



Carer Health Checks

A Peer Evaluation of the Carer's Health Check Pilot in Northumberland

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Acknowledgements

The evaluation team would like to thank all of those who volunteered their time to take part – we hope we have represented their views with fairness.

We acknowledge the funding made available by Carers Northumberland and Northumberland Care Trust to provide training and support to undertake this evaluation.

We would also like to acknowledge the input of Michele O'Brien whose passion and enthusiasm for the development of carer services was key in getting the project off the ground.

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Executive Summary

The HM Government vision “Carers will be supported to stay mentally and physically well” resulted in Northumberland being one of six counties to be selected to participate in a Carers Health Check pilot study.

The objectives of this study were to interview carers and former carers to obtain their general thoughts and feelings of the Carers Health Checks and to feed back that information to Northumberland Care Trust. Carers and former carers trained as Peer Evaluators were involved at every stage of the process.

The Carers Health Checks were applauded by all of the interview volunteers,

I felt as though having done it [the health check] that I wasn't alone, that somewhere, someone was still caring' (11)

I liked the whole concept of it, to be honest. The idea that you felt valued enough for somebody to come out and actually care about your health (10)

The Carers Health Check drawn up by Northumberland Care Trust was very comprehensive, incorporating both an NHS Health Check and a well-being or lifestyle check to assess the carers physiological and emotional needs. Some respondents found the checks uncovered ailments that needed further exploration and were directed to their GP; all felt reassured that a busy Health Care Professional took the time to visit them in their own home. This opportunity to spend time talking about themselves rather than the person they care for was highly valued by all, leaving the carer with a welcome feeling of recognition.

Stress, anxiety, tiredness, isolation and poor physical health are familiar problems for carers. These, coupled with the reluctance of carers to seek help for themselves necessitates that Carers Health Checks should be conducted annually and that carers should be contacted to make an appointment when their next Carers Health Check is due.

The study also showed that advice and support from Health Care Professionals in Northumberland can be inconsistent, ranging from excellent to patchy. Many of carers interviewed were reliant on third party organisations for information. This study suggests that Health Care Professionals refer all carers to Carers Northumberland.

Involvement Framework

“Many former carers, or those currently caring with the capacity to do so, would like the opportunity to put their expertise to good use, particularly if it can help current carers. They are natural contributors to the Big Society and it is important to build on the diversity of support that carers can offer”.¹

The key element of this research was the involvement of carers and former carers, who had volunteered in addition to their own caring duties to evaluate the thoughts, opinions and experiences of carers who had participated in the health checks. Not all of those involved were able to attend every group meeting or participate in all aspects of designing and undertaking the evaluation, but all added something important to make the final evaluation study happen.

“To have been involved has helped to soften the intensity of our every day caring while still feeling useful and that we have something else to contribute as well as socialising and gaining skills”.

Quote from a Peer Evaluator

1. Introduction

The role of carer is becoming more recognised and valued at national level by successive HM Governments and at a regional level by Local Government and Care Trusts. The importance of helping carers to maintain their own health (physical, mental or emotional) is essential if they are to continue to care for their dependants. To support carers the Government introduced a pilot scheme of Carer Health Checks at six locations across the country. Northumberland was selected as one of the pilot sites.

An important aspect of this study was for carers and former carers to be trained as 'Peer Evaluators' and supported to undertake the evaluation. Drawing upon a wealth of life experiences, their caring experience and new found researching skills the peer evaluators developed an evaluation study plan and design, developed an interview schedule and interviewed carers who had been given a health check as part of the Carer Health Checks pilot. Using analytical techniques they also examined the interviews to determine the impact of the health check upon the carers involved.

2. Carer Health Check Background

“Our vision is that:

Carers will be supported to stay mentally and physically well” .²

In 2008 HM Government produced “Carers at the heart of the 21st century families and communities”, a ten year strategy to develop support for carers. It recognises the increasingly important role carers play in today’s society and acknowledges that carers need more help and support than had been available in the past.

The HM Government vision “Carers will be supported to stay mentally and physically well” is one of the priority areas identified as needing to be addressed. It is very important as carers often neglect their own needs, ignoring symptoms of physical, mental or emotional ill health. The reasons why carers do this are many and varied.

A number of short term pilot schemes were introduced to look at how the NHS can better support carers. One such pilot was for annual Carer Health Checks. The aim of which was to detect emerging health problems at an early stage. The Carer Health Checks were introduced September 2009 and were conducted until the pilot ended in March 2011, followed by data analysis and a report. The carer health checks were comprehensive, covering basic physiological checks, lifestyle factors, mental and emotional well being.

Should the pilot scheme prove to be a success it’s the intention that the annual health checks will be rolled out nationally.

The hypotheses behind the Carers Health Checks are:

That checks will give carers and health professionals an opportunity to detect and treat, at an early stage, emerging health problems the carer may have.

- That checks will contribute to a better outcome for carers.
- That carers who have recently stopped caring because of bereavement will benefit from the checks.
- That early intervention to support carers will result in effective use of resources and possible savings.
- Avoiding or minimising the risks of more intensive (and more expensive) intervention.
- Avoiding or minimising the need to provide alternative support if the carer is unable to continue caring for health reasons. ³

The Northumberland Carers Health Check pilot is a partnership between Northumberland Care Trust, NHS North of Tyne and Carers Northumberland.

Northumberland has a population of 310,600, with considerably poorer health statistics than the England and Wales average. Estimates say there are as many as 34,000 people in Northumberland providing regular help, with as many as 7,000 providing support for more than 50 hours per week.⁴

The health checks were in most part conducted in the carers own home, at a time that was convenient, to recognise the fact that it's not always easy for carers to attend their GP surgery. Initially the health checks were delivered by community matrons and nurses – often from the carers own GP practices. Later a dedicated team of three nurses were employed to cover the North, South and West regions of the county.

3. Peer Evaluator Selection

In order to bring together a group of carers to be trained and supported to carry out a peer evaluation of the health checks, Carers Northumberland together with Northumberland care Trust contacted a range of carers known to them. Some of these carers had taken part in a previous peer evaluation of a carer initiative and others had voiced an interest in being more actively involved in carer issues and projects. A group of seven carers and former carers volunteered to take part in a series of research skills workshops and in undertaking the peer evaluation. Of the group who volunteered three had been involved in the previous peer evaluation. Not all of the group were able to attend every workshop or group meeting and some dipped in and out, however all contributed something important to the evaluation.

4. Research Focus and Methodology

The evaluation team consisted of an NHS commissioning support officer, Carers Northumberland Senior Development Officer and carers/former carers trained as Peer Evaluators. The Peer Evaluation team were trained and supported by Dr Alison Steven of Northumbria University. The peer evaluation training was spread over almost a year. The programme was designed and delivered by Dr Alison Steven. The training was broken down into the following components:

- An introduction to evaluation and research
- Developing the project, ethical issues and assumptions
- Data collection and management
- Data analysis and writing up

After exploring a range of approaches and methods the group agreed on an evaluation aim and decided that a qualitative approach using semi structured interviews to collect data would be the most appropriate design. The evaluation aim and objectives are as follows,

Study aim: To evaluate the effects of the carers health checks pilot.

Objectives: In order to fulfil this aim the study will cover:

- General thoughts and feelings about the checks and,
- The process (implementation/ undertaking) of the health checks.

Ethics

The R&D manager for the local NHS trust covering the area was contacted regarding the evaluation. Given that the study did not include patients or NHS property and fitted the National Institute of Health Research definitions as of evaluation rather than research it was not considered necessary to go through Integrated Research Application system. However best ethical practice was maintained throughout as detailed in Appendix B.

Data collection

Semi-structured interviews were selected to collect qualitative data from carers who had undertaken a carer health check. The interviews lasted between 15-30 minutes and were conducted by prior arrangement at a venue of the participant's choice – usually their home. Three of the peer evaluators undertook the interviews with support from the Carers Northumberland staff member. Peer evaluators worked from a list of predetermined questions developed and piloted during the training sessions. See Appendix B: Interview instructions and schedule. However the interviews were semi-structured and therefore allowed to develop during questioning and follow any relevant path as the interview progressed, thus obtaining additional valuable data.

Sample

Fifty carers selected at random from the pool of carers that had undertaken the Carers Health Check were invited by letter to participate in the interview process. The letter included a consent form and an information sheet (Appendix D) explaining the carer health check pilot, the interview process, that consent was voluntary and could be withdrawn at any time, and that the participant's details would remain confidential and any quotes used would be rendered anonymous.

The interviews were transcribed anonymously; any information that could lead to the identity of the participant was removed. The recordings were destroyed at the end of the study period. In compiling the report direct quotes have only been used if they are unidentifiable.

Analysis

The data was analysed using the framework approach. Each transcript was analysed individually by 2 members of the team and then the analyses were merged. Common themes were extracted in relation to the main areas of questioning and uncommon or one off comments and views were also integrated into the final account.

Each participant is to have a copy of the finished report.

5. Carer Health Check Requirements

The Carers Health Check had to fulfil a number of requirements set by the Department of Health. It must include the vascular checks for coronary disease, stroke, type 2 diabetes and kidney disease that form the recently introduced NHS Health Check being offered to adults in England between the ages 40 to 74 and also a well-being check or life style check.

The Northumberland Care Trust carefully considered the Department of Health Requirements and produced the Carer's Health Check CHC1 form to conduct the Carers Health Check (See Appendix A).

The CHC 1 form is divided into the following sections:

1. Standard Check and Summary: Basic physiological and well being test results etc.
2. Health and Healthcare: Existing health problems or long term health conditions, medication, family history, medical history, Abbreviated Mental Test, Patient Health Questionnaire PHQ9 and life style questions etc.
3. Health relating to caring: concerns how caring can affect health, concerns performing clinical tasks in the caring role etc.
4. Health History: GP/Practice Nurse Appointments, screening, hospital admissions etc.
5. Support Services: Contact with Care Management/Social Services, Carer's Needs Assessment, Northumberland Carers Guide, registered with third party provider e.g. Carers Northumberland etc
6. Individual Carers record: An outline of care responsibilities of the carer.

To recognise the fact that it is often difficult for carers to get away from their caring duties, carers were to be offered the Carers Health Check to be conducted at their home address unless another venue was preferred for privacy or convenience by the carer.

6. Interview Findings

Thirteen carers and former carers volunteered to be interviewed by the Peer Evaluators.

Framework Analysis

The framework analysis resulted in the identification of:

- How the carer found out about the Carers Health Check.
- Feelings about the Carers Health Check.
- The nature of the Carers Health Check.
- Benefits and differences.
- Thoughts on carer support.

These will now be discussed in greater depth. Participant codes have been included to illustrate the variety of sources drawn upon. The salient points have been highlighted in bold to assist reading.

6.1 How the carer found out about the Carers Health Check

Those interviewed found out about the Carer Health Checks predominantly, and unsurprisingly, from Carers Northumberland. Two participants were informed by alternative routes, one was told about the check by a community matron and another during a regular hospital outpatient's visit. However the referral process was not smooth for all respondents. One carer who initially found out about the checks through Carers Northumberland reported feeling 'miffed' after attempting to request a health check via the GP but without success. This person eventually went back to Carers Northumberland and was referred for the check directly by them.

6.2 Feelings about the Carers Health Check

When asked their feelings about the idea of a health check without exception **all thought it was a good idea**. One thought they 'might as well have one' and another suggested that anything that recognises carers as having issues was great and a third was of the view that '*prevention is better than cure so why not have a medical check up*'(013). There was an underlying feeling that the health checks are good because **carers do not prioritise their own health needs** as one participant notes,

'People in my situation don't always put your own health needs first. If you do have a problem, to go to visit the doctor for what could be an unknown length of time, leaving the person you care for...You're just put off'(010)

Therefore to be offered a health check which focused on them, and could be undertaken a location and time convenient for them was seen as beneficial. In addition one respondent remarked that it was 'about time' suggesting that for them the idea of carer health checks was overdue.

6.3 The nature of the Carers Health Check

Respondents were asked several questions regarding the nature and content of the check and their thoughts regarding service provision.

The length of time that the health checks took to conduct was reported as varying from 20 minutes to over an hour. **All respondents felt that the duration of the check was about right** for them. There were remarks conveying surprise at how thorough the check was even though it only took 30 minutes, at how structured it was, and conversely that it was a limited medical check.

Most of the checks were carried out by nurses not known to the carers. Some were described as district nurses or nurses from other GP practices, which surprised one respondent, and two were recognised as being nurses with a specific remit regarding the carer health checks. Over half of the respondents said **it did not matter who did the check**, but two said they preferred someone they already knew who understood their situation. One person highlighted identification and security issues, saying,

'as long as I knew she was who she said she was, I'm careful who comes to the door'(05).

Others remarks related to the **need for qualified professionals** to undertake the checks and one carer felt it would be beneficial to have someone who themselves had experience and understanding of being a carer.

The majority of the checks were carried out in the carers home with only two being carried out in the GP surgery and one in a hospital setting. For some **having a nurse go to their home overcame a feeling of not wanting to waste a doctors time**,

I f somebody comes to the house I'm not annoying the doctor... it was really good that somebody came to the house, it highlighted the things I needed to go to the doctors with, I went and it helped me!' (05)

When asked about the questions included in the checks all of the respondents answered positively viewing the **questions as relevant and appropriate**. Words used by respondents to describe the questions included 'sensible', 'comforting', 'clear', 'covered everything'. None of the respondents felt there was anything missing from the check. As one respondent put it,

'[the check was] Very appropriate, I felt they hit the nail right on the head' (10)

However another respondent felt that not all the questions were relevant to their situation as they seemed to be geared towards older carers. This perhaps highlights underlying assumptions in the health check and **a need to tailor questions to fit an individual's situation.**

6.4 Benefits and differences

Many of the respondents were hopeful that something positive would come from having the check and several reported aspects of the health checks which they felt had indeed made a difference to them.

6.4.1 Focusing on carers in their own right

In **focusing on the carers in their own right** and not on the cared for, the health checks appear to have offered a legitimate space within which the carers health and situation could be considered. Many remarks were made regarding the 'busyness' of the caring situation which leads people to forget or not pay attention to their own health needs as the following participants reported,

'you are so busy caring you forget about yourself [you] just carry on' (04)

'you don't think about yourself when looking after someone' (08)

In addition their own health was seen as key to them **maintaining the ability to care,**

'need to be fit to carry on caring' (05)

'if you are ill you cannot carry on caring' (06)

Thus the health checks were viewed as offering the benefit of **reassurance** regarding health situations- *'it told me I was alright'* (06) or of picking up any issues and getting them dealt with so that the person would be **fit to continue in their caring role.**

6.4.2 Psychological and emotional benefits

Being able to talk to someone about their situation was reported by participants as a positive aspect of the health check, for one participant it made a difference *'having someone to talk to'* (08), another expressed a feeling of relief saying *'its nice to get things off your chest to someone who's not involved'* (09).

Issues related to **stress and depression were mentioned by over half of the participants.**

One participant reported that they were 'totally wiped out' and needed to get out of the depression they were in or they would have 'blown up'. Although other assistance in dealing with the depression had been sought, the health check helped in that process as the person states

'I am now coping better ...because I've talked to people, like in the health check. It was somebody different to tell how I felt about it'(07)

Another respondent felt that they were already recognised as a carer by their GP however the health check was felt to have

'benefitted me mentally , that I was able to look after (cared for person)'(09)

Alongside the **recognition of the carers role**, participation in the health check seems to have counteracted a feeling of isolation that some carers had for example the following participant expresses it thus,

' I felt as though having done it [the health check]that I wasn't alone, that somewhere, someone was still caring' (11)

The theme of **loneliness, isolation and invisibility** continues as seen in the following excerpt from another carer,

'I think one of my issues about caring has always been that I feel that I, and probably most carers, feel we're invisible and can't be heard or can't be believed. So anything which goes some way to redress that, sort of, improves one's self confidence. So somebody or some scheme which actually says, "Hey... Yeah, carer's health check. You know, you matter" is good' (01)

The reference made to 'being believed' also suggests that carers do not feel valued, listened to or credible. The health check seems, for this participant, to have acted as a counterbalance to those feelings – **an acknowledgement and legitimisation of their experiences and ongoing situation**. Another respondent also hints at such feelings summing up the health check experience thus,

I liked the whole concept of it, to be honest. The idea that you felt valued enough for somebody to come out and actually care about your health' (10)

Therefore a number of emotional and psychological issues seem to be at play in the caring situation and the health check appears, from the perspectives of those interviewed, to offer recognition of some of these and a space to perhaps explore and being to address some of them.

6.4.3 Physical benefits

Physical health benefits were also reported. For one respondent the check picked up a very high blood pressure which was then followed up with the GP, others had cholesterol level tested and followed up which one felt had made a difference and another participant noted,

'We have discussed the cholesterol issue, so that, yes that wouldn't have happened otherwise' (01).

Therefore the **physical tests led to some action and follow up** where necessary. One participant had a problem with their foot which was picked up at the check and they were referred for specialist treatment, this person describes the difference the check has made thus,

'I need to keep myself fit to look after my husband, while before I'd had this toe and I've got sore hands and I just lived with those things, now I don't need to (05)

Alongside the physical benefits, having issues identified may have also acted as a reassurance to carers that their own health was being dealt with.

6.5 Thoughts on carer support

When asked their thoughts and experiences about current carer support many of the respondents were very positive about the assistance and information given to them by the charity Carers Northumberland. The following excerpt covers some of the issues reported,

Carers Northumberland are superb, in terms of just being there and offering advice and support. The GP is understanding if you go along with a specific problem and the reception staff are very understanding in terms of making appointments to fit in with us but they're not supportive in they don't know what to do specifically for carers. The practice manager said "we don't have many carers on our books" I think it's just too new to them, the concept that there are people who need a different kind of support is alien to them. I get information and support through Carers Northumberland and my network of other carers (08)

The support offered by health and social care services appeared to differ from respondent to respondent. One carer described the support given by mental health professionals as marvellous, while another described their GP as 'very good, he takes account of how I'm feeling'. However one respondent described the GP practice as 'ignorant of carers needs' and another told of asking to go on the 'carers list' and the surgery not knowing what they were talking about.

Therefore while a few examples of what was perceived as good professional support were given (i.e. mental health nurses, GP surgeries) one participant summed up the care and support available thus,

'professional help is patchy'(13) .

However these findings need to be considered in relation to the sample of respondents and the way in which the health checks pilot was undertaken. Many of the carers interviewed were recruited to the study via Carers Northumberland channels and the health checks were often also instigated in this way which may have skewed the findings.

7. Limitation and Barriers

Both the Carers Health Checks and the Peer Evaluations have suffered setbacks and delay.

At the start of the Carer Health Checks pilot study, Community Health Care Professionals were slow to respond as they were finding it difficult to maintain an existing high workload and introduce Carer Health Checks. Implementation and uptake were therefore not as rapid as initially hoped. To rectify this, dedicated team of three District Nurses were recruited to work on the Carer Health Checks later on in the project.

Of the fifty carers invited to participate in the Peer Evaluation interviews only six carers responded and returned their consent form. To increase the number of interviews it was decided to ask for volunteers at the monthly Carers Northumberland group meetings. Meetings were selected from across the county to ensure a good distribution of volunteers. Delays were incurred awaiting the scheduled meetings to take place.

There may have been some confusion over the wording of the invitation letter sent to the carers. The letter opened with "Dear carer", not all people who had the Carers Health Check were carers. Some recipients were former carers, while others did not recognise the fact that they were carers and therefore disregarded the invitation to participate in the interviews.

Interviews were unable to commence until April 2011 due to delays in obtaining the necessary Criminal Records Bureau checks for the Peer Evaluators.

The initial team of trainee Peer Evaluators were reduced to only three due to the withdrawal of some from the training programme due to personal or caring responsibility reasons.

Lack of time also meant it was not possible to interview the Health Care Professionals as had been originally intended. While this would have been good for completeness of this study, the Health Care Professionals have been interviewed and their experiences and comments recorded for the Northumberland Care Trust report in which this report will be referenced in the appendices.

The severe winter of 2010/2011 was also a major delaying factor, causing havoc in rural Northumberland. The deep snow and untreated roads often made all but emergency call outs impossible. As a result, the Health Care Professionals were unable administer the Carer Health Checks. Appointments had to be cancelled and rescheduled at a later date. This resulted in a delay to the programme of approximately four weeks.

8. Discussion

Potential unintended consequences

Some issues arose which seemed to suggest that **if follow up systems and resources were not in place then the health checks may conversely lead to unresolved issues or unanswered questions**. For example one respondent mentions the first check revealing very high anxiety and stress levels but that nothing was really done about this, the nurse 'hit a brick wall' . Another respondent told of a nurse saying they would get back in touch, but this never happened.

Others highlighted discomfort at the feedback mechanism for test results - they would only hear something if there were anomalies in the tests, one person identified the postal service as a weakness in this mechanism and suggested it would give more peace of mind if the nurse got in touch simply to say everything was normal.

Furthermore there is also an issue regarding follow up checks which appear to have been part of the original pilot but which due to resources and time issues may not have happened –again this may have left some carers in limbo, expecting another check which never materialised.

Positive benefits

For the group of carers interviewed **several positives seem to emerge from the experience of having the carer health check**. There were reported physical and psycho-social benefits associated with the check. For some signs and symptoms were picked up and addressed, while for others having the chance to talk to someone about their situation was beneficial, and may have assisted in lessening feelings of isolation or loneliness. Underlying the evident benefits described was a feeling that the health checks offered recognition of the carers situation and showed that they were valued. In addition some recognised that they avoided going to the GP as they felt they would be wasting the GPs time. However having the check at home or in another convenient location and carried out by a nurse avoided these feelings coming into play.

In addition, the 'busyness' of caring and a focus on the cared for means that carers often do not get around to looking after themselves. However **the health check gave recognition to the caring situation and legitimises the time for carers to think about, and take care of themselves**. It also offers the opportunity to talk and get new information, advice and help.

Overall the positive effects of the health checks seem clear, at least to the group of carers interviewed for this evaluation, however the potential for unintended consequences needs to be carefully considered by commissioners and providers of such services so that seamless care can be implemented.

9. Suggestions

The Carers Health Check is an important tool as it provides the carer with essential reassurance for both their medical and emotional needs and gives them confidence to continue caring.

Health Care Professionals need to recognise how important their role is in enabling the carer to continue caring and to understand the legitimate and separate needs of each carer on an individual basis. This needs to be consistent countywide.

The study highlights the need for Carers to have someone outside of their immediate situation to talk to, someone to listen to them. The Carers Health Check allows the Health Care Professional to share quality time with the carer and familiarise themselves with the carers situation. This opportunity to spend time talking about themselves rather than the person they care for was highly valued; it gave the carer a much needed feeling of recognition and reassurance.

It should not be forgotten that in many cases the caring situation is fluid, the everyday needs and pressures placed upon the carer often change as do the care requirements of the person they care for. Therefore it is vital that the Carers Health Check be conducted annually, with follow up appointments where required.

The study shows reluctance for carers to seek help for themselves, therefore a system that enables the Health Care Professional to contact the carer when their appointment is due (similar to dental appointments) would ensure that all carers are offered the opportunity to partake in a Carers Health Check. Such a system would require a maintaining a current database of carers at GP practices.

Any actions arising from the Carers Health Check must be followed up and test results should be fed back to the carer.

There needs to be more recognition from the Health Care Professionals of the expertise that third party organisations such as Carers Northumberland have to offer. They are ideally placed to work alongside the Health Service, offering additional advice and continuing support to the carer.

Carer Support Group Meetings organised by Carers Northumberland give the carer the opportunity to integrate with other carers where they can empathise, share experiences and support each other. During the interviews the Peer Evaluators often heard the comment “Oh **you** know, **you** understand”, because no one understands a carer better than another carer. The meetings are held at strategic locations across the county allowing carers access at a local level.

Referrals should be made by the Health Care Professionals to Carers Northumberland for each carer.

10. References

- ¹ HM Government (2010) Recognised, valued and supported: Next steps for the Carers Strategy. 1.15, 11
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- ³ Department of Health (April 2009) Carers Strategy Demonstrator Sites. Stage 2 Application Pack for Health Check for Carers. 8.3, 8
- ⁴ Northumberland County Council (2008) Northumberland Carers Strategy 2008 – 13. 8-9

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Appendix A: Carer Health Check Form

CHC 1
Julv 2010

Carer's health check record

Northumberland **NHS**
Care Trust

Name:

NHS Number: GP:

Address:
..... Post Code:

Telephone: Mobile Tel:

Carer lives at same address as person cared for: Yes/No

Caring tasks/responsibility has significantly reduced or ended within the last year: Yes/No

Assessor Name: Date:

Agreement to register with GP Practice as a carer (if option available): Yes/No

Consent to share the health check summary (this page) with GP Yes/No

1. Standard check and summary

Blood pressure	<input type="text"/> / <input type="text"/> mmHG		
Pulse rate	<input type="text"/>	Regular <input type="checkbox"/>	Irregular <input type="checkbox"/>
Height	<input type="text"/> M	Weight	<input type="text"/> Kg
BMI	<input type="text"/> Kg/m2	Urine	<input type="text"/>
<u>Blods</u>			
U/E	<input type="text"/>	RBG	<input type="text"/>
FBC	<input type="text"/>	Cholesterol Profile	<input type="text"/>
Pulse oximetry	<input type="text"/>		
Main health issues identified in this check (summary)	<input type="text"/>		
<u>Results</u>			
Carer Strain Index	<input type="text"/>	Abbreviated Mental Test	<input type="text"/>
PHQ9 Score	<input type="text"/>	Other (e.g. falls assessment)	<input type="text"/>

2. Health & healthcare

1. Do you have any health problems or long-term health condition(s)?

	Yes/No Detail:
--	------------------------------

2. Do you currently receive (or should be receiving) treatment? Yes/No

3. What medication do you take? (Include over the counter medication)

--

4. Family history of any long-term health condition(s)

--

5. Have you experienced any of the following? *(Tick)* *Action (Tick)*

Increased thirst	<input type="checkbox"/>	
Increased or frequent urination	<input type="checkbox"/>	
Unable to get to toilet on time	<input type="checkbox"/>	Continence assessment <input type="checkbox"/>
Blackouts	<input type="checkbox"/>	
Bowel problems	<input type="checkbox"/>	Consider abdominal check <input type="checkbox"/>
Chest pain	<input type="checkbox"/>	Consider cardio-vascular check <input type="checkbox"/>
Poor/restricted mobility	<input type="checkbox"/>	Mobility assessment required <input type="checkbox"/>
Falls	<input type="checkbox"/>	Falls assessment required <input type="checkbox"/>
Breathlessness	<input type="checkbox"/>	Consider cardio-vascular check – resp. assess <input type="checkbox"/>

6. Which vaccinations have you had? *(Circle)*

Seasonal flu / Pneumococcal / Other.....

7. If you have not taken up the offer of vaccination, why not? (e.g. access to surgery, care arrangements, time)

--

8. How good is your memory? *(circle)*

Memory function normal / Forgetful / Mixes past with present / Memory lapses

If indicated complete Abbreviated Mental Test
Full MIMS to be arranged (see Appendix 1)

Yes/No	Appendix 1
Yes/No	

9. Patient Health Questionnaire PHQ9

	Over the last 2 weeks, how often have you been bothered by any of the following problems?	‘Not all’ Score (0)	‘Several days’ Score (1)	‘More than ½ the days’ Score (2)	‘Nearly everyday’ Score (3)
1	Little interest or pleasure in doing things				
2	Feeling down, depressed or hopeless				

Total Score*

--

* If score more than 3, complete full questionnaire

Appendix 2

10. Do you have problems with any of the following?

Your eyesight? **Yes/No**
Your hearing? **Yes/No**
Your foot care? **Yes/No**

Your diet or preparing meals? **Yes/No**
Oral health or getting to the dentist? **Yes/No**

What would help you overcome these problems?

11. Smoking status (circle)

Never smoked tobacco / Ex-smoker / Smoker

Would you like advice about smoking cessation?

Yes/No

12. Alcohol

How often: (circle) **Monthly or less / 2-4 times per month / 2-3 times a week / 4+ times a week**

Drinks per occasion: (tick) 1-2 3-4 5-6 7-9 10+

3. Health relating to caring

1. Do you have any concerns about your health as it relates to your caring role/tasks? Yes/No

Ref. SP 2

i.e. are you worried that you might become ill or have an accident due to caring, (physical tasks, emotional stress, etc)?

2. Do you have any concerns about performing clinical tasks in your caring role? Yes/No

Ref. SP 3

(i.e. giving meds, cleaning wounds, etc)

3. Is the person you care for or anyone else ever abusive towards you, Yes/No

Ref. SP 4

this may also include people like loan sharks or anti-social neighbours?

4. Do you ever have thoughts about harming yourself or the person you care for? Yes/No

Ref. SP 8

Additional comments/information

4. Health history

1. When did you last visit your GP / Practice Nurse (approximately)?

/ /

2. When were you last offered a screening (approximately)?

/ /

3. If you have not taken up screening, why not?

E.g. do you have trouble getting to your GP;
Someone to stay with cared for.....

4. Number of admissions to hospital in last year?

	Details:
--	----------

5. Number of visits to A&E or by OOH doctor in last year?

A&E	Details:
OOH	

5. Support Services

1. Do you have contact with Care Management / Social Services; this may be through the person you care for?

Yes/No

Contact name (if known):

2. Are there any other health or social care professionals or agencies that support you e.g. mental health?

Contact name(s) (if known):

3. Have you had a Carer's Needs Assessment?

Yes/No/declined

4. Do you have a Northumberland Carer's Guide?

Yes/No

This is a purple information book, if no offer a copy or suggest referral to Carers Northumberland (Q6) who can supply one.

5. Are you registered with Carers Northumberland, a Princess Royal Trust for Carers Centre that supports carers in Northumberland?

Yes/No

6. Would you like someone from Carers Northumberland to contact you about further support? The support they can help with includes for example:

- A regular newsletter for up to date information
- Arranging a free home safety and access check
- Helping you decide if you need a benefits check
- Getting a carers emergency card
- Additional carer support
- Help to reduce social isolation and regain confidence

Ref. SP 11

Yes/No

6. Individual Carer Record. Before completing give the carer a *Participant Information Sheet* and ask them to sign the *Participant Consent Form*.

Date of Carer's Health Check:

1 Date of birth

2 Postcode

3 Are you ...?

Male

Female

What is your ethnic group?

Please tick one box only

White:		Mixed:		Asian or Asian British:	Black or Black British:	Chinese or other ethnic group:
White British <input type="checkbox"/>	White and Black Caribbean <input type="checkbox"/>	White and Black African <input type="checkbox"/>	White and Asian <input type="checkbox"/>	Indian <input type="checkbox"/>	Black Caribbean <input type="checkbox"/>	Chinese <input type="checkbox"/>
White Irish <input type="checkbox"/>	White and Black African <input type="checkbox"/>	Pakistani <input type="checkbox"/>	White and Asian <input type="checkbox"/>	Bangladeshi <input type="checkbox"/>	Black African <input type="checkbox"/>	All other ethnic groups <input type="checkbox"/>
White Other <input type="checkbox"/>	Any other Mixed background <input type="checkbox"/>	Any other Asian background <input type="checkbox"/>	Any other Black background <input type="checkbox"/>	Any other Black background <input type="checkbox"/>	Other Black groups <input type="checkbox"/>	

5 Which of the following best describes your situation?
Please tick one box; if more than one applies, tick whichever describes your main activity

- In paid work full-time In paid work part-time (30 hours or less per week)
- Self-employed Student
- Looking for work/unemployed Retired from paid work
- Permanently sick or disabled Looking after home or family full-time
- Other (please specify) _____

6 Over the last twelve months would you say your own health has on the whole been: Good Fairly good Poor

7 In the last week, how many hours of care do you estimate you have provided? (by 'care' we mean providing support or assistance to someone in poor health, who has a disability or who is frail because of old age)

Hours of care in the last week

8 How many people do you currently care for?

One person Two people Three or more people

In questions 9 to 12 please answer for each person you care for. (If you care for more than 3 people, please answer for the 3 people you provide the most care for.)

9	How long have you been caring for this person?	Person 1	Person 2	Person 3
	Less than 6 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	6 months – 2 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Over 2 years but less than 5 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Over 5 years but less than 10 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Over 10 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10	Is the person you care for ...	Person 1	Person 2	Person 3
	Your spouse/ partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Your parent/ parent-in-law	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Your grandparent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Your child or grandchild (aged under 20)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Your adult child or grandchild (aged 20 or over)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Another relative or family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Your friend/ neighbour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11	Is the person you care for ...	Person 1	Person 2	Person 3
	Under 15 years old	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Aged 16-19 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Aged 20-24 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Aged 25-64 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Aged 65-84 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	85 years or older	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12	Please tick each of the following if it describes the person(s) you care for:			
	The person you care for...	Person 1	Person 2	Person 3
	Has a physical disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Has a learning disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Has a sensory impairment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Has a mental health problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Is frail and/or has limited mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Has dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Has a long-term illness, is recovering from illness, or is terminally ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Has HIV / AIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Has problems related to substance abuse / addiction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Has other needs (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Support Plan Action taken as result of the health check (please tick box):

Some areas may need to be completed following results; **carers must consent to any referral or action**, either immediately at the time of check or through a follow-up phone call.

No further action required

Nurse follow-up

e.g. condition/medication information, further tests or treatment, etc.

Follow-up by GP

Referral to Care Management

e.g. a new referral or for re-assessment/additional support/ carer's needs assessment.

Referral to Carer Support Worker (Carers Northumberland)

e.g. for further information about carer support, arranging a free home safety and access check, financial information/benefits advice, arranging a carers emergency card, etc.

Other:

Vision services

Hearing services

Healthy Living Advisor

Oral Health

Podiatry

Smoking cessation

Alcohol advice

Safeguarding advice / action

Other (detail)

Appendix B: Interview instructions and schedule

The Interview – Carer

Introduction -

(before switching on the recorder)

Brief introductions – who you are (& you are a carer like them).

Explain simply what the project is about:

We want to find out how people feel about the health checks, what their experience has been and what differences the health checks may have made.

We are doing this so that carers views and experiences can be fed back to the care trust and can be taken into account when any future decisions or changes need to be made. We want to make a difference and have carer and ‘patient’ views heard.

Explain the interview process

The interview will last about 30 minutes – possibly a little longer but that is completely up to them – it will only last as long as they want it to (or as is convenient for both them and you).

The interview will cover:

their general thoughts and feelings about the health check and ,

their experience of having the health check.

Explain confidentiality and anonymity

Only you (interviewers), the secretary at the care trust and the research co-ordinators (A Steven Northumbria University & Tara Twigg North of Tyne NHS trust) will know their identity. Their identity (name and address) will be kept confidential (that is no one else will be told who they are).

The recording of the interview will be typed up by the secretary and all names will be removed so that it is anonymous.

Explain consent

They agreed on the letter to be interviewed –thank them for agreeing and ask if they are still happy to go ahead with the interview.

Ask if it is ok to record the interview

Tell them that they can stop the interview or change their mind about taking part at any point.

Interview questions/ topic guide

Switch on the recorder (place it somewhere between you and them e.g. on a coffee table, arm of the chair.

I'd like to ask a few questions about the health check you had...

1. How did you find out about the Carers Health check? (Were they invited/approached or did they ask)
2. At the time how did you feel about the idea of a Carers Health Check?
3. Did you think there could be any possible benefits to you from the Carers Health check? (Why have it?)
4. When did you have your Carers Health Check? (How long ago, or day of the week, did you have to wait long?)
5. Where was the Carers Health Check conducted? (Time/place convenient?)
6. Who performed the Carers Health Check? (Nurse or other?)
7. Do you think it matters who carries out the Carers Health Check?
8. How long did your Carers Health Check take? (Too long/short (why?) rushed?)
9. What about the questions asked/included within the health check – what did you think of them? (Issues, clear, ambiguous, difficult, appropriate or not, sensitive?)
10. Do you think anything was missing?
11. Have you seen any benefits? (e.g. have they had other screening or tests since the check, or have they been given extra help/advice, has anything happened as a direct consequence of the Carers Health Check?)
12. Has it made any difference to you? (Can they give examples e.g. has the Carers Health Check enabled them to stay healthy so they can continue to care, are they looked upon differently by their GP/surgery/nursing staff etc since having the Carers Health Check?)
13. Do you think others could/should be included in the Carers Health Check? (e.g. person cared for, or family, spouse etc?)
14. What do you think about current support for carers (GP, Care manager, Carers Northumberland)
15. The Carers Health Check was part of a pilot study. Would you continue to have regular health checks if it wasn't introduced?
16. In short, how would you summarise the Carers Health Check? (Its affect on you, its relevance to carers in general)
17. "I have no further questions is there anything you'd like to add?"
18. Is there anything that you've said during the course of this interview that you would like withdrawn from the transcript.

Appendix C: Ethical considerations

- The details of the sample contacted were not known to any of the group – in accordance with data protection this contact was undertaken by Northumberland care trust
- Only details of those volunteering to participate were made available to the evaluation group
- All of the Peer Evaluators signed confidentiality agreements
- All data collected was transferred to password protected university servers for safe keeping
- Participation was purely voluntary and participants were informed that they could withdraw at any point
- It was intended for two Peer Evaluators to conduct each interview; however because of the geographical spread and the low number of Peer Evaluators available it was necessary to conduct some of the interviews singly. Carers Northumberland has a 'safe lone working procedure'; this was followed for lone interviews.
- ID was presented before gaining entry into the carers home. Prior to commencing the interview the carer was given a brief reminder of the health check project, an explanation of the interview process, their confidentiality and anonymity assured, consent reaffirmed and permission to record the interview was obtained.
- In case of emotional distress the peer evaluation team carried phone numbers and information for support services such as carers Northumberland
- In case the peer evaluators suffered any emotional or other distress they had contact numbers for other members of the support team.
- After the interview, the carer was offered the chance to withdraw anything they had said during the interview recording to be deleted from the transcript.

Appendix D: Invitation letter

Dear Sir/Madam,

You have recently undergone a Carers Health Check. When you had your health check it would have been explained that it was part of a national pilot scheme of which Northumberland Care Trust had been invited to take part.

Northumberland Care Trust wants to find out how useful the pilot has been, to influence decisions about the best way to support carers in the future. To do this we need to ask those carers who participated for their views.

Feedback regarding your experience of your Carer Health Check would be of great value to us and we would therefore like to invite you to participate in the evaluation of this pilot.

If you received a Carers Health Check but are no longer a carer, we hope that you will still feel able to participate in the evaluation and give us your feedback. Your views are very important and valuable.

Please find enclosed an information sheet explaining how we would like you to feedback your experience and views. Should you require any further information please contact us on the telephone numbers or email addresses included on the enclosed sheet.

If you are interested in being involved please complete the reply slip at the bottom of the information sheet including your name and contact details and stating whether you agree that you are happy to be contacted by the evaluation team and if you require further information. Please also include any further information that you would like us to be aware of.

If you do not wish to be involved, please disregard this letter.

Please use the pre-paid envelope to return your reply slip by **Thursday 21st April 2011.**