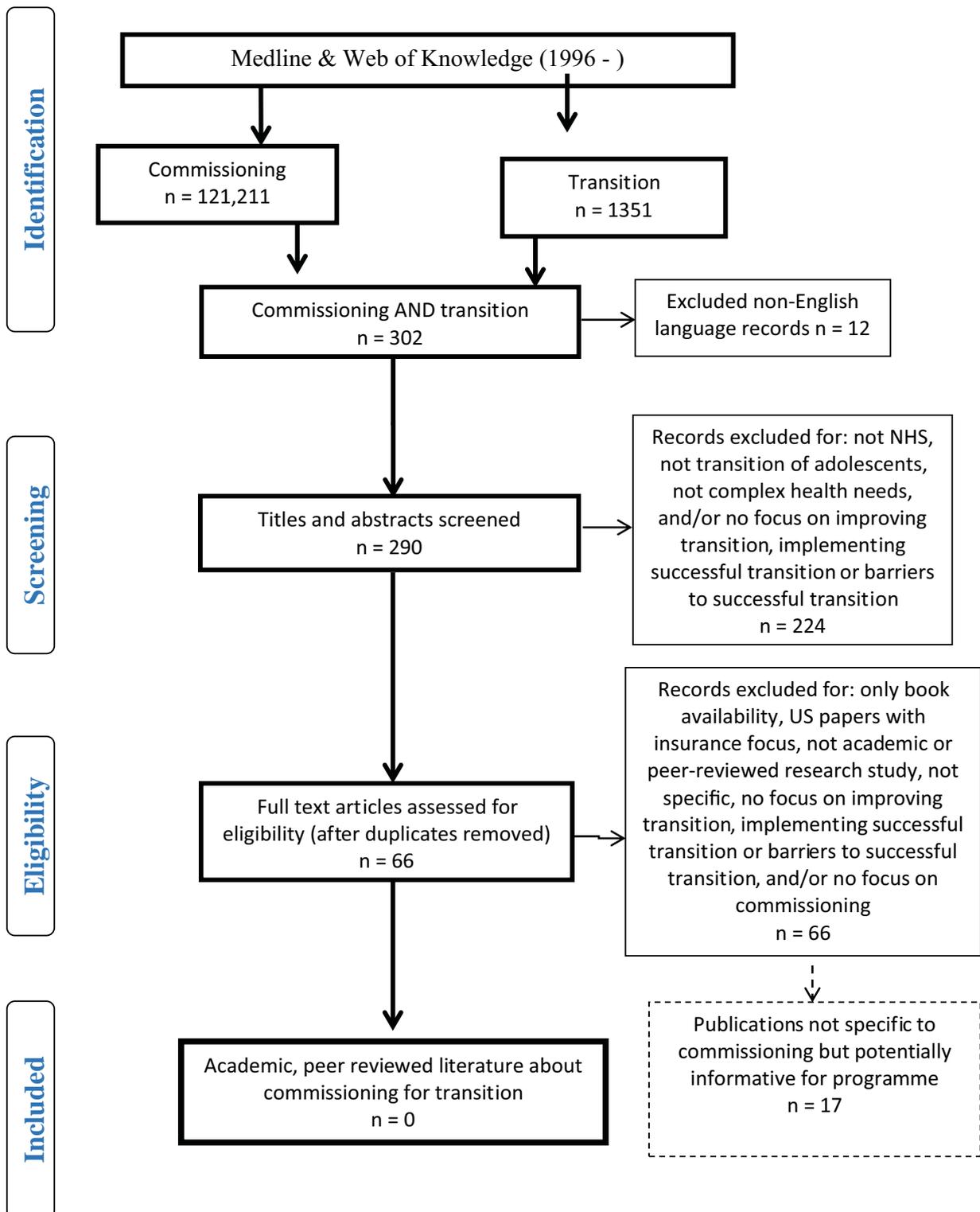
Title and abstract criteria

1. Non-English Language
2. Transitions other than from children’s services to adult services
3. Populations other than young people with ‘complex health needs’ as defined for the research programme
4. Only identify current problems to transition, no mention of approaches to improve transition or barriers to successful transition

Full text criteria

1. It was a book
2. Not an academic or peer reviewed research study
3. Transition papers with no focus on commissioning (or related) processes
4. Focus of the paper not on commissioning or transition processes in the NHS

The PRISMA diagram (Figure 18) shows how the searches of Medline and WOK databases were structured. Separate searches for papers on commissioning and transition identified 302 papers relevant to both topics, which were then screened and assessed for eligibility according to the exclusion criteria. The most common reason for exclusion was that the paper focused only on transition, with no content about commissioning. No academic publications on commissioning for transition were identified. Of the 66 whose full-text was reviewed, 17 were identified as potentially informative for the wider work of the NIHR Programme.

Figure 18: Academic literature PRISMA diagram

Results from the academic literature

Our failure to identify any papers about commissioning for transition led us to undertake a grey literature search which will be presented in the next section. However, review of the 17 papers in the academic literature identified three key themes about barriers to and suggestions for successful transition:

- 1 Consequences of poor transition
- 2 Barriers to successful transition
- 3 Components of successful transition

1 Consequences of poor transition

Two key long term consequences from problems in transition were disengagement of young people from adult services and poor health outcomes;^{37, 155, 219-221} Patients often experienced a gap in care which led to disengagement from adult services due to limited accessibility, non-familiarity and non-adherence to follow-up appointments. Poor health outcomes were both physical and psychological, including: patient non-adherence to post-transition medication and increased anxiety described by parents, carers and paediatricians.

2 Barriers to successful transition

The literature outlines structural and process barriers to successful transition, some of which are likely to have implications for commissioners. Barriers were related to challenges in ‘communication’ and ‘implementation/management’.^{155, 222} Inadequate patient-provider communication and lack of information sharing between providers proved problematic.^{221, 223} Communication barriers also involved lack of appropriate education (between providers)^{37, 219, 221, 223, 224} and lack of cooperation between providers.²⁶ Patients lacked knowledge of self-management and decision-making skills and about how to navigate transition; paediatric providers lacked training in adolescent development and management of transition; adult providers lacked training in paediatric diseases, adolescent development and management of transition. Disagreements and lack of consensus on transition between providers and NHS Trusts led to further complications for management of transition.¹⁵⁵

Challenges for implementation included process barriers, paucity of resources and insufficient evidence.^{37, 221} The challenge of providing a holistic transition process and meeting the needs of a wide spectrum of types of disability were described. Another barrier

was the difficulty in obtaining sufficient funding to allocate resources efficiently for a variety of populations and purposes, such as planning, staffing, infrastructure and training.²⁶ Further research on testing and evaluation of models is needed to support the development of a generalised transitional plan, skill-assessment techniques and appropriate outcome measurement tools.^{155, 219, 223, 224}

3 Components of successful transition

The majority of key issues highlighted in theme 2 are very relevant and addressed by this third theme. Indeed, the literature reviewed provided a number of recommendations that might lead to an improvement of current transition standards, including examples of transition plans and components of successful transitional healthcare. These were related to two key areas: communication/education and planning/processes.

Communication/education

Provider communication barriers may be addressed by increased cooperation between all professionals involved in a holistic transition process and information sharing through written medical summaries.^{155, 219, 223, 224} Patient communication barriers may be resolved by peer support groups or use of new IT opportunities such as texting and social media,^{53, 219, 220, 222} Provider educational barriers could be resolved by development of training curricula.²²² Patient and carer educational barriers could be addressed by the development of multi-faceted education programmes and provision of appropriate resources materials; including: written checklists, health passports, e-learning and skills assessment. This will further enable the development of required self-advocacy skills as more independent patients are noted to be associated with higher transition success.^{53, 155, 221-223}

Planning/processes

Joint transition clinics.^{53, 155, 221-224}

Successful transition plans included ongoing preparedness assessments^{53, 219, 224} and early meetings with adult clinicians.^{53, 155, 219} Successful plans were flexible, personal, appropriately timed and holistic.^{53, 155, 219, 224} The planning and other processes were often enabled by a trained and dedicated professional, variously described as a nominated key worker, transition care coordinator or specialist nurse.^{159, 220}

STAGE 1 (cont'd): Review of grey literature

Grey literature is defined as “information which is produced on all levels of government, academics, business and industry..., but which is not controlled by commercial publishers”. It is more broadly described as material not published commercially or indexed by major databases, e.g. policy papers, discussion papers, briefings not covered in the bibliographic search. The same search terms used for the academic literature were applied wherever possible (Box 5). We hand-searched the following sources: Social Care Institute for Excellence (SCIE), Health Management Information Consortium (HMIC) (Department of Health, Kings Fund), Nuffield Trust, Public Health England (PHE), NHS Evidence (NICE), NHS Institute for Innovation and Improvement, NHS Improving Quality, Health Services Management Centre (HSMC), National Research Register Archive, UK Clinical Research Network, and Google Scholar. These searches were further supplemented using the ‘360 Review’ technique on any key literature, looking at its references, citations and other papers written by same authors. ‘Snowball’ referencing was used to retrieve references cited in key primary research texts. Papers were also retrieved from email subscription, discussion listings, and supplemented by literature obtained within the wider programme of research. The identified literature was screened for inclusion using exclusion criteria (Box 6). The search of grey literature was completed in June 2014; we decided to keep the search open and update it throughout WP3.2 up to July 2016.

Box 5. Grey literature search strategySCIE search terms

‘Commissioning for Transition’ – simple search box didn’t permit combining terms with ‘AND’ / ‘OR’ in same manner as Academic database search.

HMIC search terms**‘Commissioning’ control vocabulary selected:**

Locality Commissioning OR General Practice Commissioning Groups OR Practice Based Commissioning OR Commissioning Agencies OR Hospital Commissioning OR Lead Commissioning OR Commissioning

AND

‘Transition’ control vocabulary selected:

Palliative care OR "Quality of patient care" OR Patient transfer OR transition to adult services OR Mental health services OR Learning disabilities

AND

Management practice OR Primary Care Trusts OR Healthcare OR Primary care OR Organisational culture

AND

‘Adults’ or ‘Young People’

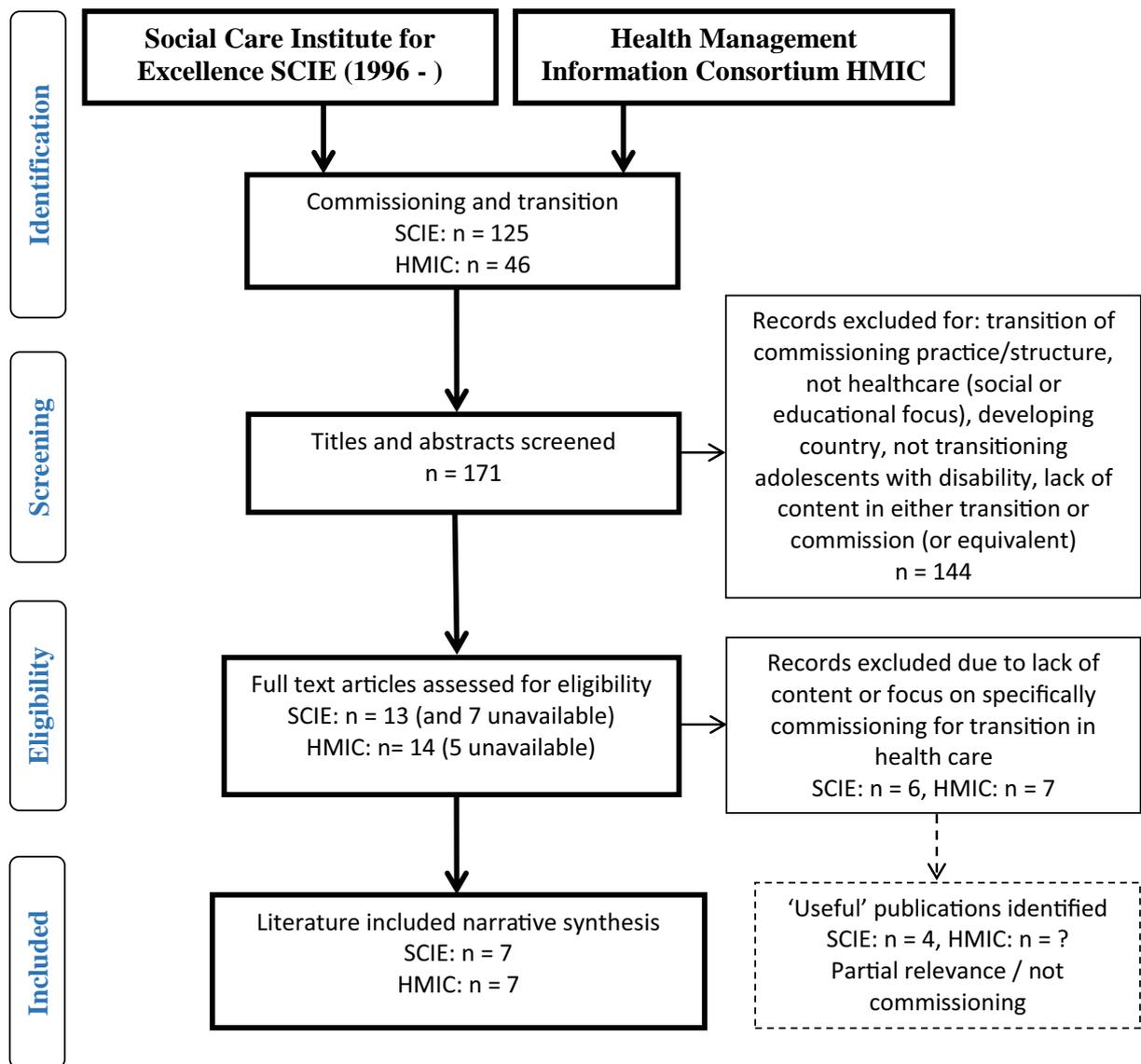
Nuffield Trust and PHE search terms

Hand searched publications on website under Commissioning topic where possible

Box 6. Grey literature exclusion criteria

1. Non-English Language
2. Non-comparative health care system – developing countries
3. Older populations
4. Lower grade cases, or non-disability cases e.g. dentistry
5. Lack of commissioning or lack of transition content
6. Only book availability
7. Focus of the paper not on commissioning or transition processes in the NHS
8. Lack of focus on health care (purely social or educational services)

Figure 19: Grey literature PRISMA Diagram



Results of grey literature review

This review identified two main areas with evidence:

1 Commissioning

2 Organisation and delivery of care

1 Commissioning

Within the grey literature, no specific policies relating to commissioning for transition were identified. However, we identified some key themes from policies with a focus on improving outcomes for children and young people, key delivery plans with a focus on personalisation of care, and some commissioning guidelines. Together these themes may provide useful insight into some of the issues which may be relevant for commissioning for transition.

The four themes related to commissioning were:

Transition protocols

Clinic structure

Funding

Co-ordination

1.1 Transition protocols

Recommendations were made by the Department of Health for robust or a 'successful and consistent' transition protocol.²²⁵⁻²²⁷ There is currently a lack of joint planning and commissioning and the need to improve this, specifically between children and adult services, was recognised. In order to facilitate this the key responsibilities of commissioners were described as: (i) developing service specifications based on local needs assessments; (ii) stimulating the market place to fill identified gaps in service provision and (iii) stimulating providers to provide best practice services based on research evidence.²²⁷ CQUIN (Commissioning for Quality and Innovation) was suggested as a mechanism to aid effective commissioning practice.²²⁵ Further, the need for a transition protocol to embed the principles of personalised planning as part of the personalisation agenda was highlighted.²²⁶ Finally, there was a practical suggestion that the management of transition in hospitals, primary care and community care should be factored into the overall rating which is calculated as part of CQC inspection models, in order to incentivise improved performance.

1.2 Clinic structure

The ‘age conundrum’ was identified as a barrier to successful transition.²²⁵ This means that at age 18 a young person is treated in adult services but for children and young people with complex health needs, including learning difficulties and mental health difficulties, this is not necessarily the most developmentally appropriate age to transfer to adult health care providers. Further, age boundaries were perceived to be set arbitrarily and as such considerable variety and inconsistencies existed between different services. There was a variety of suggestions about how this ‘age boundary’ challenge might be addressed. Some suggested a distinct young person’s service, e.g. spanning age 14-25; whilst others suggested a flexible approach to managing transition within the existing structures.¹³ Development of young person focussed services in the community were also suggested to provide additional support for children from 11-25.²²⁸

1.3 Funding

With respect to transition funding, resources were noted to be lacking, and funding arrangements complex. There was at least one suggestion that early investment now would release resources in future

Funding for transition was noted to be complex, fragmented and often not clear. In order to improve this it was suggested that funding responsibilities for equipment and short-term breaks should be agreed earlier between commissioners and providers in order to avoid delays during transition.¹³

Current funding for adolescent health and social care was deemed insufficient, particularly with respect to developmental disorders and mental health, where workloads were perceived to be rising amidst inadequate staffing and resources.²²⁵

Upstream investment, in terms of commissioning of evidence based preventative measures, and early stage intervention in children and young people services were advocated. This shift in investment was cited as having the potential to enable the child or young person to receive appropriate services more swiftly and for a shorter time and as a means to future savings.²²⁵

There may be few services suitable for young adults (e.g. a lack of age appropriate short break facilities, few chances of meaningful employment, few residential places that can take

young people with very complex health needs and few health specialists with a holistic approach to a young person's care.²²⁷

1.4 Co-ordination

Appleton (pages 11, 18-23)²²⁵ argues that effective commissioning practice: depends on important relationships between key groups. "Engagement between commissioners and local clinicians, as well as with young people and their families will be increasingly important in the new commissioning environment. Building relationships has been highlighted in a number of reports as a critical factor in successful transition planning. Commissioner's interest and support for CAMHS and AMHS working together and in partnership with other services are essential". "Commissioners can help services to join up by facilitating a local Transitions Forum, including representatives from CAMHS, AMHS, the voluntary sector and service user groups to review and monitor transition protocols, and provide an arena for debate and service development".

"Current commissioning models often place CAMHS commissioning and AMHS within different frameworks, structures and organisations. Not facilitated joint working across the two sectors and has not enabled a sharing of ideas and solutions. As a result, separate service development has taken place that has not properly addressed the issues relating to transition" (Appleton²²⁵ Pages 10 & 11. "Commissioners should ensure that joint agency planning and commissioning takes place to enable the development of person centred, co-ordinated and integrated packages of care and support for children and young people, to enable smooth transition to adult services and avoid crises".²²⁹

2 Organisation and delivery of care

2.1 Transition plan (TP)

Transition planning, stated and updated in a document shared with the young person, was recommended by the Department of Health and the Care Quality Commission to start early and continue if necessary into adult care. It will be tailored to the needs of young person and family and be age and developmentally appropriate. It was advised that TP should also include education, social services and voluntary agencies as active partners.^{13, 227, 229}

Transition planning is not happening everywhere and opportunities are being missed to focus on employment and housing options at an early stage, for example by embedding career planning in person-centred transition pathways.²²⁶

There is debate about whether a health passport is implied in a TP or whether it should be a separate document.^{13, 230}

2.2 Primary care involvement

It is acknowledged that primary care should take a more active role in transition care for young people.

2.3 Key worker

A key worker is a person who assists an individual to negotiate transition.

A number of papers recommend that patients should have a key worker.^{13, 229, 230}

Co-ordination of transitional healthcare is critical and, if this does not already exist, a key worker is ideally placed to oversee a young person's transition, ensuring links with a counterpart within the receiving adult service".²²⁷

2.4 Transition manager for clinical team

A coordinator is a person working in a service that involves Transition, who works at a managerial level to ensure effective processes such as reminding young people by text of forthcoming clinics, ensuring transition plans are drawn up etc.

Named leader to coordinate, best practice must be followed.^{13, 229}

2.5 Holistic care

Key characteristics of an effective holistic transition process include: young person centred, wide age range, informal, flexible, voluntary, confidential, free, independent, early intervention, continuity; support of multiple needs (emotional, mental, personal, physical, social welfare, practical, safeguarding etc.), with complementary interventions delivered under one roof.

Transition is likely to include arrangements for: Independent living, employment, health and social inclusion.²²⁹

The National Autistic Society lists a range of services commissioners might consider funding.²³⁰

“A comprehensive local Children’s Palliative Care service spans health, social care and education. It is a whole-family approach and has the following characteristics: It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions children’s to adult’s services. It ensures review of the care plan at key points in transition”.²³¹

2.6 Effective coordination

The Department of Health recommended that there be a transition lead in every region to support the delivery of a regional multi-agency transition strategy, supported by an implementation group involving all key stakeholders, in particular young people and their families.²³²

CCGs and Local Authorities must listen and learn from young people and their families’ experiences.¹³

One of the five ambitions of the NHS pledge - NHS Mandate for 2014/15 is that “services will be integrated and care will be coordinated around the individual, with an optimal experience of transition to adult services for those young people who require ongoing health and care in adult life.”²²⁸

STAGE 2: Interviews with key informants

Design

Semi-structured in-depth interviews with key stakeholders directly involved in commissioning at two sites in the North East of England. The interviews focused on informants' views about what successful commissioning for transition should look like; how commissioning for transition is currently undertaken; and what the barriers and enabling factors to successful commissioning for transition are. NHS Research Ethics (REC) guidance deems interviews with NHS staff to be 'service evaluation' and therefore this part of the research did not require approval from NHS REC. The researcher, SM, obtained a research passport from a local NHS Research and Development Office, and a letter of access from each NHS Trust prior to conducting interviews. We obtained ethics approval from Newcastle University Faculty of Medical Sciences Ethics Committee (ref: 00767/2014).

Sampling and recruitment

Interviewees were selected using a mixture of purposive and snowball sampling methods. The study steering group members were asked to nominate potential interviewees according to role/involvement in commissioning for transition, including representation from CCG, Health and Wellbeing boards and Local Authorities which commission services from the lead NHS Trust, as well as with local general practitioners and the third sector. The nominated interviewees were considered for participation based on their job title. Interviewees who agreed to participate were then also invited to nominate further participants.

We anticipated that around 25 completed interviews would be required to reach theoretical saturation and coverage of a range of views and perspectives at various organisational levels, but we were prepared to conduct more or fewer interviews as necessary. During recruitment, 46 potential interviewees were emailed a letter inviting them to participate. If no response was received to the initial contact then a maximum of three follow up attempts were made by telephone. Where participants declined to participate and provided a reason for declining, the reason was recorded and they were asked to nominate another potential interviewee to participate in their place. Recruitment was continued until new data no longer added content - i.e. to the point of saturation.

Participants were asked to sign a consent form giving permission for the interview to be recorded and transcribed, and confirming that they had read the information sheet. Before asking participants to give informed consent, they were provided with the opportunity to ask questions about the study, or seek clarification on any issue arising from the information sheet.

Data collection

The interview schedule was developed using a modified critical incidence technique, and was informed by grey literature and conversations with the research team and the WP3.2 Steering Group. The schedule was designed to encourage the participants to reflect on successful and unsuccessful practices for commissioning for transition, and to cover topics such as: i) interviewees' perceptions of the organisational structures, processes, relationships, barriers and facilitators related to commissioning for transition throughout the whole commissioning cycle, and ii) interviewees' perceptions about the relative influence of policy drivers, past relationships with providers, and external influences on commissioning for transition. The wider research team and Steering Group commented on the schedule. The schedule was further refined in the course of conducting the interviews, based on preliminary analyses.

The interviews were conducted by the second author in a setting chosen by the interviewee, either face-to-face or by telephone. They lasted from an hour to an hour and a half, were audio-recorded verbatim and later transcribed. Data were collected from 22nd April 2014 to 28th August 2014.

Data analysis

The transcripts were analysed using framework analysis. In framework analysis the researchers' initial assumptions are articulated as an initial conceptual framework – this includes assumptions based on any literature read by the researchers and experiential knowledge of the topic. This framework is then expanded and modified, in iterative cycles, throughout the data analysis using the themes emerging from the study. This cyclical process produces a cumulative, refined framework that integrates the initial conceptual framework and the results emerging from the study data.

Researchers from different disciplinary backgrounds and with different expertise contributed to the data analysis. This included the researchers directly involved in the data collection and analysis: Maniatopoulos (GM)-sociology, organisation and management; Kolehmainen (NK)-NHS clinical practice, childhood disability, and implementation science; McCafferty (SM)-healthcare commissioning, health economics. It also included the wider research team Colver-Paediatrics; Le Couteur-Child Psychiatry; Vale-Health Economics; Reape-Health Services Management; and the WP 3.2 Steering Group. The deliberate involvement of the diverse

expertise within this wider research team allowed a nuanced, multifaceted analysis and reconciliation of any tensions in the coding and concepts. The analysis consisted of the four steps which form the framework analysis method:

1 *Familiarisation*: two researchers (GM, NK) familiarised themselves with the data by reading through a sample of transcripts until they felt they had developed an initial sense of the data.

2 *Identifying the initial coding framework*: three researchers (GM, NK, SM,) independently recorded their initial impressions and any deductive themes. Two researchers (GM, NK) then met to discuss these initial impressions; to relate them to their previous knowledge and expertise; and to agree the initial conceptual framework. This process was subsequently repeated for six rounds, with the two researchers reading further transcripts between each discussion round. The discussions consisted of the researchers talking through the emerging issues and themes and relationships between these, and agreeing themes, codes and relationships which were added to the framework. Through this, each round resulted in a refined version of the framework, integrating and dividing themes, and clarifying the concepts in the framework.

3 *Indexing*: Once the framework became stable (i.e. few modifications were required on each round), one researcher (GM) used it to 'index' the remaining transcripts one by one. This involved the researcher 'sifting and sorting' the remaining data and allocating these data into the coding framework. The researcher took notes of any changes to the framework and issues, and these were discussed with a second researcher (NK) to agree further elaborations to the framework. This process was repeated until all data were indexed and the final framework agreed. This final framework summarises the study findings as the "conceptual model to illustrate the process of commissioning for transition" (aim 3 for the overall the work package, see above).

4 *Charting*: Data from the transcripts were summarised according to the themes and codes (i.e. categories) to reduce the data while carefully retaining the original meanings of the interviewees' words. References to illustrative quotations were tagged and managed using Microsoft Word and NVivo10.

Quality assurance

A range of recommended quality assurance techniques were employed to ensure credibility, transferability, dependability and confirmability.²³³

Credibility

- During the data collection, contact was established through demonstrated interest in the responses, attentive listening, understanding and respect for what the participant says.²³⁴ The sequencing and posing of questions was carefully considered, and was dynamic so that the questions promoted positive interaction between the participant and the interviewer and stimulated the participant to share their experiences and points of view. All interviews included an opportunity for participants to comment on any topic covered in the interview, or any new topic which they felt was relevant.^{218, 234-236}
- Triangulation: accounts between participants and across two regions were compared and contrasted by the two researchers described above (GM, NK).
- Member-checking: the themes and their content were shared and discussed with the WP3.2 Steering Group.
- Frequent de-briefing: study progress, methods, emerging themes and any issues were reported to and scrutinised by the research programme senior team at regular intervals.

Transferability

- Reporting of the sampling frame and criteria (see above), and the key population characteristics (see Results).

Dependability and confirmability

- Involvement of several researchers helped to ensure that the framework was adapted to reflect the data rather than making the data 'fit' the framework.
- Involvement of new researchers (GM, NK) in the data analysis encouraged further peer examination through critical discussion.
- Audit trail: researchers kept field notes (SM) and a logbook of data analysis (GM), and established an electronic data analysis and synthesis trail of the development of the themes (GM in Word, NK in NVivo).

Results

Overall 29 interviews were conducted (see Table 40). Participants covered a range of roles relevant to commissioning for transition across CCGs, Health and Wellbeing Boards and Local Authorities, local general practitioners, and the third sector.

Table 40: Summary description of the participants

Region	Participant role in commissioning process	Employer
North East of England	Commissioners at different levels of seniority, and related managers (n=4)	Local Authority, Commissioning Support Unit, CCG
	NHS Directors (n=1) and senior clinicians (n=2)	NHS
	General practitioners (n=2)	
	Transition planning workforce (n=2)	Local Authority
	Regional Coordinator	North East Autism Consortium
Bradford	Commissioners and related managers at different levels of seniority, and related managers (n=3)	CCG, Commissioning Support Unit
	NHS clinician (n=2)	NHS
	General practitioner	
	Transition managers and co-ordinators (n=4)	Local Authority
Other regions	National clinical leader (n=2)	NHS England
	NHS clinical leaders (n=3)	Birmingham Mental Health NHS Foundation Trust Sheffield HSCT
	Voluntary sector leaders (n=2)	The J's Hospice, SNOOP

Definition of successful transition

No agreed definition of successful transition care was reported in the participants' narratives. However, some key characteristics of successful transition care emerged. These included that transition care should: (i) be personalised, (ii) be planned, co-ordinated and collaborative, (iii) focus on broad developmental and life participation outcomes, (iv) build pathways from children services to adult services, rather than just relying on individual care packages, (v) ensure co-ordination and continuity of relationships and knowledge across sectors and life domains rather than just a simple transfer of the young person from one service to

another, (vi) use universal services such as primary care where possible, with tailored enhanced support where required.

Box 7. Selected quotes about perceived characteristics of successful transition care

Personalised, planned, co-ordinated, collaborative and with focus on broad outcomes:

“(...) what all the legislation is telling us, and all the national direction is about, is about personalisation. (...) if we start doing, planning for outcomes. (...) [in current practice] we keep on just focusing on the here and now. What we should be doing is (...) predict what the needs will be in the future (...)” (Commissioner/related manager 1, North East of England)

“(....) a smooth journey and needs met. (...) the much wider picture. So your health needs will impact on your employment outcomes or your education (...) and what you do with your aspirations within your community (...) there’s an introduction to that new service, there’s someone to coordinate that arrangement (...)” (Member 1 of transition planning workforce, North East of England)

“(...) I think successful transition (...) has to be addressed and introduced as a concept at the age of 14+ school review (...) then the families, and the young people, and the professionals begin, hopefully, to develop some type of joint work between them. So successful transition has to start early. (...)”. (Voluntary sector leader, Third sector, Other regions)

Builds pathways, ensures continuity, and uses universal services:

“(...) if the systems were right, so if you had children’s services interfaced properly into adult services there was a clear pathway (...) children would just sort of flow through (...)”(Commissioner/related manager 1, North East of England)

“(...) a successful transition is where the person undergoing transition has the change of care seamlessly, without any interruption in their therapeutic relationship, in their treatment strategy, and in their engagement. (...) the aspects of continuity, information continuity, relational continuity, therapeutic continuity.” (NHS clinical leader 1, NHS, Other region)

“(...) this concept of universal (...) you might have somebody who’s complex and needs CAMHS and learning disability team or whatever, and has some physical needs as well. But still can access the already commissioned services. And if they interfaced well then the transition could be seamless and wouldn’t need active commissioning. (...)”

(Commissioner/related manager 1, North East of England)

From the analysis, a range of issues and themes related to commissioning successful transition care emerged. These clustered around four meta-themes:

1 The broad context of commissioning for transition: legislation, policy and wider life transitions

2 Commissioning for transition: structures, processes, pathways and relationships

3 Service-level co-ordination, sign-posting, and relational support

4 Outcomes and contract evaluation

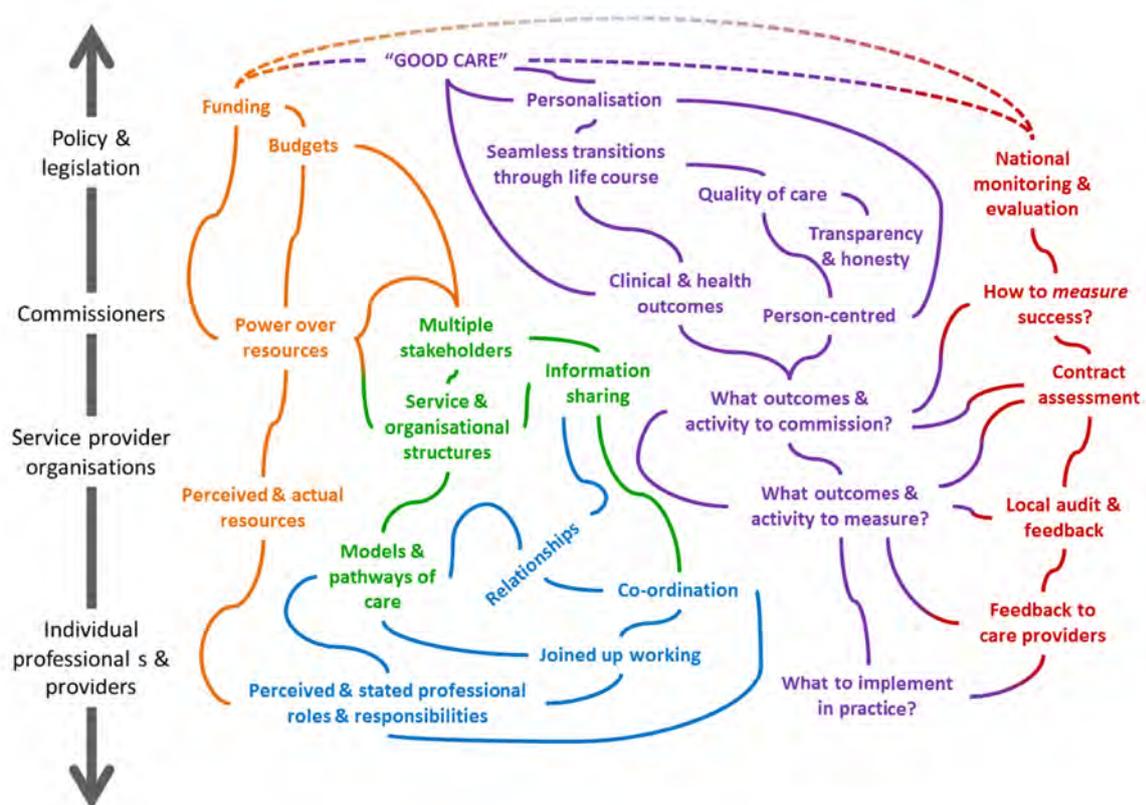
These four meta-themes, with summaries of their key content, are presented below.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews. It is available on request from the authors of the report.

5 A conceptual model to illustrate the process of commissioning for transition

From the analysis, we identified key characteristics of successful commissioning, and developed the first iteration of a conceptualisation of the process of commissioning for transition, as per objective 3 above. This is depicted, visually, in Figure 20. The figure provides a summary output of the results in terms of stakeholders' perceptions of the organisational structures, processes and relationships that drive commissioning for transition. It illustrates the interrelated nature of the themes that emerged, and reflects the complexity of the commissioning process as described by the participants.

Figure 20: A visual summary conceptualisation of the process of commissioning for transition as it emerged from the data analysis



Orange = Financial and legislative. **Green** = the structures, processes, pathways and relationships in commissioning for transition. **Blue** = Service-level co-ordination, signposting, and relational support. **Purple** = Outcomes. **Red** = Contract evaluation and feedback.

Implications for the next stage of WP 3.2

In the light of the qualitative analysis of WP 3.2 the following criteria (Table 41) were applied for the next stage of this study to further explore enablers of successful commissioning practice for transition and identify lessons to inform guidance on commissioning for transition across the NHS (including CCG's, Local Authorities and Health and Wellbeing Boards).

Table 41: Criteria for site selection

Derived from the interviews. Potential site-level sampling criteria for commissioning with particular issues relevant to transition	Potential exemplar sites. We seek sites where the criteria are being actively addressed by Commissioners.
1 Commissioning for Quality and Innovation (CQUIN) framework is implemented towards successful transition. <i>Source theme/subtheme:</i>	Site identified
2 Commissioning for transition co-ordinators within a framework of Developmentally Appropriate Healthcare, rather than for services. e.g. Diabetes. <i>Source theme/subtheme: 3.1 and 3.2/2.1</i>	Site to be identified
3 Joint commissioning i Cross-sectoral joint commissioning - Links to Education, Health and Social Care plans EHSCP. ii Within-health joint commissioning –including with involvement of PRIMARY CARE. <i>Source theme/subtheme: 3.2</i>	Site identified Site identified
4 Where Commissioners and Providers effectively commission together <i>Source theme/subtheme: 2</i>	Site identified

Further, outcome based commissioning was considered desirable (mentioned often in transcripts) but no-one was clear what the outcomes should be and if and where outcome commissioning is being practiced

Stage 3 Conducting the case studies

Using the findings of the literature review and qualitative analysis of the interviews of Stage 1 and 2, the criteria in Table 41, sites were then identified for visits.

Research Strategy

A case study approach was followed to collect empirical data from three Clinical Commissioning Groups (CCGs) in England. Yin²³⁷ defines the scope of a case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident”.²³⁷ Case studies, by their nature, are sensitive to complexity and can be used to provide in-depth insight into complex social phenomena. As a research strategy, case studies are well suited to addressing explanatory ‘how’ and ‘why’ questions.²³⁷ Robson²³⁸ suggests that the case study is an appropriate method towards the “development of detailed, intensive knowledge about a ‘case’, or a small number of related ‘cases’”. In this context, one of the most important uses of the case study is “to explain the casual links in real-life interventions that are too complex for survey or experimental strategies to elicit”.²³⁷ A case study can be single or multiple. For this study, a number of cases were studied jointly in order to explore local initiatives that address commissioning for transition.

Sampling and recruitment

Participants within selected Case Study sites, were selected using a mixture of purposive and snowball sampling methods. The WP steering group members were also asked to suggest potential sites where one of the criteria (see Table 41) was met.

Within the identified sites, participants were considered for participation based on their involvement in local initiatives that specifically addressed commissioning for transition. During recruitment, potential participants (commissioners and service providers) were invited to participate by a letter sent by e-mail. If no response was received then a maximum of three follow up attempts were made by email or telephone.

Participants were asked to sign a consent form giving permission for the interview to be digitally recorded and transcribed, and confirming that they had read the information sheet. Before asking participants to give informed consent, they were provided with the opportunity to ask questions about the study, or seek clarification on any issue arising from the information sheet.

Data collection

Data collection took place from December 2015 to March 2016 in three areas covered by three Clinical Commissioning Groups (CCGs) in the North West, South East and West Midlands. Across the three sites, a total of 11 semi-structured in-depth interviews were conducted. The interviews aimed to provide a mapping of local initiatives to address commissioning for transition. The breakdown of interviews by site and role is summarised in Table 42. Interviews typically took around one hour and were conducted face to face usually at the workplace of the interviewee.

Table 42: List of participants

Site	Participants/Position	Organisation
NW	General Manager, Child Health, Hospital Trust	NHS provider
NW	Senior Commissioning Manager for Children and Families at CCG	CCG
NW	Quality and Safety Lead, Partnership	CCG/LA
MID	Accountable Officer for the CCG	CCG
MID	Associate Director of Commissioning for Maternity and Children's Services	CCG
MID	Project Manager for age 0 to 25 service, CCG	CCG
SW	Paediatric Liaison and Transition Nurse, Hospital Trust	NHS provider
SW	Assistant Director of Nursing for Specialist Services, Lead Children's Nurse, Hospital Trust	NHS provider
SW	Consultant Paediatrician, Hospital Trust	NHS provider
SW	Service Design and Delivery Manager, Commissioning Department of the CCG	CCG
SW	Quality improvement lead in the Maternity and Children's Strategic Clinical Networks	Strategic Clinical Network

The interviews focused on participants' experiences of local initiatives to address commissioning for transition, in terms of processes relationships, barriers and facilitators, and lessons learnt. We acknowledge that a potential limitation of our study is lack of participants from adult services and lack of voice of any service users.

Data analysis

Interviews were transcribed and analysed inductively, without the aid of a software programme. This process was structured using thematic analysis.²³⁹ Core categories and themes were identified for each participant and then compared within each case. One member of the research team (GM) undertook the analysis of interview data and emerging categories. The themes were then reviewed and discussed within the wider project team meetings. In this report, all participants have been anonymised.

Case Study A. North West: Financial Incentive - Commissioning for Quality and Innovation (CQUIN)

Background

The following case study explores the development and implementation of Commissioning for Quality and Innovation (CQUIN) payment framework to improve transition. In 2009 the CQUIN payment framework was introduced to make a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of patient care. This means that a proportion of income depends on achieving quality improvement and innovation goals, agreed between the Trust and the commissioners. The key aim of the CQUIN framework is to secure improvements in the quality of services and better outcomes for patients.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

Conclusion Case Study A

In the North West the CQUIN was considered as a necessary first step to quality improvement as it helped to develop a culture, at least within Children's Services, of shared purpose and values around transition. In this context, it was perceived as a useful scheme aiming to standardise the Transition process for young people with long term conditions through the introduction and use of the 'Ready, Steady, Go' forms, a recently developed programme supported by NHS England. Overall, participants reported that the implementation of the CQUIN contributed towards raising the profile and visibility of the transition process. Moreover, it also helped to raise awareness among clinicians of the move to improve transitions and it also contributed towards improved conversations between specific adults' and children's services.

However, a number of barriers were also reported such as a lack of general adult services' engagement in spite of some successes. In some cases, this was compounded with a lack of specific Adult Services for children to be transferred to and the need for some young people to be transferred to other Trusts which participants reported it is more difficult to plan for. Moreover, it was reported that CQUINs focus on numerical indicators and its conceptualisation in terms of finance and targets rather than quality and innovation may actually negate quality improvement. Finally, concerns were raised about the appropriate use of the 'Ready, Steady, Go' programme especially as transition plans extend throughout the life course of transition beyond the timeframe of the one year CQUIN initiative.

Case Study B. South West: Commissioners and Providers working effectively together

Background

The following case study explores the facilitating role of the regional Strategic Clinical Network (SCN) in the South West towards the development and implementation of a regional CQUIN across 14 Trusts related to transitional healthcare (2014-2015). The South West case study provides a novel instance where commissioners and providers worked effectively together through the regional Strategic Clinical Network (SCN). Strategic Clinical Networks, work in partnership with commissioners (including local government/social care), to support their decision making and strategic planning. SCNs facilitate work across the various stakeholder boundaries such as commissioner, provider and voluntary organisations in order

to promote improved care for patients, carers and the public. The following case study further explores the development and implementation of CQUIN in one of the provider Trusts.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

Conclusion Case Study B.

In the South West the Strategic Clinical Network (SCN) did play a central role in facilitating the development and the implementation of the regional CQUIN. The facilitative way of working across the 14 Trusts provided strategic leadership and was an important driver for reconfiguring the commissioner and provider relationships. All participants reported the network played an important role in both raising commissioners' and providers awareness around transition and providing a space for the Trusts to share ideas, knowledge and experience in relation to best practice in transition (shared learning about good practice in terms of transitional healthcare). At a Trust level, the CQUIN contributed towards the development of a Trust wide Transition steering group which was responsible for developing the transition service, ensuring that the transition policy had been followed accurately, and that it was revised as practice evolved. It also provided the opportunity for the appointment of a Transition worker responsible for collaborating with professionals from their own and from other services and developing good working relationships to ensure co-ordination of care for the young person.

However, a number of barriers were also reported such as a lack of general adult services' engagement in Transition steering group meetings and a lack of clarity about adult care commissioners' roles and responsibilities. Evaluating commissioning outcomes for transition through feedback from service users was another challenge for the Trust. Patients' participation and feedback was limited and fragmented across different services. Finally, echoing the findings of the North West case study, conceptualising CQUIN in terms of finance and targets did not necessarily translate into meaningful conversations about quality and innovation.

Case Study C. West Midlands: Joint commissioning (within health and between agencies)

Background

In the West Midlands a partnership was developed between two CCGs and a Local Authority to support the development and procurement of a fully integrated mental health service for 0-25 year olds. This resulted in a change from the previous system through the provision of a seamless service that would include services for the full range of mental health conditions across the age range. Following a tendering process, a partnership led by a Children's Hospital, as the preferred bidder, won a £124m five year contract to deliver mental health services for children, young people and young adults.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

Conclusion Case Study C.

In the West Midlands the overall aim of the partnership was to support the development and implementation of a fully integrated mental health service for 0-25 year olds. The new service addressed problems identified by the commissioners namely disjointed provision of mental health services for individuals up to age 25 years between the different provider organisations. Overall, participants reported that key feature in the development of the new service was the enthusiasm and commitment of commissioners to improve transitional healthcare for young people with mental health problems. Further, participants emphasised the importance of health, social and third sector involvement and co-production with service users of the new service specification. As well as the enthusiasm of stakeholders at a local level, an important feature of the development of the new service was support by a National Children' lead and the regional Collaboration for Leadership in Applied Health and Social Care (CLAHRC). Finally, another key feature was a focus on outcomes through feedback from service users.

However, a number of barriers were also reported such as uncertainty around post-25 years transition and related challenges with adult service engagement. Moreover it was reported that negotiating the decommissioning process with the outgoing provider was a very challenging process. Participants thought also that there was some reluctance to adopt the new service by some stakeholders. Finally, inadequate information sharing procedures were evident following the configuration of the new mental health service.

Interview schedule WP 3.2

Introduction

Summarise ethics considerations – and assure anonymity

Have participant complete consent form.

The purpose of this interview is to gain an in-depth understanding of the commissioning processes which underpin transition of patients from children and young people's services into adult services. Specifically, we are interested in the transition of CYP with complex health needs.

Whilst we are aware that this transition or transfer is often creates challenges or is considered problematic for patients and practitioners alike, what is less clear is

- a) What the commissioning processes for transition currently are
- b) How the commissioning processes influence or affect transition outcomes

We are keen to gain your specific perspective as provider/ commissioner and to learn about how you have interacted with other providers/ commissioners around the area of transition.

We are also seeking to map commissioning processes and would welcome detail about key relationships, stakeholders and gatekeepers in the commissioning arena.

Interview Topic Guide

Background/ Context

1. Can you tell me what you understand about the term 'transfer' or transition' in health care?
 - a. How would you define a "successful transition"?
2. Can you tell me about your role and:
 - a. How you are or have been involved in transition?
 - b. How you are or have been involved in commissioning?

Probes: key relationships; inter/intra organisational networks; resource allocation; contracting/spending review

Successful Commissioning Outcomes

3. Can you describe an example of when transition (or commissioning) has been undertaken successfully? (Outcomes)

Probes: e.g. new relationships established, the result of the transition, positive patient feedback, quality standards (which ones?) Etc.

Successful Commissioning activities/ actions/ and processes

4. With respect to the example shared can you describe the activities/ actions/ or process that were undertaken to achieve this outcome?

Probes: what activities and actions were undertaken, including key elements of the commissioning process, key stakeholders and gatekeepers, barriers/ facilitators/ Relationships/ networks/ provision/ politics.

[NB. Labels of ‘successful/unsuccessful’ are used to encourage discussion on a range of aspects related to the quality of commissioning rather than to emphasise effectiveness]

Unsuccessful Commissioning Outcomes

5. Can you describe an example of when transition (or commissioning) has been undertaken unsuccessfully? (Outcomes)

Probes: e.g., the result of the transition, difficulties identifying/ engaging a provider?

Negative patient feedback, failure to meet quality standards (which ones?) Etc.

Unsuccessful Commissioning activities/ actions/ and processes

6. With respect to the example shared can you describe the activities/ actions/ or process that were undertaken which resulted in this outcome?

Probes: what activities and actions were undertaken (or neglected), including key elements of the commissioning process, key stakeholders and gatekeepers, barriers/ facilitators/ Relationships/ networks/ provision/ politics.

[NB. Labels of ‘successful/unsuccessful’ are used to encourage discussion on a range of aspects related to the quality of commissioning rather than to emphasise effectiveness]

Any other points

7. Are there any other issue which you consider to be relevant that you would like to discuss?

Close and thanks.

Appendix 10 Patient and public involvement

In this appendix we present an example of a newsletter for participants and an example of a facilitator guide (reproduced with permission) developed with the Council for Disabled Children for dissemination of our results to young people.

TRANSITION

Young People's Newsletter

Issue 6, October 2016

THANK YOU

At the end of October 2016 this study will come to an end and all the final visits will be complete.

The success of the research is down to you for staying involved for the full 3 years!

We will keep you updated on our progress with analysis and send you a copy of the final report in 2017.

Inside this issue:

- Timeline of the Transition Research Programme (page 2-3)
- Our comments on the NICE Guidelines for transition (page 4)

If you'd like to contact us, please do:

Professor Allan Colver: Chief Investigator
 Email: transition@ncl.ac.uk Telephone: 0191 282 5963
<http://research.ncl.ac.uk/transition/>

Example: Newsletter for participants

NICE Guidelines for Transition: Our thoughts

The National Institute for Clinical Excellence (NICE) is a group established by the government. They look at the evidence for new treatments and advise on broader topics such as 'obesity' or in this case 'transition from children's services'. For a topic like transition, there is little good quality evidence – but the committee still makes recommendations which then must be taken account of by the NHS.

Below is a summary of the main recommendations of the guidance (<https://www.nice.org.uk/guidance/ng43>). We have highlighted the areas where the Transition Research Programme is hoping to provide evidence.

Overarching Principles

1. **Support young people** and their careers in service design, delivery and evaluation.
 - Ensure transition support is **personalised** and transition support focuses on the strengths of the individual.
 - Use person-centred approaches such as treating the young person as an equal partner in the process, agreeing goals etc.

Transition Planning:

2. **Start transition planning early** (aged 13-14yrs), ensure the transition planning is **developmentally appropriate** and involves the young person, **make local available such as summer holidays**, communication passports, and materials for planning.
 - Help the young person identify a single practitioner (a **key worker**) to coordinate their transition care and support.
 - **Social networks** – put young people in touch with peer support groups if they want such contacts.
 - If the young person has long-term conditions, ensure they are helped to manage their own condition.
 - **Parental involvement** – ask the young person regularly how they would like their parents/carers to be involved. Discuss the transition with the young person's parents/carers to understand their expectations.

Support before and after transfer

3. **Before:** Ensure that a practitioner from the **local authority** **works the same places before they transfer** from children's services. This could be by arranging **joint appointments or having joint visits**.
 - **After:** If a young person has moved to adults' services and does not attend meetings or consultations, services should try to contact the young person and their family, and involve the GP if appropriate. If the young person still does not want to engage, the relevant provider should refer back to the named worker with clear guidance on re-referral or alternative ways to support them.

Supporting Infrastructure

4. **Each health organisation, in both children's and adults' services, should nominate a senior executive to be accountable for developing transition strategies and policies; and a senior manager to be accountable for implementing transition strategies and policies. The senior executive should be responsible for championing transition at a strategic level.**
 - Jointly plan services for all young people making a transition from children's to adults' services.
 - Service managers should ensure there are **developmentally appropriate needs**.

Thoughts of Professor Allan Colver [Chief Investigator], August 2016:

Overall, I am pleased that NICE have produced Guidance on Transition. It raises the profile of Transition and requires health services now to have arrangements in place.

I think the guidance is so long, with so many recommendations, that it will be daunting for the health service to implement it.

I hope that the Transition Research Programme will provide evidence of what works and so allow subsequent guidance to be more succinct and achievable.

Example: Facilitator guide



Developmentally Appropriate Healthcare (DAH)

Workshop Facilitator Notes
A practical guide to facilitate focus group sessions.



Acknowledgements

With special thanks to the young people involved in the Transition Research Programme for their engagement and input into these guides.

Purpose

This toolkit is designed to share the learning from the Transition Research Programme with young people to help them understand the research and to see if their experience of transition is similar to what the research tells us.

Notes for facilitators

The activities below should be facilitated by skilled and knowledgeable staff who know the young people well, and are confident in supporting young people to discuss and process their experiences. Further guidance and information is available in [Appendix 1](#).

For difference groups of young people, difference images and language may be more or less appropriate. The facilitators should select the most appropriate images/language for the young people who will be involved in the activities. The questions/statements can be rewarded if needed, as long as the core meaning remains intact.

About the TRP

Purpose: The [Transition Research Programme](#) is a 5-year programme of research examining how health services can contribute most effectively to the successful transition of young people with complex health needs from childhood to adulthood.

Aims: The overall aim of the Programme is to provide NHS commissioners and trusts with evidence about what might help young people with long-term health problems as they transfer from child to adult services. This will help them to allocate resources and structure services accordingly. Within this larger aim, the Programme has three objectives. These are to:

- 1) To work with young people with complex health needs to determine what successful transition means to them and what is important in their transitional care
- 2) To identify the features of transitional care that are effective and efficient
- 3) To determine how transitional care should be organised, provided and commissioned

Young people's involvement: The Programme has a young person's working group called [UP](#). As the TRP is about improving young people's experiences of transition we think it's vital that young people have a say in *how* our Programme is run. This is where UP come in! They offer us help and advice and also complete various tasks for the Programme. Their help has been invaluable to the Programme.



After the activities

We are keen to hear how many young people are engaged in activities relating to the research and whether their views agree with the findings. We would be grateful if you could keep track of the following from the session you facilitate and report it to us via the survey in [Appendix 2](#):

- Number of young people who were involved in the session?
- Did all of the young people agree on which statements they felt were true or false? If not, in what ways did they disagree?
- Did the young people identify similar influencing factors from the Transition's Got Talent activity?

The research

At the beginning of the study the researchers were aiming to determine the barriers and facilitators to the implementation of Developmentally Appropriate Healthcare (DAH) for young people.

What is Developmentally Assisted Healthcare (DAH)?

- Person-centred / individual
- Physical / mental / emotional capacities
- Need to understand more about this
 - When is it done well? / When is it done badly?
- DAH can help children and young people understand more about their health and how to manage conditions

With the initial scope of the research in mind, they began by talking to and interviewing managers and clinicians and other health care professionals in order to try and find out more about what DAH was and how it was being implemented.

During the initial stages of this process they soon realised that the situation was not clear cut, there were differences in opinion about what DAH was, in many cases there was no set definition or recognition of DAH and it was not at the same stage in the process of implementation across all of the research sites.

Also, during the course of the research we realised that a factor implemented in a specific way in a specific context could be a barrier in one context but a facilitator in another. As a result of this we have shifted focus and in what follows we have arranged our findings around a list of the key factors that influence the implementation of DAH:

1. Everyone has a different idea about DAH

There is a lack of a clearly defined and embedded concept. If there is no clearly defined concept and set of associated practices then this makes it difficult for



people to associate the work they do with DAH and understand it: *'when you use that word I don't know what it means' (Interview).*

There is a need to find a way for health professionals to agree on a unified idea about DAH.

2. Find a way to make sure all health professionals use it properly.

A clearly defined policy or strategy enables people to develop familiarity with the idea and develop an understanding of the associated practices that staff are required to do to put it into effect. But for implementation to be successful people need to agree with it and put it into practice: *'just because there is a policy does not mean to say that people are going to look at it or stick to it' (Field note).*

Find a way to make sure all health professionals use it properly

3. Find the evidence to show it works.

The role of research can contribute to the base of knowledge that is needed to identify and provide DAH services for young people, as well as raise the profile of the issue. Notably, two of the participant organisations have a history of research on transitional care, which serves as an important foundation: *'the research I was doing got a bit of momentum. It kind of just became more visible ... informing, certainly, the XXXX services within our trust (Interview).'*

4. Get spokespeople to talk about it.

Get Leaders / Key people / Champions / Health Professionals / Charities / Government / Children and Young People, etc. who are invested in pushing DAH forward are an important part of the implementation process. The emphasis here is on more than one person because: *'it doesn't work if you just have one enthusiast in one clinic. Of course it helps in that particular clinic, but it doesn't take the Trust forward' (Interview).*

However, in terms of sustainability of these services, particularly in a Trust without a specific agenda to push DAH forward, champions may be vital for the continued existence of these services: *'champions are a good thing to have because not everybody champions the adolescent cause' (Interview).*

This is also true for other Trust-wide initiatives in Trusts without a specific agenda to push DAH forward: *'we do different stuff. But it's, I suppose, it relies on me doing it. (...) if I dropped dead tomorrow, everyone would carry on doing what they're doing without, you know...' (Interview).*



5. Make it a priority - Children and young people matter!

Small numbers of young people and competing demands. Young people are often perceived to be *'very rarely unwell'*, and there are larger populations that the hospital needs to provide for such as the elderly: *'I don't look after any children or young adults. The median age of my patients is about 70'* (Email correspondence). As such, for some, innovations around young people's health are not always seen as a priority.

6. Ask the children and young people to help design services.

This can be through feedback, participation, planning, etc. Young person's involvement in creating change. Involving young people in the design of the service can serve to inform and legitimise the work that is being undertaken: *'developmentally appropriate young people's healthcare isn't just about the delivery of healthcare, it's about the involvement of young people in designing the delivery, in checking the delivery and in informing what you need to do when things aren't right'* (Interview).

7. Better training for health professionals to work with children and young people.

Training around Adolescent Healthcare or DAH. Training can help to raise awareness and understanding of DAH (and adolescent development) and lead to a better understanding of the requirements of DAH in practice. Although, not a substitute for practical experience, it serves as a good way of creating a network or body of people who are engaged in adolescence and DAH: *'a good group of people across the Trust that we can actually send these youngsters to who've got more awareness of the issues that they could have'* (Interview).

8. Culture change – change the idea that health professionals 'don't have enough time'.

Also, there are too many Doctors involved with one child or young person. Continuity and Change in the structure of the organisation, at the level of staffing: *'the turnover's too fast, of staff.... We'll never follow a young person through. ... Nurses have been swapped over to cover different areas. Somebody's just left, so the young person, young, uh, the nurse has left to move into her role, there's a new one moved in. She's been off sick. There's maternity leave. It's not about people. The consultant's changed. So, you, it's not about a key worker, it just doesn't work ... it's about consistency of approach, not a person'* (Interview). This can create practical issues, where continuity of care in terms of specific personal is a problem, whereas continuity in terms of procedures enables innovations and good practice to be sustained.



9. Different approaches to DAH.

Some people suggested that a particular approach for dealing with young people was needed: impacting upon communication skills (communicating with young people and their family, information giving, teaching self-management skills), consultation dynamics (giving young people time on their own, incorporating the family, managing times and spaces) and assessment criteria (covering psychosocial and vocational aspects as much as biological/physical aspects): 'We need to be a bit less formal with them ... a bit more of an informal type approach, and bit more person-centred rather than a rigid clinic system where you're in and out, see the doctor, and that's it' (Interview).

Others think that DAH does not impact on their clinical approach or, indeed, that DAH is not about the clinical approach but environmental issues: 'So as I say you're not mixing two year olds with 14 year olds, so I think it's really the physical environment. I personally don't think that your approach to the patient is any different (...) clinically, whether they are 2, 12, 22; it makes no difference, you treat -- you're there to treat their medical condition. But I think the environment in which they receive that treatment is probably more important' (Interview)

10. Finding time.

Time is an important (but perhaps disputed) factor in the provision of DAH. Paediatric patients often get considerably more time in their appointments than their adult counterparts (the exception may be the young adult clinics). Yet in some cases this seems to be less frequently acknowledged than some of the other factors: 'X says that would be difficult for Adult clinicians due to the time that they get for their clinic appointments. Y and Z suggest that clinicians could make time if they wanted to, and that actually it is more about the anxieties that clinicians feel when talking to YP' (Field note).

11. Physical spaces – Children and young people have nowhere to meet.

There is often no fixed space for adolescence, and any space that is allocated for adolescence is often subsumed within the spaces for children or adults. In such situations, clinicians need to work to find alternative solutions, drawing on a range of resources within their scope of influence. Children and young people have nowhere to meet.

12. Teamwork.

Teamwork is an important feature of being able to provide DAH. Part of this is consistency and joined up working both within and across specialties and organisations – however much of the evidence to emerge from our findings suggests that this does not always happen.



Health professionals should support each other to enable there is not a repeat of advice and services for the children and young person.

13. Cultural differences and distinction.

The difference between paediatrics and adults are a factor: 'Paediatrics is quite different to adult medicine, most adult physicians have become, what I'd call, ologists in that they've specialised in a very specific area [...] Whereas paediatricians are general physicians and they look after everybody' and 'the adult teams don't necessarily, their way of working doesn't necessarily fit with how the children's ward works. Um, the, um, communication between, you know, we all think we speak the same language but reality is we just don't' (Interview).

What this might mean for young people

DAH is about the experience a young person may have when attending a clinical or medical appointment. It attempts to identify a set of principles and a way of working that can improve a young person's experience.

Young people may identify with any or all of the research statements. During the activities and the discussion, the young person may well begin to identify with different statements. This may reflect a change in knowledge or understanding of their experiences of transition. It is valuable for the facilitators and the young people to discuss and reflect on any changes. IT is also helpful for young people to articulate if they do not identify with any of the statements.

Video Example Questions

- Are all children and young people are the same?
- Respect – do you feel children and young people are always respected?
 - What do you think this means?
- Does it help if health people try to 'relate'?
- How would health people gain your trust?
- Stereotypes – How can this hurt?



Activity 1: Factors that influence... True or False

Facilitator to use the key factors outlined from 1-14 and to ask young people to suggest if they agree or disagree that the factor would influence their experience of seeing a medical professional (GP, consultant, nurse).

(For smaller groups this can be done as one group with people raising their hands for each statement)

Activity 2: Transition's got Talent

<https://research.ncl.ac.uk/transition/youngpeoplepage/theyoungpeoplesworkinggroup-up/>

Using the film clip, Transition's Got Talent developed by UP young people's group, facilitators should play each scenario in the clip giving the young people in the room an opportunity to be the 'judging panel'.

After each short scenario, pause the film and ask the young people:

- Is this a good example of working with young people?
- How would this make you feel?
- Complete the sentence, 'This situation would be better for young people if...'
- All children and young people are the same
- Respect – do you feel children and young people are always respected
 - What do you think this means?
- Does it help if health people try to 'relate'?
- How would health people gain your trust?
- Stereotypes – how can this hurt children and young people?

Record the sentences on flip chart to share back at the end of the session.

At the end of all of the scenarios read back the statements that the young people completed as part of this activity.

Facilitate a short discussion on:

- Are they similar to the influencing factors that the research suggests?
- Are there any differences?
- Which do they think are the most important?



Appendix 1: Guidance and Further Information

The activities in this toolkit should be facilitated by skilled and knowledgeable staff who know the young people well, and are confident in supporting young people to discuss and process their experiences. This includes providing emotional support to deal with difficult experiences or reactions. The young people should be comfortable in discussing their experiences and feelings in the setting.

Appendix 2: Please share young people's feedback on the research and activities with us via our online survey:

<https://www.surveymonkey.co.uk/r/TransitionResearchProgrammeDAH>

- Number of young people who were involved in the session?
- Did all of the young people agree on which statements they felt were true or false? If not, in what ways did they disagree?
- Did the young people identify similar influencing factors from the Transition's Got Talent activity?

Acknowledgements

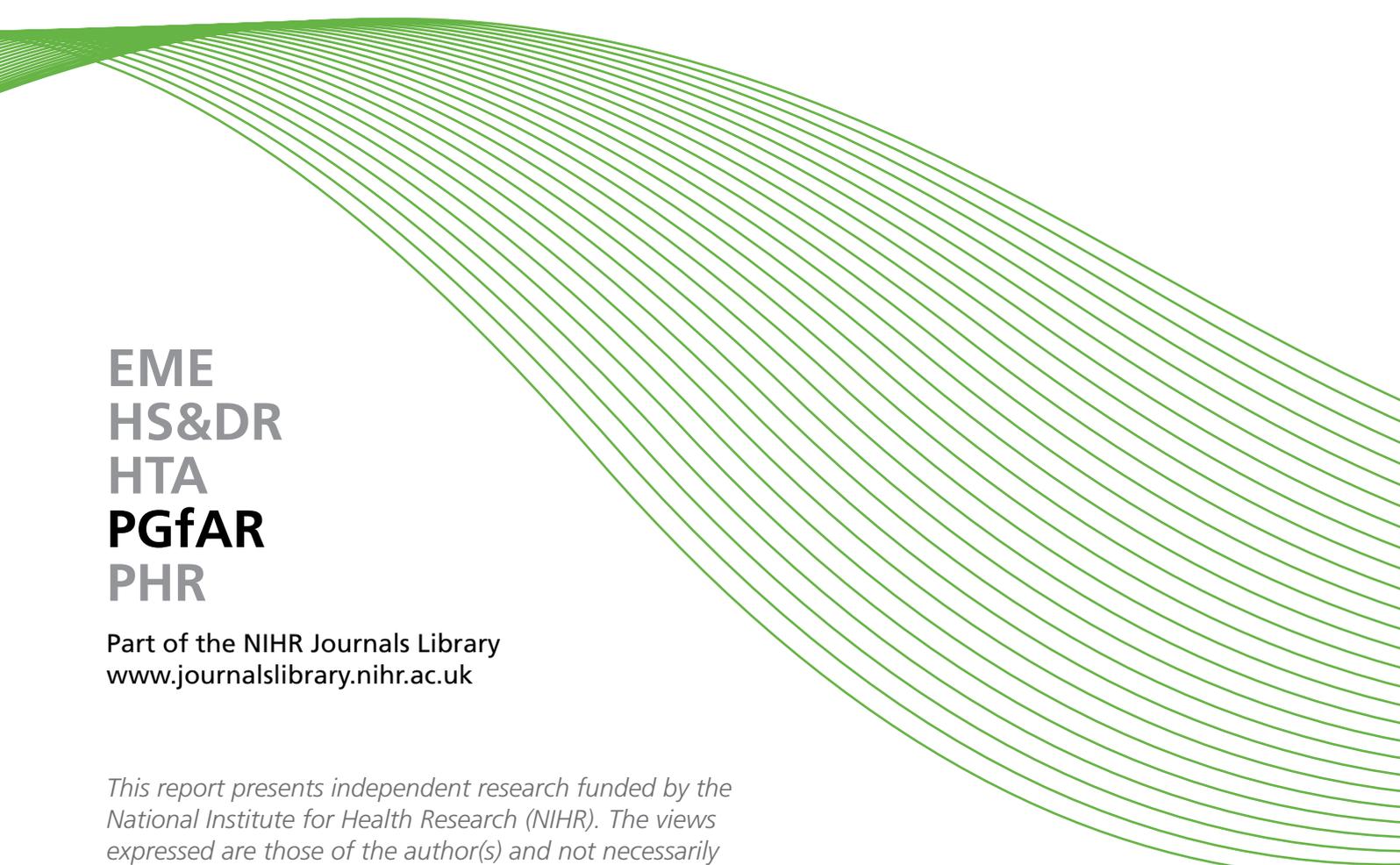
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