**Abstract**

Care planning has been described as a “better conversation” that helps people with long term conditions to be in control of planning their care. Each person with long term conditions faces individual challenges and each health care setting is fundamentally different, so there is a need for empirical testing of the specific mechanisms through which care planning may lead to health improvements. A rapid realist review was conducted to unearth underpinning mechanisms leading to outcomes in particular contexts. These are expressed in the form of realist theories, which are developed and refined through the review process. Fifty-one full text studies were included in the review. Seven program theories were iteratively tested and refined. A detailed description of what care planning is and what it should look like in practice has been achieved in the form of realist theories.

**Introduction**

**Background**

Supporting people with long term conditions is a major challenge to the sustainability of health services globally (UN Secretary General, 2011). In the UK, long term conditions account for 70% of inpatient bed days (Department of Health, 2012), 78% of General Practice (GP) appointments (Salisbury et al., 2011) and around 70% of health and social care spending (Department of Health., 2012). An increasing prevalence of long term conditions and soaring costs create an urgent need to redesign health services (Tinetti et al., 2012).

People with long term conditions spend just a few hours a year interacting with healthcare services and are otherwise self-managing their conditions (Eaton et al., 2015). Although the everyday activities that individuals undertake for themselves and positive interactions with healthcare professionals are recognized as being central to effective self-management (Stenberg and Furness., 2016), these two aspects are often dealt with as if they were independent of one another rather than potentially mutually reinforcing (Rogers et al., 2005). Evidence suggests that people who are ‘activated’, i.e. have the knowledge, skills and confidence to manage their health effectively, are more likely to make healthy lifestyle choices and have better health outcomes and care experiences (Hibbard and Greene., 2013). This may lead to better use of resources (Hibbard and Greene., 2013). The time spent interacting with clinicians is therefore key to providing resources that encourage self-management, through helping people with long term conditions to become ‘activated’.

**What is Care Planning and Why is it Important?**

The ‘House of Care’ (Year of Care, 2011) has received prominence in the UK as a practical framework for a whole system approach that can deliver a unique and coordinated response for each individual (Coulter et al., 2013; NHS England, 2014). At its heart is care planning – a ‘better conversation’ that allows people with long term conditions to be in control of planning their care and identifying their needs and goals, alongside professionals who understand them and bring together services to achieve desired outcomes (National Voices, 2013; Eaton et al., 2015).

Care planning was initially tested and implemented in single conditions (Year of Care, 2011) and it is now being utilized to improve the care of people with multimorbidity (Eaton et al., 2015). Despite this progressing research area, little is known about the most favorable contexts for care planning interventions, and the mechanisms they trigger. Increased detailed knowledge is required to maximize the translational potential of any future research on care planning. Theory driven methodologies such as the one used here, offer a key contribution to this body of knowledge.

**Aims**

The aim of this study is to:

[a] Detail care planning interventions and their components as reported in the literature;

[b] Hypothesize, based on the literature, the underpinning mechanisms triggered by these interventions, in different contexts;

[c] Develop a theoretically informed explanatory framework for how care planning works best, why, for whom and in what circumstances.

**Methods and analysis**

Realist reviews are theory-driven and seek to understand not only whether an intervention works, but also the mechanisms leading to success or otherwise (Pawson & Manzano-Santaella, 2012). Realist review methodology acknowledges that within complex interventions there are many dimensions and layers that warrant exploration, for example, in this study there are behaviors of people with long term conditions and practitioners, as well as multiple interactions between the numerous components of care planning. A realist review does not seek to explain all these layers; it is specifically focused on the demi-regularities in care planning which create preconditions for particular behaviors (Pawson, 2006). Explanatory theories are developed and referred to as program theories.

Program theories take the shape of Context, Mechanism, Outcome Configurations (Pawson and Tilley, 1997), with mechanisms consisting of the resources provided by an intervention and the reasoning of actors (Pawson and Tilley, 1997; Dalkin et al., 2015). Intervention resources (M) are introduced in a context (C), in a way that enhances a change in reasoning (M). This alters the behavior of participants, which leads to outcomes (O) (Dalkin et al., 2015). The purpose of a realist review is thus to develop and test, through an iterative process of literature searching and analysis, CMO configurations that carry the greatest possible explanatory potential for care planning.

Saul et al. (2013) developed rapid realist review (RRR) following the same principles, so that a realist approach can be applied to a knowledge synthesis process in order to produce a product that is useful to policy makers where there are time limitations. RRR is explicitly designed to engage knowledge users and stakeholders to define the research questions, and to streamline the review process. In addition, results are presented with a focus on context-specific explanations for what works within a particular set of parameters rather than producing explanations that are potentially transferrable across contexts and populations (Saul et al., 2013).

We have used RRR methodology to explore how, why, for whom and in what circumstances care planning is effective in improving health, whilst keeping within the time and resource parameters of this study. The realist and meta-narrative evidence synthesis (RAMESES) publication standards (Greenhalgh et al., 2011) are followed throughout this article. Saul et al.’s protocol (2013) suggests the following essential team members for a rapid realist review: project manager; local reference group and expert panel; librarian; review team; synthesis lead and academic or research lead. Since the present review forms part of a PhD thesis, the expertise usually provided by the local reference group and expert panel was instead provided by the PhD supervision team who represent the co-authors of the review and have a breadth of knowledge of both care planning and realist methodology.

 The RRR is the first phase in a four-phase realist evaluation, comprising:

1. A RRR to develop and test program theories through existing literature
2. A focus group with experts who are involved with leading the implementation of care planning
3. Interviews with healthcare professionals who are implementing care planning in practice
4. Interviews with people with long term conditions who receive care planning

The program theories will become more refined at each phase of the study as they are tested with a broad range of program stakeholders. Whilst phase one does not limit studies to qualitative methods, we have used qualitative analysis to best answer the research questions. Realist approaches are method neutral and can employ quantitative and qualitative methods (Manzano, 2016; Pawson and Tilley, 1997). Pawson and Tilley (1997) propose that the choice of data collection and analysis should be guided by the types of data that are needed to answer the research questions, or more specifically, to test the initial program theory in all its dimensions. Marchal et al. (2012) reviewed 40 realist studies that followed Pawson and Tilley’s approach between 2004 and 2010. Of those studies, 5 used interviews as their only method of investigation and 27 used interviews combined with other methods. Eight out of the 40 studies mixed quantitative and qualitative primary data. This RRR uses qualitative analysis techniques to develop and refine program theories which will be tested in the subsequent phases using a combination of qualitative methods, including observation, field notes, focus groups and interviews. Ensuring close collaboration with stakeholders throughout this four-phase study will be key to the successful translation of knowledge into clinical practice (Heaton et al., 2015).

**Formulation of the Explanatory Framework**

A key element in realist review is to explore the presence of ‘educated guess’ theories or Initial Program Theories (IPTs) about how a particular program works and test their explanatory value; they are not considered definitive until they have been tested (Saul et al., 2013). Throughout the testing and refining process, new IPTs are also sought from the studies included to better explain the data (Wong et al., 2010). Eleven IPTs were developed by the Principal Investigator through: scoping policy documents, protocols and key research papers using the Google and Google Scholar search engines; mind mapping sessions with the supervision team; attending care planning training events (n = 3) and observing care planning consultations (n = 2). An example of initial program theory development can be seen in the supplementary files.

**Testing the Explanatory Framework**

*Inclusion and exclusion criteria:* Although the focus of the study is care planning for people with multimorbidity, literature on care planning and multimorbidity is limited, therefore studies were included if they considered managing single or multiple long term conditions through care planning conversations and/or shared decision making and/or support for self-management. If a relevant study focused on single long term conditions, this was considered during analysis. Studies were excluded if they were not about the interaction between people with long term conditions and health care professionals or if they did not contain any of the key concepts outlined above.

*Identifying primary studies:* Initial searches were undertaken in two electronic databases; ProQuest Hospital Collection (comprising 5 sub-collections: Family Health Database; Health & Medical Collection; Health Management Database; Nursing & Allied Health Database; Psychology Database) and CINAHL. Searches were initially restricted to these two databases because they provided a broad collection of healthcare journals, evidence-based resources and full-text dissertations to begin the RRR. Knowledge users helped to streamline the searching by suggesting key papers and reference lists (Saul et al., 2013) to keep within the time parameters of the study. The databases were searched from their inception dates to December 2015, using an adaption of the Population Intervention Comparison Outcome (PICO) search strategy (Sayers, 2008). Language restrictions were applied (English only) and publications of any type were included. Details of the search strategy are described below.

The search terms were created according to how care planning has been conceptualized as combinations of process resources, including preparedness, goal setting, communication, shared decision making and support for self-management (Lhussier et al., 2013). For each database, searches were undertaken using these resources as subject headings where possible. For example, ‘shared decision making’ and related free text terms (with truncations), ‘AND communication’. The search terms were broad and covered *participants, intervention* *resources* and *outcomes* and these were combined with the AND/OR Boolean operators. In the first stage of searching, for each search strategy the first 100 titles and abstracts were screened against inclusion and exclusion criteria to ensure a manageable number of papers. 165 potentially eligible studies were obtained in full text in the second stage and were re-screened. 22 of those studies were acquired from reference lists of key papers, and through forwards and backwards citation searching (see figure 1 in the supplementary files).

**Data Management, Analysis and Synthesis**

Data synthesis was undertaken by the Principal Investigator (Sarah Brown) and synthesis results were regularly shared and discussed within the supervision team to ensure validity and consistency in the inferences made. 51 full text articles that were included after the second stage of screening were reviewed in more depth and assessed for relevance and rigor, as per realist approaches (Pawson, 2006). Key information (including aims, findings and links to theory) was recorded on a data extraction form (an example can be found in the supplementary files). In particular, we attempted to identify prominent recurrent outcomes patterns in the data and then sought to explain these through the means (mechanisms) by which they occurred and under which conditions (context). For example, we noted that in the included studies people with long term conditions may be more engaged during the care planning consultation when they had been sent their latest test results prior to their appointment (Mathers et al., 2011; Hong et al., 2010; Tribal Consulting, 2009). During data synthesis we then aimed to provide an explanation of this outcome pattern through the identification of mechanism(s) and further exploration of the role of context. As we delved further into the included studies for an explanation, data emerged that people who were prepared in this way felt they could spend time reflecting on their current health status and preparing questions to ask (M), but only when they understood their role in self-management (C). We interpreted this as a CMO configuration and were able to refine the IPT being tested. This process was supported by using NVivo qualitative software to link relevant sections of text to capture themes that might contribute to theory testing. The software also allowed an audit trail of developments and refinements to the initial program theories to be kept for transparency. The coded sections of text were used to either confirm, refute or refine the initial program theories.

**The Focus of this RRR**

This rapid realist review explores the strategies/interventions, contextual factors and mechanisms that work in configuration to influence how care planning works in practice, with a focus on multimorbidity. Some other initiatives are thought to support care planning, including peer support groups and education programs, however, this RRR focuses on the care planning consultation itself and the interactions that take place within it. The primary research questions were: what is care planning and what does it look like in practice? How does care planning work for people with multimorbidity? In what circumstances does it work best?

**Findings**

Figure 1 shows the number of studies included at each stage of the review. It outlines how we arrived at the 51 full text articles that formed the core of this review. Further information about each article can be found in table 1 and table 2 (supplementary files). The eleven IPTs that were tested through the literature are listed below.

1. When results are sent to people with long term conditions ahead of their care planning consultation (resource) following an ‘information gathering’ appointment (context), they have chance to think about and accept their current health status (reasoning) and consultation time can be used as purposefully as possible (outcome).
2. When results are sent to people with long term conditions ahead of their care planning consultation (resource), time-pressured practitioners (context) are able to spend consultation time focusing on the needs of the person with long term conditions rather than reporting results (reasoning), giving them better job satisfaction (outcome).
3. When question prompt sheets are sent to people with long term conditions ahead of their care planning consultation (resource), the pre-existing conception of the consultation being doctor-led (context) shifts; people with long term conditions feel like permission has been given to ask for information specific to their individual needs and their confidence to ask questions increases (reasoning), so they become more engaged and ask more questions (outcome).
4. When question prompt sheets are sent to people with long term conditions ahead of their care planning consultation (resource), practitioners who are open to people actively participating in the consultation (context) spend time focusing on what is important to the person (reasoning), which gives the practitioner better job satisfaction (outcome).
5. When practitioners give evidence-based information and support people with long term conditions to set goals (resource) in the context of both parties being engaged in the care planning process, improved knowledge of the person leads to increased confidence (reasoning) to make informed decisions about their health care goals (outcome).
6. When a written care plan is shared within and across teams (resource) for people with multimorbidity who require care from different providers at once (context), they receive one coherent message which enables them to feel more engaged in the care planning process (reasoning), so they adjust their lifestyle appropriately (outcome).
7. When practitioners simplify explanations by using non-medical language (resource) for newly diagnosed people who may not know much about their condition(s) (context), the newly diagnosed person feels more confident to ask questions (reasoning), resulting in improved compliance with treatment or lifestyle improvement approaches (outcome).
8. Practitioners who have had communication training (resource) and are committed to partnership working (context) can interpret the needs of people with long term conditions and modify their communication style to suit them (reasoning), which results in engaged, informed people (outcome).
9. People with multimorbidity engage in discussions around sensitive topics (resource) when they are engaged and informed (context) because they feel able to contribute to the conversation and mention anything that is of importance to them (reasoning), leading to a better relationship and shared decision making (outcome).
10. When support services are offered (resource) to people with multimorbidity who are experiencing psychological/emotional distress (context), they feel reassured that their practitioners care about their personal wellbeing (reasoning), leading to increased trust and reduced stress and anxiety (outcome).
11. When practitioners ask lifestyle questions (resource) to people with long term conditions, whom they have a longstanding relationship with (context), people with long term conditions understand that this will affect the way they lead their life (reasoning), therefore they initiate healthier behaviours (outcome).

As the analysis progressed, some of the IPTs were discarded because they were not sufficiently substantiated by the data, and others were merged. The development of the eleven IPTs into seven tested and refined program theories is described in detail below. They are titled ‘preparation’, ‘appropriate consultation length’, ‘collaborative goal setting’, ‘communication’, ‘formal care plan’, ‘shared decision making’, and ‘support for self-management’.

**1 Preparation**

The literature reviewed suggests that people with long term conditions find it useful to receive their clinical results prior to their consultation (Year of Care, 2011; Lhussier et al., 2013; Mathers et al., 2011; Doherty et al., 2012; Hong et al., 2010) and this information sharing is considered vital to effective care planning (Coulter, 2009; Year of Care, 2011). Many people have reported feeling more informed and better prepared for their appointment after receiving their results because it gives them time to think about their health status and prepare questions (Year of Care, 2011; Mathers et al., 2011; Doherty et al., 2012). Morton and Morgan (2009) suggested that this preparation enables people with long term conditions to get the most out of the care planning consultation.

As part of the Year of Care pilot program, Doherty et al. (2012) produced a paper describing the key drivers, theoretical underpinnings and supporting evidence for the development of the program. One of the fundamental stages to Year of Care care planning is the sharing of a person’s biomedical results, usually by mail prior to the consultation, with a reflection tool to use in order to prepare for the consultation. This step is considered the heart of the ‘informed, engaged patient’ (Doherty et al., 2012). On evaluation of the pilot study, a person with diabetes stated that being prepared for the consultation works “really well” as there’s “no surprises when you come” (Doherty et al., 2012, p. 186b). Other people with diabetes reported feeling less nervous when they received their test results in advance (Year of Care, 2011). However, some healthcare professionals were concerned about the suitability of the results letters for all, suggesting that receiving their test results in advance of the consultation may scare some people off, as “health is one of those things some people would rather not know” (Doherty et al., 2012, p. 186b). Despite this speculation, other reports have suggested that there is very little evidence that people become anxious after receiving their results, stating that it is simply “a perception in some practices” (Tribal Consulting, 2009, p. 51).

Hong et al. (2010) facilitated a non-randomized controlled trial with 106 participants attending diabetes outpatient clinics in Ireland. They explored the impact of sharing personalized clinical information, including recent test results, on the interaction between people with diabetes and healthcare professionals in clinical consultations. They found that people in the intervention group were more likely to initiate conversation during the consultation than those in the control group, and the mean time in which the person with diabetes was involved in the conversation was significantly longer for the intervention group than the control group (6.34 vs. 3.34 min, *P* < 0.01). This suggests that receiving information and test results prior to the consultation significantly impacts on a person’s likelihood to engage during the consultation.

The study only explored peoples’ involvement in the consultation and did not take into consideration how or whether the letter was utilized differently by different people in the intervention group. Some people compare their current results with previous tests (Year of Care, 2011), whilst others choose not to read their results at all (Mathers et al., 2011). Mathers et al. (2011) suggest that people who choose not to read their results may simply need time to adapt to the care planning process. They produced a report on the evaluation of the Year of Care project across three pilot sites. A practitioner in the North East of England described a person who brought her unopened letter containing her test results to her first care planning consultation. The second time she had opened the letter and understood parts of it. The third time she had read the letter and generated some ideas to discuss (Mathers et al., 2011). This suggests that people need to have some understanding of care planning and their role in self-management, for the sending of test results in advance of the consultation to trigger positive mechanisms, which is an idea supported by others: “patients will not be engaged in the process of care planning without an understanding of what it constitutes” (Tribal Consulting, 2009, p. 60).

*Refined program theory 1:* When test results and question prompts are sent before the consultation (resource), to people who have an understanding of their role in self-management (context), they spend time reflecting on their current health status and preparing questions to ask (reasoning) which leads to greater engagement in the consultation (outcome).

**2 Appropriate Consultation Length**

Lack of time in consultations has been identified by people with long term conditions and by healthcare professionals as a key barrier to care planning (Newbould et al., 2012; Bower et al., 2013; Blakeman et al., 2006). This notion is discussed by Noël et al. (2007), who carried out focus groups to explore the collaborative care needs and preferences of people with multimorbidity. Participants indicated that the amount of time allocated for a typical appointment was insufficient to address their multiple concerns, as one participant stated, there were “too many things to talk to the doctor about in such a short time and keep your mind in gear” (Noël et al., 2007, p. 58).

With regard to perceived length of time in consultations, there is a clear difference in responses between people who receive standard care and people who attend care planning consultations. Doherty et al. (2012) reported that most of the people involved in the Year of Care pilot study reacted positively to longer consultations. They reflected upon their experiences, stating “[healthcare professional] seems to have more time to deal with you personally, it’s more personal” and “you feel more at ease and able to discuss things because you know [healthcare professional] is not in a hurry to palm you off and see the next person” (Doherty et al., 2012, p. 186c). Healthcare professionals have also identified longer consultations having a positive impact on care for people with long term conditions, as people are utilizing the consultation time to “deal with small things so they’re needing to come back in to see GPs less” (Year of Care, 2011, p. 74).

Longer care planning appointments allow more time to motivate people with long term conditions to make changes, where changes need to be made (Year of Care, 2011). However, this time is not always used in the intended way. Healthcare professionals have reported that having more time to engage people in the consultation is only conducive if staff are receptive to building on peoples’ own ideas and agendas through partnership working (Tribal Consulting, 2009; Coulter & Ellins, 2007), in an environment where there are enough time and resources to do so (Year of Care, 2011).

In practices where care planning was working well, practitioners reported feeling positively about partnership working, stating, “It’s more rewarding” … “working with them rather than at them” … “[it’s] more a two-way discussion” … “it focuses your mind on their motivation to make changes” (Year of Care, 2011, p. 87). When practitioners are committed to partnership working, people with long term conditions have indicated that they recognize positive changes in their health care. One person with diabetes stated, “I thought about the negatives and positives and how we could take things forward. There was an improvement after one week. She helped me identify what was important to me” (Year of Care, 2011, p. 88). Other people reported, “It is a two-way thing” and is “a good mixture of professionalism and time” (Year of Care, 2011, p. 88). This suggests that a combination of time and a change in attitude at one level of the system (healthcare professionals) can influence a change in behavior (greater engagement with care planning) at another level of the system (people with long term conditions).

The work of Hong et al. (2010) suggests that consultations do not have to be longer for people with long term conditions to be more engaged in the conversation. Their study shows that although participants who had been given personalized clinical information prior to their consultation were involved in conversation for a significantly longer period than those who had not been given information, the overall consultation length for the intervention group was not significantly different to the overall consultation length for the control group (18.3 vs 16.7 min, *P* = 0.35). This suggests that pre-clinic information increases involvement without lengthening the consultation. If an appropriate length of time is allocated for the consultation, to people who are prepared (Hong et al., 2010) and in the context of partnership working (Tribal Consulting, 2009; Coulter & Ellins, 2007), positive mechanisms are triggered which lead to greater engagement with care planning (Doherty et al., 2012; Year of Care, 2011; Hong et al., 2010) and improvements in health (Year of Care, 2011).

*Refined program theory 2:* Allocation of appropriate consultation time (resource) in the context of partnership working and preparedness (context) means that practitioners can spend time discussing what is important to the person with long term conditions (reasoning), which enables the person to engage in the conversation (outcome) and take ownership of their health (outcome).

**3 Collaborative Goal Setting**

Collaborative goal setting and action planning may make someone with a long term condition feel respected, cared about, encouraged and capable of making a meaningful contribution to their state of health (Entwistle and Cribb, 2013). Evidence suggests that people are much more likely to take action in relation to the decisions they make themselves than decisions that are made for them (Year of Care, 2011). People with diabetes articulated how setting their own goals helped them to take ownership of their care and this made it more feasible for them to take action to manage their diabetes (Year of Care, 2011). Four of the studies reviewed reported on whether people felt they had achieved the goals they had set for themselves, and all four gave positive results. Battersby et al. (2007) reported a 60% improvement in problem and goals measurement scores; Glasgow et al. (2005) found improvements in achievement of goals related to healthy eating and physical activity; Hart (1978) found a two-fold improvement in goal attainment among the intervention group compared to controls; and Schillinger et al. (2009) reported that 88% of participants in the intervention group had succeeded in developing their own goals and action plans, leading to partial or complete success in goal achievement for an average of 2.5 plans per participant.

Other researchers have uncovered factors that might hinder or help people to achieve their goals. For example, a theme throughout the literature is that goals should be attainable in order for people to succeed in achieving them (Mathers et al., 2011; Bower et al., 2013; Year of Care, 2011; Langford et al., 2007). Langford et al. (2007) describe a case study whereby a young lady was diagnosed with diabetes following pregnancy. Initially, she managed her symptoms well in a model that was largely provider driven and based on her medical conditions. However, following lifestyle changes (becoming a single parent, battling depression, gaining weight and taking up smoking) she stopped taking her medication and attending medical visits, resulting in a poorly controlled condition. When she became part of a diabetes self-management program, the ongoing support she received in and between appointments helped to improve her problem-solving skills. She was empowered to set small, attainable goals which were feasible as part of her everyday life. The goals later became more specific e.g. around physical activity and diet. As a result of achieving these goals, her Patient Health Questionnaire (PHQ-9) depression score and her HbA1c diabetes level returned to normal (Langford et al., 2007). Although this is just one case study, it is a prime example of how care planning resources (specifically personalized goal setting) can trigger positive mechanisms which lead to positive health outcomes.

Another case study illustrates how personalized goal setting can lead to positive health outcomes (Battersby et al., 2007). A man with Chronic Obstructive Pulmonary Disease (COPD) and other complex health problems, who had been worsening over the last five years, was supported to identify his problems and set a goal. His engagement in the process meant that his goal was realistic and important to him, so he was fully committed to achieving it. He was also very involved in the care planning process, which made him think about what was happening to his health and why. This led to recognition of his priorities and increased his motivation. As a result, he was able to reduce the impact of the problem on his daily activities from 8 to 4 (8 = severe interference, 0 = no interference) and completely achieved his goal (he scored an 8 on progress toward achieving his goal at the outset and scored 0 by the end of the trial: 8 = no progress, 0 = complete success). These outcomes also appear to have contributed to his overall wellbeing, as his Mental Component Summary Score improved by 21 points over time.

In the Year of Care pilot study (Year of Care, 2011), people with diabetes identified the importance of considering advice from their clinicians but ultimately identifying their own goals, which encouraged ownership and responsibility and enabled them to achieve their goals (Year of Care, 2011). Positive health outcomes were also reported as a result of goal setting. One person reflected on setting goals and stated, “I achieve a lot – I have become very conscious of what I eat and do more exercise. I started going to the gym to lose weight”. Another person reported, “as a result [of goal setting] … I walk more and have lost weight. I have also changed my diet” (Year of Care, 2011, p. 86). Not only do these quotes reflect positive lifestyle changes from the process of goal setting and action planning, but for some people, outcomes were becoming long term (Year of Care, 2011).

*Refined program theory 3a:* When people with long term conditions receive support in identifying priorities/goals (resource) and they want to improve aspects of their health (context), they feel better equipped (reasoning) so they set meaningful, achievable goals (outcome).

The outcome in refined program theory 3a becomes a mechanism (resource) in refined program theory 3b below.

*Refined program theory 3b:* When achievable goals are set by people (resource) who understand how their behaviors and lifestyle impact on their condition(s) (context), they feel they have ownership of their plan and their self-efficacy improves (reasoning) so they make healthier lifestyle choices (outcome) and their health improves (outcome).

**4 Communication**

Effective communication between people with long term conditions and healthcare professionals has been defined as encompassing: the exchange of information; the management of uncertainty and emotions; and the building of relationships between patients and professionals (Street et al., 2009). It has also been defined as a tool for supporting self-management and shared decision making (Street et al., 2009). How one person communicates will affect the communication of the other; it is a “process of mutual influence” (Epstein & Street, 2007). Research suggests that some practitioners routinely provide more information; engage in partnership working; use supportive communication including reassurance and encouragement; and are more willing than others to talk about psychosocial topics. The conversations they have tend to be the most effective (Coulter, 2009; Harding et al., 2015).

People feeling listened to, and their perspectives understood and valued, is essential to enable genuine co-production and ‘shared mind’ with healthcare professionals (Harding et al., 2015). In a qualitative study exploring the effective self-management of asthma, participants highlighted the importance of being listened to by health care professionals (Deacon & Rickards, 2013). Those who feel listened to experience positive outcomes, such as a reduction in the need for additional appointments (Macdonald, 2007). Conversely, those who do not feel listened to describe detrimental effects: “I’ll plummet fast… ended up in hospital” (Deacon & Rickards, 2013, p. 83). When healthcare professionals actively encourage engagement by asking people to tell their stories, listening to their views and acknowledging their experiences, this appears to build trust in the relationship. Peoples’ conﬁdence in sharing their experiences also improves, enabling more collaborative, power-sharing dialogues (Lawn et al., 2013).

Noël et al. (2007) reported that some people with multimorbidity felt their concerns were sometimes overlooked or ignored, and they were most likely to attribute this to their physicians lacking empathy. In a quantitative study by Mercer et al. (2012), examination of the relationship between GP empathy and enablement of people with long term conditions showed that although high empathy did not guarantee high enablement (presumably due to other factors that negatively influence enablement such as emotional distress, multimorbidity, etc.), enablement never occurred with low empathy. This suggests that empathy from the healthcare professional is a basic pre-requisite for enablement of people with long term conditions (Mercer et al., 2012).

One of the biggest barriers to effective communication with respect to people with long term conditions is related to health literacy. Health Literacy is a concept relating to how people find out about health, and how they understand and use that information to achieve good health. Addressing health literacy is increasingly seen as an important way to reduce health inequalities and improve health outcomes, especially for those with long term conditions (Batterham et al., 2014). There is consistent evidence that people with low health literacy have poorer health status, higher rates of hospital admission, are less likely to adhere to prescribed treatments and self-care plans, experience more drug and treatment errors, and make less use of preventative services (Coulter & Ellins, 2007). Achieving greater health literacy is integral to improving the health of disadvantaged populations and to tackling health inequalities. Coulter & Ellins (2007) suggest that well designed written information, such as leaflets, combined with oral information, can improve health literacy. Research with people with a cancer diagnosis has shown that having an understanding of medical terminology enables them to better participate in consultations (Luxford & Newell, 2015). This then increases the likelihood that they can contribute to decision making (Luxford & Newell, 2015).

Another barrier to achieving focused communication is the combination of the complexity of the illness weighed against the limited consultation time, and resistance and reluctance to address difficult issues. In a longitudinal qualitative study by Chew-Graham et al. (2013), several instances were explored where healthcare professionals’ own agendas of ensuring compliance took prominence over people with long term conditions’ explanations and concerns. For example, a person in the midst of a divorce recognized in the consultation that the management of her asthma had been impaired by recent stressors. The healthcare professional did not empathize or explore the issue beyond acknowledgement. Instead, the healthcare professional used the person’s fear of further exacerbations to encourage compliance with medication and the review process itself. As a result, the person’s expectations of the review were changed, trust was lost, and the relationship was damaged.

Not all care planning aims to change ingrained behavior (i.e. not all people need to or want to stop smoking). For some people, their aim is to learn about self-management strategies. In terms of communication, for healthcare professionals this means providing current information, risks and beneﬁts, eliciting questions and adjusting information to suit the needs of people with long term conditions, i.e. using “language that is understandable by the patient” and checking that the person understood what was communicated (Lown et al., 2009, p. 167). Bower et al. (2013) reported that some people described a frustrating lack of information sharing, with two people stating that health care professionals appeared unsure about their condition or appropriate treatment (Bower et al., 2013). The perceived lack of information may have been attributed to the fact that communication skills are reported to be a major challenge for healthcare professionals due to lack of specific training and the complexity of having to consider social values and circumstances (Harding et al., 2015). In these situations, healthcare professionals can refer people with long term conditions to more specialist practitioners, and this helps to increase trust and respect in the relationship (Noël et al., 2007).

People with long term conditions who are ‘active’ communicators put their perspective into the conversation and have the potential to influence the healthcare professional’s behavior and decision making (Harding et al., 2015). An example of this is given by Lawn et al. (2013), who examined interactions during care planning to understand processes that foster empowerment and disempowerment. In their study, high levels of guidance, ranging from persuasion to dominance, were provided. The use of ‘we’, rather than referring to people as individuals, was common across consultations. When a practitioner said, “There’ve been lots of habits we’ve had to get into” (Lawn et al., 2013, p. 389), her language inferred that healthcare professionals and people with long term conditions were one and the same, with “we” used to express what people could and should be doing, often confusing and disempowering them, by creating a sense that they could/should not be responsible or trusted with ownership of the process.

*Refined program theory 4:* When practitioners use communication techniques (listening, empathy, reflecting) (resource) in an environment with a facilitative level of knowledge, skills and motivation of both practitioners and people with long term conditions (context), people with long term conditions feel supported and their self-motivation increases (reasoning) so they engage in shared decision making and self-management (outcome).

**5 Formal Care Plan**

The care plan has two main roles: one is to provide information for clinical teams, and the other is to provide support for the person’s self-management. Traditionally, the care plan was more about the former. In care planning, it is more about the latter, or both. The care plan contains attainable goals identified by the person, to enable progress tracking, reflection on daily habits and levels of activity, and it identifies actions they will take to ensure they achieve their goals, and key barriers preventing them from doing so. (Coulter et al., 2015; Bower et al., 2013). Bower et al. (2013) suggest that only pro-active people use care plans; care plans do not make people pro-active, and they work most effectively for people who have an exceptionally strong motivation to make changes and divert physical and emotional energy from other aspects of their day to day lives to make those changes.

In care planning, one of the main roles of the care plan is to support self-management, therefore it is most effective if the person whom it refers to has ownership and responsibility (Lhussier et al., 2013). Bower et al. (2013) conducted a large scale mixed methods study exploring the process and outcomes of care plans and elements of care planning. In their report, they stated that people with long term conditions had at least some input into the plans and “they were used, and found useful, by the majority of patients” (p. 160). One person was uninterested in a care plan he described the nurse as making on his behalf, instead, putting it out of sight. His care plan was used to record test results; the sections on goals and action plans remained blank (Bower et al, 2013). This suggests that ownership of the care plan was with the practitioner rather than the person with long term conditions, therefore it was more likely to be viewed as an information leaflet to be read by the clinical teams rather than to be used, reviewed and amended by the person themselves.

Gibson and Powell (2004) explored the process and outcomes of care plans for people with asthma. They reported that optimal self-management involving a written care plan led to significant reductions in asthma related hospitalizations and reduction in emergency room use. This may be because a written care plan including goals and action plans for asthma facilitates the early detection and treatment of an exacerbation (Gibson et al., 2003). Gibson et al. (2003) found, in a systematic review of asthma self-management education, that when a person had ownership of a written action plan and was instructed in its use in the context of self-monitoring and asthma reviews, there were highly significant improvements in asthma outcomes. The risk of being admitted to hospital fell by over 40% and presentations to the emergency department with asthma fell by over 20%. Gibson and Powell (2004) found, in a review of randomized controlled trials evaluating asthma action plans, that written action plans specifying when and how to increase treatment, based on personal best peak expiratory flow (PEF), using 2-4 action points, and recommending both inhaled and oral corticosteroid consistently improved health outcomes. This suggests that for people with asthma, action plans that contain specific, pre-prepared information have the most impact.

Similarly, in a meta-analysis of COPD and self-management, Effing et al. (2007) reported that there were significant reductions in hospital admissions for people utilizing a written care plan. In these cases, involving COPD and asthma, self-management was about managing exacerbations and the care plan was kept in reserve and used and followed in specific situations. In day-to-day living with long term conditions where self-management relates to lifestyle, the impact of adhering (or not) to a plan is perhaps less immediate and therefore may require people to have more motivation. The condition, setting and personal circumstances are thus key contexts which may affect engagement with care plans. This means that for people with multimorbidity, where personal, social and lifestyle factors are often key areas of focus, care plans need to reflect this and be used in a way that enhances engagement and motivation.

Bower et al (2013) explored the mechanisms that may explain how and why a care plan helps certain people to self-manage. They described a person in her mid-fifties, who had diabetes since childhood and was “exceptionally engaged and informed about her condition” (Bower et al., 2013, p. 207). During her interview, she described an open and positive long term relationship with her diabetic nurse, with whom she had originally discussed and created her care plan. She had been living with diabetes for decades, and therefore was an ‘expert’ in her own condition. Her wealth of knowledge and experience, combined with her practitioner’s medical knowledge and their positive long term relationship might have promoted an equal power relationship between them, which may have empowered her to set goals, and as she is an “exceptionally engaged” individual she utilizes her care plan to monitor her progress. She described her care plan as a “thing that I’d written at one stage and it reminds me that I do need to just keep an eye on what’s going on with me in general” (Bower et al., 2013, p. 207).

Bower et al. (2013) also explored healthcare professionals’ views on the impact of the written care plan for people with long term conditions. A practice nurse who used written care plans for weight management said the plans helped people to reflect on daily eating habits and levels of activity, and to identify the key barriers preventing them from achieving their goals. Thus, the nurse believed that having a written care plan was a vital tool for self-management, “I thought it was good for the patients to have written information, because they can compare” (Bower et al., 2013, p. 259).

*Refined program theory 5:* When individualized written care plans are owned by (resource) people who are proactive and motivated to change or continue to self-manage (context), their self-efficacy to perform self-care behaviors increases (reasoning) so they make healthy lifestyle choices (outcome).

**6 Shared Decision Making**

Shared decision making has been defined as “a meeting between two equals” (Makoul and Clayman, 2006) where practitioners and patients work together to select tests, treatments, management, or support packages, based on clinical evidence and peoples’ informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and systems for recording and implementing peoples’ treatment preferences (Coulter and Collins, 2011). Shared decision making is unlikely to be achieved if practitioners do not agree with its guiding ethical principles (Elwyn et al., 2012). At its core, shared decision making accepts that individual self-determination is a desirable goal and that clinicians need to support people to achieve this goal, whilst achieving autonomy by building good relationships and respecting individual competence and interdependence of others.

However, some healthcare professionals argue that some people don’t *want* to be involved in decisions, lack the capacity or ability, might make ‘bad’ decisions, or worry that shared decision making is just not practical, given constraints such as time pressure. Others claim they are ‘already doing it’, though data from patient experience surveys indicates that this is generally not the case (Elwyn et al., 2012). It is therefore clear that the first step for successful shared decision making is to ensure that practitioners support the underlying rationale. Nevertheless, even when this step is in place, practitioners are likely to face implementation challenges. Low health literacy or low numeracy are barriers to shared decision making and some people come from cultural backgrounds that lack a tradition of individuals making autonomous decisions. Therefore, although good clinical communication skills, including building rapport and structuring the consultations, are key to effective shared decision making, there are other barriers and enablers to take into consideration.

Research shows that for the relationship between the practitioner and the person with long term conditions to enable the desired outcome (shared decision making), both should be motivated to invest in better quality relationships and improved outcomes (Elwyn et al., 2012). For people with long term conditions, this means working in partnership with healthcare professionals, to be better informed and involved in their care, to share decisions and to contribute to health management (Ahmad et al, 2014). However, some practitioners believe this view of the person’s role is unrealistic as they are not capable of engaging in decisions that are essential to collaborative care planning (Russell et al., 2008). Blakeman et al. (2006) interviewed 16 GPs who were working in practices involved in the Expert Patients Program: a lay-led self-management program for people with long term conditions. They found that GPs expressed the need to feel in control to fulfil their professional responsibility, and most had concerns about giving patients too much responsibility without sufficient support or guidance.

Ensuring shared understanding within teams concerning the purpose of shared decision making is a vital component of program implementation (Lloyd et al., 2013). A mixed methods study by Kennedy et al. (2014) describing a failed attempt at the implementation of WISE (Whole System Informing Self-Management Engagement) illustrates this concept. The implementation of WISE was met with issues at each level of the system, beginning at the organizational level. It was not prioritized by practices, so little effort was invested in WISE techniques. This had a negative effect on healthcare professionals’ perceptions on the program and the way in which they implemented it, which ultimately affected the care of people with long term conditions.

Lhussier et al. (2013) state that the practitioner’s role is to provide information to, and clarify and understand the preferences of, the person aiming to “share” the decision. To achieve this, they not only need to demonstrate core “patient centered” communication skills and empathy, but also be able to model and support the individual making the decision that is right for them without unduly leading or influencing them, which can involve considerable skills of deliberation and negotiation (Lhussier et al., 2013). An example of this is given by Lawn et al. (2013). They describe occasions where practitioners dismissed input from people with long term conditions, making decisions for them instead of supporting and encouraging them to become active communicators in an equal partnership. This example provides evidence that when practitioners do not support people to make decisions about their health, shared decision making cannot occur.

Another barrier to shared decision making could be lack of health education for people with long term conditions. Bower et al. (2013) felt that a more appropriate approach to shared decision making should focus on educating people to make informed decisions. Bower et al. (2013) describe, through the responses of a healthcare professional research participant, the fine line between educating people to make informed decisions and telling them what to do. They reported that healthcare professionals did not want to come across as telling people what to do because enabling choice was considered central to maintaining a good relationship (Bower et al., 2013). Again, this reflects the importance of practitioners supporting people to make the decision that is right for them (Lhussier et al., 2013).

In a study by Lown et al. (2009), principles of appreciative inquiry were used to encourage participants (experienced practitioners and people with long term conditions) to discuss examples and share stories of their own experiences in which shared decision making went well. One participant reflected, “[shared decision making] really does require a really kind of intimate attachment between the patient and the doctor…” (Lown et al., 2009, p. 165) However, sometimes, people may find it difficult to understand and express their feelings and values. The inability to share certain feelings is often due to lack of trust for the healthcare professional, as discussed by participants, one of whom reflected, “… [It helps] having an open and candid dialogue and relationship so that pretty much anything can be discussed”. The participant went on to say, “if you have the trust, then you find that you are… more willing to put those things out on the table” (Lown et al., 2009, p. 165).

In another study by Lawn et al. (2013), the healthcare professional’s battle for control of the consultation appeared to have the goal of forcing clients’ submission and dependence. Lawn et al. (2013) state that in these circumstances, people with long term conditions might become dependent or withdraw from contact with healthcare professionals altogether, which would have a negative impact on the relationship and on the person’s wellbeing. They found that engaging people with long term conditions in the consultation appeared to build trust in the relationship and people became more confident in sharing their experiences, enabling more collaborative, power-sharing dialogues.

Although shared decision making is based on the idea of an equal power relationship, ongoing perceptions and realities of control are evident in the healthcare environment. Healthcare professionals may not be able to give the person with long term conditions what they want, and people with long term conditions might have different priorities when it comes to their health/lifestyle. However, in these situations, Lown et al. (2009) suggest that shared decision making can still be achieved since negotiation may occur within a single encounter, or a shared decision may take place over several visits, therefore there may be areas of agreement and lack of agreement in the same relationship or consensus and lack of consensus. Sometimes, practitioners and people with long term conditions can agree to disagree and still maintain a respectful relationship (Lown et al., 2009).

*Refined program theory 6:* When healthcare professionals and people with long term conditions effectively communicate their knowledge and expertise (resource) in the context of a relationship built on trust and respect (context) people feel well informed and well supported (reasoning) which leads to shared decision making (outcome) and a decision that fits with their values (outcome).

**7 Support for Self-Management**

Definitions of long term conditions such as ‘health problems that require ongoing management over a period of years or decades’ (World Health Organization, 2005, p. 13) fail to acknowledge that people with long term conditions spend just a few hours a year interacting with healthcare professionals and more than 99% of their lives managing their conditions themselves. The challenges they face vary depending on their personal circumstances; the number, nature, and stages of their conditions; the need for lifestyle, specialist and technical interventions; and their capacity to self-manage effectively (Eaton et al., 2015).

Support for self-management has been described as a “portfolio of techniques and tools that help patients choose healthy behaviors” (Bodenheimer et al., 2005, p. 4) and is essential to successful care planning (Helmore, 2009). It is the responsibility of the practitioner to gauge the extent of the person’s knowledge, skills and confidence to self-manage his or her health, to strengthen this where necessary, and to ensure that relevant interventions and support services are available (Year of Care, 2011; Coulter et al, 2015; Ross et al., 2014). Not only should practitioners recognize and suggest relevant support services, they should also do so using a whole-person approach, treating people as individuals who are active in their own care (Ross et al, 2014).

In a study by Reeve et al. (2012), people with long term conditions felt their care was personal, but not *personalized*, because practitioners had not used a whole-person view to influence decisions that were made about their medical care. As a result, they described feeling “trapped on a conveyor belt” with health care becoming an additional burden on, rather than a resource for, living (Reeve et al. 2012). Giving personalized information to people, for instance about their parameters and treatment options, enables them to take an active role in long term condition management because increased knowledge promotes engagement and empowerment (Rijken et al, 2014).

Considering the emotional and social aspects of a person’s care is intensive and leads to an increased burden of a wider range of issues for those involved, which means that practitioners need to know which community services are available. For some healthcare professionals, this is the most difficult aspect of their job in terms of care planning (Fuller et al., 2004). Not knowing which resources are available can be a barrier to supporting people with long term conditions to self-manage. In a study by Ross et al (2014), people with long term conditions expressed their keenness to be given support from services other than the one provided by their GP. Their suggestions for how care for long term conditions could be improved focused on helping people to help themselves by providing information about services available, listening, and helping them to feel safe and supported.

When the context facilitates self-management support (from a practitioner’s point of view), the desired outcome is a person with increased confidence and problem-solving skills (Ryan & Deci, 2000). Various terms have been used for this; “engagement”, “empowerment” or “activation.” Whichever term is used, the focus moves from the healthcare professional doing things to the person, to healthcare professionals supporting them to gain confidence and competence to manage the challenges of living with their condition(s). The person with long term conditions should also be willing to engage in the process, and research shows that “activated” people are more likely to engage in self-management than people who simply attend their appointments because they must (Hibbard and Gilburt, 2014).

Activation and empowerment of a person with long term conditions begins with increasing their knowledge and enabling them to play their part in disease management (Rijken et al, 2014). In a systematic review by Boger et al (2015), there was evidence that people felt gaining knowledge was key to enabling self-management. They also viewed independence as a key factor, which may be achieved through becoming more knowledgeable about their condition(s). Evidence from Boger et al.’s (2015) systematic review highlighted that the relationship between people with long term conditions and healthcare professionals is fundamental to ensuring professional support for self-management is effective. People expressed a need to be treated as individuals by healthcare professionals: “I need to feel my doctor is interested in my health, I need to feel I can talk to him and he is trying to understand me” (Boger et al., 2015, p. 14-15).

*Refined program theory 7:* Providing self-care techniques and accessible support services (resource) to people with long term conditions who require holistic, personalized support (context) equips them with the knowledge, skills and increased confidence (reasoning) to manage their own health and healthcare (outcome).

**Discussion**

This rapid realist review identified seven guiding principles that will be useful when considering the operationalization of care planning. These are: preparation; appropriate consultation length; collaborative goal setting; communication; formal care plan; shared decision making; and support for self-management. In trying to understand the interaction between context, mechanism and outcome, program theories were developed and iteratively tested and refined to explain how, for whom and in what circumstances care planning works best.

The most likely outcomes of care planning are: greater patient and professional engagement in the consultation; shared decision making; more effective self-management and health improvements. The most favorable conditions for these outcomes are when people with long term conditions are motivated and understand their role in self-management and how their lifestyle impacts on their condition(s). The relationship with their healthcare professional needs to be built on trust and respect, with both parties committed to partnership working. This rapid realist review also highlights seven key resources introduced by care planning. These are preparation; appropriate consultation length; goal setting; written care plans; communication techniques; shared knowledge/expertise; and accessible support services. These resources have been compiled from key articles accessed during this review, including the work of Coulter et al. (2015), Lhussier et al. (2013) and Year of Care (2011). Coulter et al. (2015) describe a seven-step care planning process, involving strategies that take place both inside and outside of the consultation. Lhussier et al. (2013) and Year of Care (2011) place more emphasis on the resources implemented during the care planning consultation. Although there are many dimensions of care planning, within and outside of the consultation, the scope of this review means that we have focused on the strategies used within the consultation.

One fundamental concept that is consistent across the literature we have reviewed is that care planning begins by changing attitudes at all levels of the healthcare system (Joseph-Williams et al., 2017; Year of Care, 2011). The House of Care proposes that whole system approaches and improvements are needed for a ‘better conversation’ to occur between health care professionals and people with long term conditions. This conversation is the heart of care planning, as it also enables people with long term conditions to be in control. By exploring what constitutes a ‘better conversation’ and systematically identifying, through secondary empirical data, how it impacts on peoples’ lives, we have answered questions about what works or does not work, how, for whom, and in what circumstances. This review offers a unique combination of theoretical underpinning and successful and replicable practical implementation, thus providing clarity on the successful implementation of care planning.

Based on the seven program theories, an overarching program theory has been developed to explain how all the concepts discussed in this paper may fit together to define care planning:

*Overarching program theory: an adapted definition of care planning:* When both healthcare professionals and people with long term conditions are adequately informed and prepared (resource) and consultations occur in an environment that is person-centered, supportive and respectful (context), people with long term conditions become confident to develop informed care strategies (reasoning) in order to become effective self-managers (proximal outcome) and maintain or improve their health (distal outcome).

All seven refined program theories and subsequently the overarching program theory will be tested and refined using primary data in the subsequent phases of this study. The realist premise is that the research process starts by theorizing; these theories are then tested and refined, and then tested again, and in this iterative process, our understanding of the real world is also refined (Manzano, 2016). By incorporating experiences and perspectives of different participant groups, whom will be involved with care planning at different levels of the healthcare system, we will form a better understanding of how they understand and have experienced the program (Emmel, 2013), and will be able to compare these experiences to the theories drawn from the literature.

**Strengths and Limitations of the Study**

To our knowledge, this review represents the first use of realist review in care planning research. It contributes to an emerging field in systematic review, in which theory driven reviews are undertaken to supplement and extend the findings of other review types. This review has begun to extend the knowledge base by identifying and refining some of the program theories that explain the ‘how’, ‘why’ and ‘in what circumstances’ questions related to care planning. The lack of empirical research on multimorbidity means that the findings from single morbidity studies may be only partially applicable to multimorbidity.

The pursuit of rigor in rapid realist review follows similar principles to the pursuit of rigor in qualitative research more generally. The essence is interpretation, hence key processes are immersion (reading and re-reading texts), reflection, comparison and continuing to seek explanations and test theories until saturation of the data is reached (Wong et al., 2010). The sample included primary and secondary studies of care planning, shared decision making and support for self-management in different contexts, with no restrictions by study design to achieve a maximum variety sample. Whilst maximal transparency has been attempted in describing the review process, it must be acknowledged that this is an inherently interpretive and subjective process.

A major limitation that we encountered during this review was a lack of clarity and limited background to care planning as a term, particularly in academic literature. This made searching for key papers through complex literature difficult, however, following Saul et al.’s (2013) RRR protocol, we were able to rely upon knowledge users to help streamline the searching by suggesting key papers and reference lists. This lack of clarity across existing academic literature forms the key purpose of this project and will be addressed in phase two.

**Conclusion**

This RRR has unearthed underlying mechanisms of care planning, which lead to outcomes in individual, professional or practice contexts. These causal chains are expressed in the form of realist program theories, which have been developed and refined through the review process. This, for many health care professionals, presents a departure from either a descriptive approach (detailing the intervention) or a focus on effectiveness (does care planning work better than other interventions). This RRR, in generating evidence based understandings of why and in what circumstances care planning may work best, has the potential to inform the working practices of many health care professionals. In a wider context of ageing demographics, increased multimorbidity and strained public finances, the potential relevance and application of this understanding cannot be underestimated.

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**Developing IPT 1**

**Relevant notes from Year of Care training event (September 2015)**

There is an emotional response when hearing negative information. When test results are sent out prior to the care planning review, they have time to think, reflect and set goals.

There is a space at the bottom of the information sheet that is sent out prior to the review, for patients to write any questions they may have. This affects the power balance between practitioner/patient and empowers the patient to take the lead.

Questions around what information to send and will they be anxious about it? Most patients would be less anxious having their results soon after their blood test than they would if they had to wait 4 weeks for them. If something key has shown up in the results, practitioners would want the patient to know about it.

At the Year of Care training event I had the opportunity to watch a video of an example care planning consultation. What was the impact of having the results letter?

* The patient had the chance to think about and take in their results and think of questions to ask

**Relevant notes from my observations of a care planning consultation at a North East GP surgery on 6th October 2015:**

The patient sat down and initiated a conversation about her results that she had received in the post. The doctor asked if she would like to go through the results and then asked if there was anything in particular that she had seen on the sheet and wanted to talk about. The doctor and the patient went through the results together although it was the patient talking mostly.

The doctor asked if the patient had been able to attend the DESMOND clinic, which triggered her to talk in detail about what a valuable experience it was. They continued going through the results and the doctor asked, “are you ok with that tablet?” Brief discussion about medication and the patient said she had no problems with any of the tablets. She confirmed she had had her foot check last week as part of the HCA appointment. The doctor went back to the leaflet where the patient could have written any concerns etc. and she asked if there was anything in particular she wanted to talk about (she hadn’t written anything down). The patient then went on to say she was reading about how walking can change things, so she started walking 3 laps instead of 2, and she has stopped buying chocolate biscuits.

**Early ideas for a possible IPT (01/07/2015)**

**1:**

Resource: Information in the form of summary letters and leaflets is provided to the patient outside of the care planning consultation

Context: Patient is allotted a set amount of time for their care planning consultation

Reasoning: The patient feels encouraged to engage in thinking about their treatment options outside of the clinical encounter

Outcome: Time with the physician can be used as effectively as possible

**2:**

Resource: Written encouragement to ask questions and question prompt sheets are sent to the patient ahead of the care planning consultation

Context: The patient is allotted a set amount of time for the care planning consultation

Reasoning: The patient feels encouraged to engage in thinking about their treatment options outside of the care planning consultation

Outcome: Time with the healthcare professional can be used as effectively as possible

**3:**

Resource: Information is sent to the patient ahead of the consultation

Context: The patient (with multimorbidity) is too overwhelmed emotionally to process a large amount of information about their health at once

Reasoning: The patient has the opportunity to read and reflect on important information when they are ready to do so, which enables them to come to terms with things and formulate questions to ask in the consultation

Outcome: Time with the healthcare professional can be used as effectively as possible

**Feedback received from supervision team. Supervisors suggested I have one IPT for the patient’s perspective and one IPT for the practitioner’s perspective. They were refined to incorporate this suggestion on 23/07/2015:**

**IPT 1: Patient’s perspective**

Resource: Written encouragement to ask questions and question prompt sheets are sent to the patient ahead of the care planning consultation

Context: In the traditional doctor-led consultation disease-specific information is given

Reasoning: The patient feels like permission has been given to ask for information specific to their individual needs and their confidence to ask questions increases

Outcome: Person-specific information is received

**IPT 2: Professional’s perspective**

Resource: Written encouragement to ask questions and question prompt sheets are sent to the patient ahead of the care planning consultation

Context: The practitioner is open to the patient actively participating in the consultation

Reasoning: During the consultation the practitioner can focus on what they know to be important to the patient

Outcome: Better job satisfaction

**Feedback received from supervision team: Outcome in IPT 1 could be formulated better i.e. is it patient activation or patient engagement?**

**Figure 1**

**Flow Chart of the Screening Process**

845 records identified through database searching

22 records identified through other sources

831 after duplicates removed

631 records screened by title and abstract

466 records excluded

115 full text articles excluded with reasons:

57 no evaluation data

40 outside of project scope

18 not care planning, shared decision making or support for self-management

165 full-text articles assessed for eligibility

51 full-text articles included

**Data Extraction Form**

**Title**

Langford, A., Sawyer, D., Gioimo, S., Brownson, C., and O'Toole, M. (2007). Patient-centered goal setting as a tool to improve diabetes self-management.

**Aims**

This article describes the process of collaborative goal setting as a means to improve diabetes self-management in primary care.

**Characteristics of the paper**

This article describes the process of collaborative goal setting as a means to improve diabetes self-management in primary care. In 2003, the St. Peter Family Medicine Residency Program was chosen as 1 of 6 Advancing Diabetes Self-management projects funded by the Robert Wood Johnson Foundation Diabetes Initiative. The goal of the project was to improve diabetes self-management by introducing systematic changes to improve the quality and delivery of primary care. This paper was developed in collaboration with representatives from the Department of Community Health, Saint Louis University; St. Peter Family Medicine Residency Program; and the National Program Office of the Diabetes Initiative of The Robert Wood Johnson Foundation, Division of Health Behaviour Research, Washington University School of Medicine

**Methodology and quality assessment**

In 2003, the St. Peter Family Medicine Residency Program developed the Self-Management Goal Cycle to illustrate the process of care they wanted all diabetic patients to receive. Each step of the cycle directly supports the patient’s goal setting process. They also developed The Big Bad Sugar War (BBSWAR) technique, which is modelled after Kate Lorig’s work with self-management to aid providers in the goal setting process. The BBSWAR is an abbreviation for a set of steps that serve as a reminder for providers to follow at each patient visit.

One part of the paper is particularly relevant to this review; the case study. Findings are reported below. Although it is just one case study, it is a prime example of the differences between standard care and care planning, and how care planning process resources (specifically goal setting) can trigger positive mechanisms which lead to positive health outcomes.

**Findings**

Case study: A young lady was diagnosed with diabetes following a pregnancy and was overwhelmed with managing her multiple long term conditions. Initially, she managed her symptoms well in the care of a traditional primary care model which was largely provider driven and based on her medical conditions. However, following lifestyle changes (becoming a single parent, battling depression, gaining weight and taking up smoking) she stopped taking her medication and attending medical visits, causing her diabetes to become poorly controlled. When she became part of a diabetes self-management programme, the ongoing support she received in and between appointments helped to improve her problem-solving skills. Through collaborative goal setting, she was able to share with the practitioner what was going on in her life. Consequently, she felt empowered to set small, attainable goals, which later became more specific e.g. around physical activity and diet. As a result of achieving her goals, her PHQ-9 depression score and her HbA1c diabetes level returned to normal. She also shared her successful self-management behaviours with her father who also had diabetes (Langford et al., 2007).

**Links to theory**

Goal setting techniques in the Self-Management Goal Cycle are based on the stages of change constructs of the Transtheoretical Model, self-efficacy scales, and nondirective support.

Leonard E. Egede

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Affiliations

Department of Medicine, Medical University of South Carolina, Charleston, SC, USA

Center for Disease Prevention and Health Interventions for Diverse Populations, Ralph H Johnson VA Medical Center, Charleston, SC, USA

Center for Health Disparities Research, Medical University of South Carolina, Charleston, SC, USA

Correspondence

Corresponding author at: Medical University of South Carolina, Center for Health Disparities Research, 135 Rutledge Avenue, Room 280H, Charleston, SC 29425, USA.

**Table 1: Information about empirical research studies included in the review**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Authors** | **Title** | **Type of paper** | **Sample** | **LTCs** | **Methods** | **Outcome measures** | **PT** |
| Battersby et al. | SA HealthPlus: a controlled trial of a statewide application of a generic model of chronic illness care. | Original research | 3,115 intervention patients, 1,448 controls | Not specified | Quantitative analysis, interviews and focus groups with patients, GPs and service coordinators, document analysis and case studies | Health status, resource use, personal outcomes | 3 |
| Blakeman et al. | A qualitative study of GPs’ attitudes to self-management of chronic disease. | Original research | 16 GPs  | N/A | Semi-structured interviews | Personal outcomes/ knowledge of the facilitation and barriers to self-management, knowledge and attitudes of the General Medical Services contract and the Expert Patients Program | 2, 6 |
| Bower et al. | Care planning in the treatment of long term conditions – final report of the CAPITOL project. | Original research | 2439 patients | Multimorbidity | Review of care plans and care planning, exploratory qualitative work, secondary analysis of data, quantitative and qualitative studies to examine outcomes of care plans and care planning | Self-reported vitality, QoF scores, health status, quality of life, condition specific outcomes (HbA1c control), self-efficacy, self-management behaviors, resource use | 2, 3, 4, 5, 6 |
| Chew-Graham et al. | How QOF is shaping primary care review consultations: a longitudinal qualitative study. | Original research | 34 patients,  | Asthma, COPD, CHD, diabetes | Audio recordings of consultations, semi-structured interviews | Patient/healthcare professional interactions | 4 |
| Deacon & Rickards. | A job description for the effective self-management of a long-term condition: experiences of living with difficult asthma. | Study report | 4 | Asthma | Secondary analysis of focus group data | Experiences of physical, emotional and social being | 4 |
| Entwistle & Cribb. | Enabling People to Live Well. | Original research | Not specified | Not specified | Knowledge exchange events | Personal experiences of ‘collaborative’ approaches in the management of long-term conditions | 3 |
| Fuller et al. | Is client-centered care planning for chronic disease sustainable? Experience from rural South Australia. | Original research | 40 | Not specified | Semi-structured interviews and focus groups | Satisfaction with the client-centered care planning and self-management approach used  | 7 |
| Glasgow et al. | Randomized effectiveness trial of a computer-assisted intervention to improve diabetes care. | Randomized effectiveness trial | 886 patients, 52 primary care physicians | Diabetes | Implementation of the Diabetes Priority Program | Number of recommended lab screenings, recommended patient-centered care activities, lipids, HbA1clevels, quality of life, depression score | 3 |
| Hart. | Therapeutic effectiveness of setting and monitoring goals. | Original research | 32 patients | Not specified | Implementation of a goal attainment model | Behavior change, goal attainment scores | 3 |
| Hong et al. | Providing diabetes patients with personalized written clinical information in the diabetes outpatient clinic: a pilot study. | Original research | 106 patients | Diabetes | Personalized clinical information was given to one group prior to their consultations. Controls were not given any information.  | Conversation time, overall consultation time, number of topics raised by the patient | 1, 2 |
| Kennedy et al. | Implementing, embedding and integrating self-management support tools for people with long term conditions in primary care nursing: A qualitative study. | Original research | 37 healthcare professionals | N/A | Semi-structured interviews | Experiences of the implementation of a self-management support approach | 6 |
| Lawn et al. | Control in chronic condition self-care management: how it occurs in the health worker-client relationship and implications for client empowerment. | Original research | 19 consultations from 2 GP surgeries | Not specified | Ethnographic observations and audio recordings of consultations  | Body language, overall impression of the interactions | 4 |
| Lloyd et al. | Patchy ‘coherence’: using normalization process theory to evaluate a multi-faceted shared decision making implementation program (MAGIC). | Original research | 31 healthcare professionals | N/A | Semi-structured interviews | Attitudes towards shared decision making | 6 |
| Lown et al. | Mutual influence in shared decision making: a collaborative study of patients and physicians. | Original research | 85 patients and healthcare professionals | Not specified | Research work groups | Attitudes and behaviors that facilitate shared decision making | 4, 6 |
| Macdonald. | Origins of difficulty in the nurse-patient encounter. | Original research | 12 patients and 10 nurses | Not specified | Observation and semi-structured interviews | Personal experiences of nurse-patient encounters | 4 |
| Mercer et al. | Patient enablement requires physician empathy: a cross-sectional study of general practice consultations in areas of high and low socioeconomic deprivation in Scotland. | Original research | 3,044 | Multimorbidity | Questionnaire | Patient enablement, GP empathy | 4 |
| Newbould et al. | Experiences of care planning in England: interviews with patients with long term conditions. | Original research | 23 patients | Multimorbidity | Semi-structured interviews | Personal experiences of care planning | 2 |
| Noël et al. | The Challenges of Multimorbidity from the Patient Perspective. | Original research | 720 patients | Single and multiple LTCs | Cross-sectional survey | Number of contacts with healthcare providers, self-management learning needs, willingness to see non-physician providers | 2, 4 |
| Reeve et al. | From personal challenge to technical fix: the risks of depersonalized care. | Original research | 27 patients | Advanced cancer | Semi-structured interviews | Personal experiences of living with illness and related distress | 7 |
| Ross et al. | Learning from people with long-term conditions: new insights for governance in primary healthcare. | Original research | 32 patients, 56 healthcare professionals | Not specified | Documentary analysis, semi-structured interviews  | Patients’ experiences of receiving care, professionals’ experiences of governance and incentives | 7 |
| Russell et al. | Beyond fighting fires and chasing tails? Chronic illness care plans in Ontario, Canada. | Original research | 20 patients, 13 healthcare professionals | Not specified | Semi-structured interviews | Experiences of a LTC management initiative | 6 |
| Schillinger et al. | Effects of self-management support on structure, process, and outcomes among vulnerable patients with diabetes: a threearm practical clinical trial. | Original research | 339 patients | Diabetes | Implementation of two self-management support strategies | Structure, communication processes, and behavioral, functional and metabolic changes | 3 |
| Tribal Consulting. | Evaluating the Delivery and Impact of the ‘Year of Care for Diabetes’: Project Interim Report. | Original research | 1,900+ patient responses, 51 GP practice responses, 3 case studies | Diabetes | Site visits, case studies, quantitative data collection | Overall satisfaction with the service, empathy and enablement, quality of life, number of visits to GP surgery | 1, 2 |
| Year of Care. | Report of findings from the pilot program. | Original research | 3 pilot sites | Diabetes | Semi-structured interviews, group discussions, working groups, focus groups, learning events, email correspondence, document analysis, case studies, questionnaires | Personal experiences and satisfaction with the service, health status, change in key indicators across time | 1, 2, 3, 7 |

**Table 2: Information about other papers included in the review**

|  |  |  |  |
| --- | --- | --- | --- |
| **Authors** | **Title** | **Type of paper** | **PT** |
| Ahmad et al. | [Person-centered care: from ideas to action](https://www.mendeley.com/catalog/personcentred-care-ideas-action/). | Systematic review | 6 |
| Batterham et al. | The OPtimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. | Research protocol | 4 |
| Bodenheimer et al. | Helping patients manage their chronic conditions. | Information piece | 7 |
| Boger et al. | Self-management and self-management support outcomes: A systematic review and mixed research synthesis of stakeholder views. | Systematic review | 7 |
| Coulter et al. | ‘Effectiveness of strategies for informing, educating, and involving patients’. | Policy overview | 2, 4 |
| Coulter. | Implementing shared decision making in the UK. A report for the Health Foundation. | Scoping paper | 1, 4 |
| Coulter & Collins. | Making shared decision-making a reality: No decision about me, without me. | Information piece | 6 |
| Coulter et al. | Personalized care planning for adults with chronic or long-term health conditions. | Systematic review | 5, 7 |
| Doherty et al. | Diabetes Year of Care: The Key Drivers and Theoretical Basis for a Shift in Diabetes Care. | Theoretical paper | 1, 2 |
| Effing et al. | Self-management education for patients with chronic obstructive pulmonary disease. | Systematic review | 5 |
| Elwyn et al. | Shared decision making: a model for clinical practice. | Guidance for healthcare professionals | 6 |
| Epstein & Street. | Patient-centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. | Monograph | 4 |
| Gibson et al. | Self-management education and regular practitioner review for adults with asthma (Cochrane review). | Systematic review | 5 |
| Gibson & Powell. | Written action plans for asthma: an evidence-based review of the key components. | Evidence-based review | 5 |
| Harding et al. | The state of play in person-centered care: A pragmatic review of how person-centered care is defined, applied and measured. | Pragmatic review | 4 |
| Helmore. | Care planning in long term conditions: nurse-led care plans for people with diabetes. | Information piece | 7 |
| Hibbard & Gilburt. | Supporting people to manage their health – an introduction to patient activation. | Information piece | 7 |
| Langford et al. | Patient-centered goal setting as a tool to improve diabetes self-management. | Information piece | 3 |
| Lhussier et al. | Care planning for long-term conditions – a concept mapping. | Systematic review | 1, 5, 6 |
| Luxford & Newell. | New South Wales mounts “patient based care” challenge. | Information piece | 4 |
| Makoul & Clayman. | An Integrative model of shared decision making in medical encounters. | Systematic review | 6 |
| Mathers et al. | Care Planning: Improving the lives of people with long term conditions. | Guidance for healthcare professionals | 1, 3 |
| Morton & Morgan. | Examining how personalized care planning can help patients with long term conditions. | Information piece | 1 |
| Rijken et al. | Chronic Disease Management Programmes: an adequate response to patients' needs? | Reflection paper | 7 |
| Ryan & Deci. | Self-Determination Theory and the facilitation of intrinsic motivation, social development and wellbeing. | Theoretical paper | 7 |
| Street et al. | How does communication heal? Pathways linking clinician-patient communication to health outcomes. | Information piece | 4 |
| WHO. | Preventing chronic diseases. Preparing a health care workforce. | Information piece | 7 |