

Doncaster Hospital Discharge Pathway Study: Interim Findings Report

BASHIR, Nadia <<http://orcid.org/0000-0002-1384-4849>>, GILBERTSON, Janet <<http://orcid.org/0000-0003-3338-7590>>, HAYWOOD, Annette, HOLDING, Eleanor and TOD, Angela

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Nadia Bashir

Jan Gilbertson

Annette Haywood

Ellie Holding

Angela Tod

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The findings presented in the report are however entirely the responsibility of the research authors.

Contact information

Name: Jan Gilbertson
Senior Research Fellow

Address: Unit 10 Science Park
City Campus
Howard Street
Sheffield
S1 1WB

Tel: 0114 2253539

Email: j.m.gilbertson@shu.ac.uk

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Summary

The aim of the Doncaster Discharge Pathway and Associated Discharge Services study is to undertake an in-depth qualitative evaluation of two investment areas of the Better Care Fund, formerly the Supporting and Maintaining Independence Programme (SMIP): the Hospital Discharge Pathway (HDP) and associated discharge pathways. The focus is to follow clients' journeys from hospital discharge in order to track client and carers' experience, impacts and outcomes.

Semi-structured interviews with participants are scheduled to take place within the first few weeks of referral, at or soon after 91 days (a point at which national targets for re-ablement are measured), and also at 6 months. Depending on the participant's circumstances, condition and preference the intention is to maintain regular but not frequent contact by telephone between interviews (at 6, 18/19, 39/40 and finally at 52 weeks) to obtain updates in relation to their care and outcomes

This interim report is based on face to face baseline interviews with 18 participants, as well as the 6 week catch-ups and 91 day face to face follow-up interviews with six of these participants.

Of the 18 participants included in this interim analysis 16 are female and 2 are male. Their ages range from the early sixties up the nineties with eleven of them over 80. Participants were extremely frail due to their age (>80) or chronic and acute health problems, and often experienced multiple health problems. Participants' vulnerability was extreme and complex in nature.

There were a variety of reasons why participants were admitted to hospital but the most common reason was as the result of a fall. Of the 18 participants included in this analysis, eight were admitted due to a fall. Four participants were readmitted to hospital within 91 days.

This report details emerging findings and themes. Using a handful of detailed client case studies the report provides an insight into the first 91 days of the client journey from discharge.

It should be noted the report is a partial picture of the data and the results should therefore be treated with caution. Themes may change or new themes emerge as the study progresses. Furthermore the purpose of the study and the report is not to evaluate specific services but provide a picture of how the hospital discharge pathway is experienced.

Emerging themes:

'A state of not knowing' what's happening and lack of awareness of services

Many participants didn't really know what was going to happen next and were in what we have termed **'a state of not knowing'**. Participants did not report experiencing the 'discharge pathway' and, in addition, had limited knowledge about any plans for their care that were being developed. Although some participants were content to see what would

happen (or were resigned to waiting), typically participants in the study were unaware of what was going to happen to them next and about the sort of services which would offer them help and support.

Entitlement 'a state of not knowing and not asking'

As well as a lack of information about what would happen next about the range and availability of services, it was apparent that participants did not know what support they were entitled to and what type of help they could expect. Being unsure about entitlement, combined with a limited knowledge of the available services, resulted in some participants not knowing they could ask for certain things, or left them not wanting to ask for help, and led to them feeling guilty about 'having' to ask. The reluctance to ask for help sometimes further limited the knowledge and understanding that the service(s) had of participants' needs.

Family, social networks and connections

Social networks and connections were extremely important with family, friends, neighbours and other support networks often making the difference for participants in the study. However, loneliness and social isolation were prevalent amongst participants. Participants were often reliant on family members to take them out and were unable to get out otherwise - many lacked awareness of other kinds of support that might be available to help them. Some participants (at least initially) were apprehensive about going out and socialising again and often faced practical and/or emotional (such as transport and confidence) barriers which they needed support to overcome.

Protecting independence and respecting autonomy

Participants valued their independence and, not surprisingly, wanted to maintain and/or regain as much independence as possible. A common concern highlighted by participants in the study was the extent to which they were recognised as a 'person' and dealt with as an individual by the staff and services along the discharge pathway. A number of participants mentioned wanting to be treated with respect, the importance of being listened to and not talked down to, and needing professionals to take time and have the patience to talk and listen to them.

Person centred services and the ability to tailor care to clients' needs

The ability of services to respond flexibly to a client's care needs and to tailor the way in which care was delivered to meet those needs was valued. Participants appreciated the flexibility offered by some services. What services could or couldn't do or were willing to do to meet their client's needs was a common concern. The lack of flexibility in the way in which some services were delivered or could respond to a client's needs didn't always make sense to participants in the study.

Communication

The communication participants were receiving was not always understood and it was often insufficient for them to understand what was going on. Vulnerability including problems with memory and confusion obviously made it difficult for some participants to access appropriate services and understand the processes and decisions made along the HDP, but it was apparent that participants and their families needed better communication (and not always more communication) so that they felt better informed.

Impact on participants, carers and families

Generally the impact of services was beneficial. Most participants in the study couldn't have managed without the short term intervention of services. Some participants were

dissatisfied with aspects of their care, and a few recalled horrendous experiences of hospital and of home care. Interventions usually provided invaluable support and often provided much needed company and interaction, helping to alleviate feelings of loneliness, with participants looking forward to carers' visits. Services gave reassurance to participants, family members and carers and helped take the burden off participants and their families. A common benefit for participants once they engaged with services was improved nutrition and hydration.

Emerging implications for practice so far:

The findings and themes which have emerged so far point to a number of implications for practice that DMBC may want to consider when planning for the health and wellbeing of adults in Doncaster. Some of the results also chime with recent recommendations made by NICE in their guidelines¹ on delivering home care and practical support to older people living in their own homes.

Improve practical help to get out and about, and provide additional support to (re)start socialising/activities

Exploring older people's aspirations to socialise and take up activities should be prioritised by relevant support services - the results in this study suggest there is considerable unmet (and unidentified) need in terms of older people doing what they want to do and going where they would like to go. Improved practical support and better community transport will obviously help combat problems of isolation and loneliness, but our results also highlight the importance and value of having someone to provide ongoing support to help overcome any fears and apprehension older and vulnerable people may have about re-engaging socially.

Re-examine routine ways of communicating with clients to improve their understanding of what is happening to them and the services they are receiving

Consideration of how and why information is communicated, the appropriateness and timing of information, and also who is giving the information - is it lots of different people or one person? - is needed. Services should assess how they approach communication and contemplate the possibility of doing things differently in order to enhance clients' understanding of what is going on, what services are available and what services offer. Things like service staff taking the time to introduce themselves properly and explaining what they do and how they can help, repeating messages, ensuring messages are communicated in tailored and accessible ways may help to promote understanding of services for clients and their families. Services should ensure adequate and regular follow-up on the information and advice received by clients in order to respond to any questions and uncertainties about their care and support.

Improving the ways in which a client's autonomy is respected and recognised by services and ensuring that care is person centred, flexible and holistic

Clients want to be recognised 'as people' by the services they are dealing with and treated with dignity and respect. Services need to take the time to listen to clients' needs and show patience when dealing with users. Support services should aim to focus on enabling clients to do what they would like to do in order to maintain their independence. This may involve longer visits for those receiving home care and demands much more flexible and holistic approaches to the way services are delivered. Clients, carers and families should be involved in all decisions about care and support and need to feel that what they are saying is

¹ NICE Guideline (2015) Home care: delivering personal care and practical support to older people living in their own homes nice.org.uk/guidance/ng21

being respected, adequately considered and taken on board, and is not being overlooked. Clear and mutually agreed expectations of what support services will deliver would help avoid any uncertainty experienced by clients when it comes to knowing about what they can expect and ask for from care and support services.

Introduction

This report documents the interim findings from the independent evaluation of the Doncaster Discharge Pathway and Associated Discharge Services by the Centre for Regional Economic and Social Research (CRESR) at Sheffield Hallam University undertaken with the School for Health and Related Research (ScHARR) at the University of Sheffield. This project is part of a larger programme evaluation of Better Care Fund activities formerly those for the Supporting and Maintaining Independence Programme (SMIP) in Doncaster. The evaluation team is working in partnership with Doncaster Metropolitan Borough Council (DMBC).

DMBC are interested in finding out about the client experience from hospital discharge. Whilst ASCOF 2b data provides figures on those who remain at home 91 days after hospital discharge, little is known about how well people are actually coping and what their experience has been like. The aim of the Doncaster Discharge Pathway and Associated Discharge Services study is to undertake an in-depth qualitative evaluation of two investment areas of the Better Care Fund: the Hospital Discharge Pathway (HDP) and associated discharge pathways. The focus is to follow clients' journeys from hospital discharge in order to track client and carers experience, impacts and outcomes.

It should be noted that the purpose of the study is not evaluate any particular service, rather it provides a unique insight into what navigating the health and social care system feels like to those who are experiencing it.

The HDP study received final NHS ethical approval (and Doncaster and Bassetlaw Hospital authorisation) in September 2014 and runs till the end of March 2016.

1.1. Recruitment and sampling

Originally it was anticipated that recruitment to the HDP study would take place at two points, summer/autumn 2014 and winter 2014-2015. The idea being that by recruiting clients at different times of the year we would be able to compare the outcomes for the two groups as they experience services under different seasonal pressures. Staff from the HDP would approach participants and help the research team recruit up to 15 clients at each time point, summer and winter, up to a total sample of 30 clients. It was expected that initial recruitment would come via staff from the Integrated Discharge Team (IDT) at the point at which clients are referred on to the associated discharge pathway services, with subsequent recruitment being conducted by staff from other discharge pathway services as appropriate and in line with emerging findings.

Despite concerted efforts initial recruitment to the study proved challenging, and when combined with pressures on the IDT only a handful of clients were recruited by the end of 2014. To increase recruitment the research team have worked closely with DMBC exploring various options for approaching participants (see Challenges

so far below) and engaged the Home from Hospital (HFH) service and the Positive Step service to help with recruitment. All the participants in the study have been recruited via one of these services. Key staff members from these services helped co-ordinate recruitment within that service and provided advice regarding a client's potential eligibility. Staff discussed the project with the client, provided an information sheet and elicited agreement for contact with the researcher. Researchers then contacted the client, explained the study in more detail, gained consent to take part and arranged a face to face interview.

Delays in the recruitment process means it has not been possible to recruit two distinct cohorts of participants (summer and winter) to the study. Instead a total of 22 participants have been recruited between November 2014 and July 2015. Accordingly, some participants will be followed for around 6 months rather than 9 or 12 months.

1.2. Data collection and analysis

Following consent, interviews have taken place in the participant's home or care facility as appropriate and in accordance with the participant's wishes. Interviews with participants are scheduled to take place within the first few weeks of referral, at or soon after 91 days (a point at which national targets for re-ablement are measured), and also at 6 months. Depending on the participants circumstances, condition and preference the intention is to maintain regular but not frequent contact by telephone between interviews (at 6, 18/19, 39/40 and finally at 52 weeks) to obtain updates in relation to their care and outcomes (see Figure 1: Study Flowchart, below). The purpose of telephone contact is:

- To track the participant's movement across the pathway.
- To maintain the engagement of the participant in the evaluation.
- To obtain a short update on the participant's health and wellbeing, care needs and delivery.
- To help if recall and memory of the participant is impaired.

Throughout the study we are keeping in contact with up to two key stakeholders (as appropriate) involved in the client's care. Examples may include a family member, informal or formal caregiver. This enables us to include the carer's perspective and helps insight if the client has poor recall or memory. As indicated by the emerging findings, telephone contact is also made with the key stakeholders in between interviews, as with the main participant.

Interviews are semi-structured and conducted using a topic guide developed from relevant literature and through discussion with the project team. Interviewers are all experienced researchers used to working with vulnerable groups. Interviews are audio recorded transcribed and all identifying details removed to protect anonymity. So far members of the research team have read through transcripts and met to discuss emerging issues and themes. A thematic coding framework has been developed and data has been entered onto QSR NVIVO for storage, management and analysis.

1.3. Challenges so far

Getting the HDP study off the ground, setting up meetings to discuss the study with the appropriate service staff, providing sufficient information and support for staff to feel comfortable enough to approach clients about taking part in the HDP study took time, and initial recruitment through the IDT was slow. One of the main reasons why

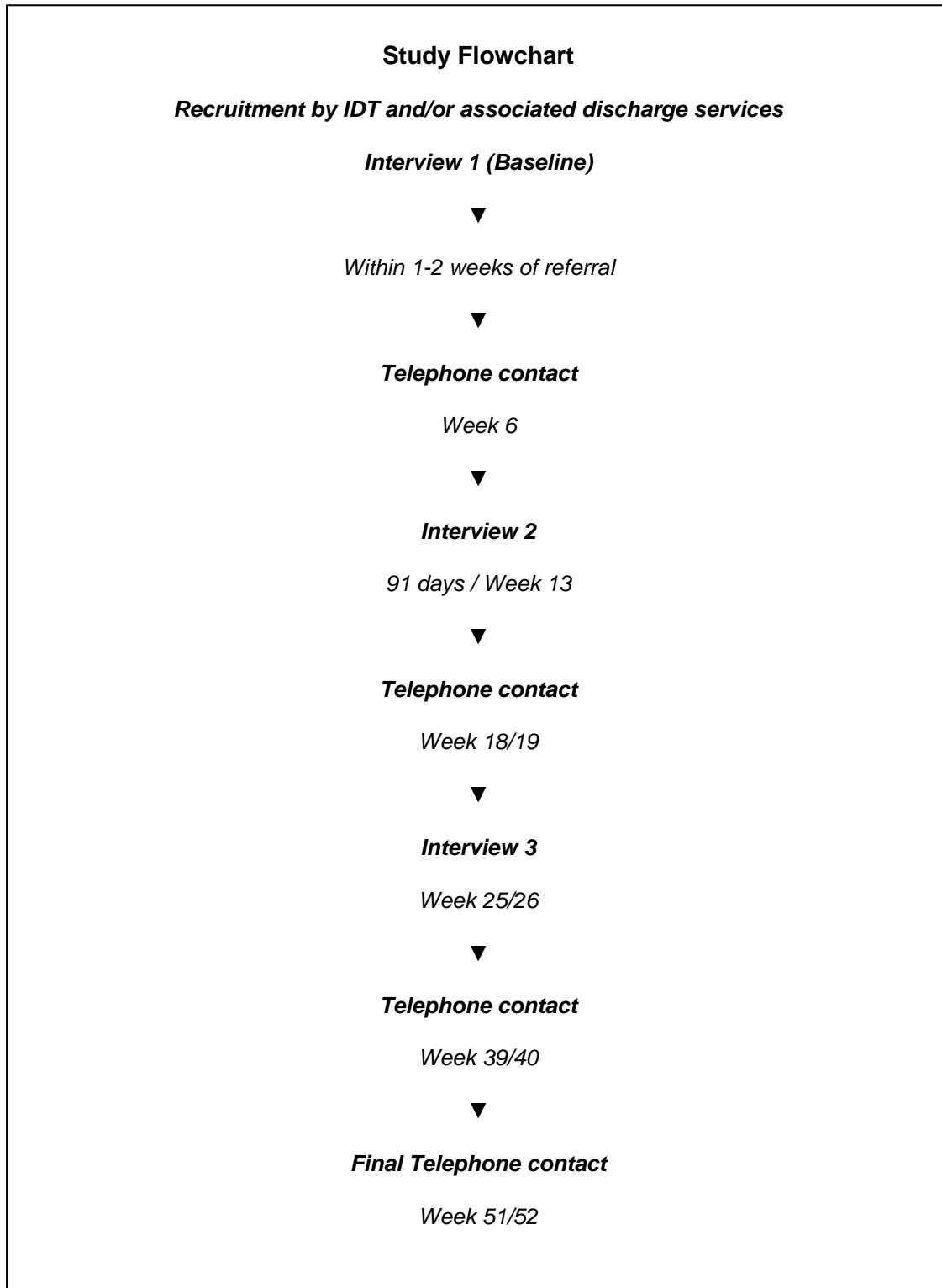
numbers were low initially was staff kept forgetting to ask patients whether they would be interested in taking part in the study. There was some reluctance to ask clients about taking part in the study and, perhaps most significantly, intense seasonal pressures on the IDT at the time. Subsequently, researchers attended the IDT monthly meeting to inform more staff about the study and consulted about how best to approach potential participants. Study information was included in the IDT fact finding assessment process at Doncaster Royal Infirmary (DRI) to increase the likelihood of fact finding staff routinely approaching clients to see if they would be willing to participate and be contacted by the research team, but very few potential participants came through.

In order to overcome the problems of low recruitment at the beginning of the HDP study options for amending recruitment, improving support for recruitment, changing the follow-up period and extending the study timescale were discussed and explored in partnership with DMBC. These included increasing recruitment through the HFH and Positive Step services, utilising DRI research nurses in recruitment, situating a DMBC member of staff in the hospital discharge lounge to help with recruitment to the study. Unfortunately, it was not possible to utilise research nurses in the study and the member of staff who was going to recruit participants from the discharge lounge was ill and off work for some time. Attempts to recruit participants from other discharge pathway services were more fruitful and by early 2015 there was a steady flow of participants via Positive Step and the HFH Service.

Following HDP participants has proved to be resource intensive with the anticipated short 'catch ups' proving particularly time consuming. The health problems suffered by many participants (e.g. hearing, mobility and other mental and physical difficulties) make telephone catch-ups difficult, and a large number of planned telephone catch-ups have had to be done face to face. Arranging any catch-up, either telephone or face to face, takes a lot of time and usually involves contacting a carer/family member to find out where the participant is and whether it is okay to contact them. A carer/family member (with prior permission from the participant) may also be able to provide further information about the participant's care, which then has to be written up in addition to the catch-ups. The task of locating a participant (particularly those without family/carer) at any point during study can be very time consuming, and the geographical spread of participants' locations makes it difficult to visit more than two to three participants in a day. Given that face-to-face catch-ups may be the most viable option to keep in touch, short catch ups are especially demanding of resources.

In light of these challenges, and to stay within the existing project budget, it was agreed with DMBC to recruit 20 participants to the study rather than the planned 30 participants. Resource constraints have also restricted the capacity of the project to work with other services in order to extend recruitment beyond Positive Step and the HFH service. Agreement to recruit fewer participants (and subject to drop out rate) will enable the project to stick to the original project timeline.

Figure 1: HDP study flowchart



1.4. About this report

To date we have conducted the following:

- 22 face to face baseline interviews with participants (usually within two or three weeks of discharge, and sometimes less),
- 20 six week catch-ups (telephone and face to face),
- thirteen 91 day face to face follow-up interviews,
- seven 18 week catch-ups (telephone and face to face),
- two 25/26 week face to face follow up interviews.

So far drop-outs have been less than expected, we have lost contact with one participant and two participants have decided not to continue with the study. Nineteen participants remain in the study.

This interim report is based on face to face baseline interviews with 18 participants, as well as the 6 week catch-ups and 91 day face to face follow-up interviews with six of these participants. The report details emerging findings and themes from these interviews and provides a thorough analysis of the baseline position of most of the participants in the study. Using a handful of detailed client case studies, the report starts to offer an insight into the first 91 days of the client journey from discharge. It should be noted the report is a partial picture of the data and the results should, therefore, be treated with caution. Themes may change or new themes emerge as the study progresses. Furthermore, the purpose of the study and the report is not to evaluate specific services, but provide a picture of how the hospital discharge pathway is experienced.

The rest of this report is structured as follows:

- Section 2: Profile of the HDP study participants.
- Section 3: Emerging findings and themes.
- Section 4: Client case studies: the first 91 days.
- Section 5 Emerging implications and next steps.

Profile of HDP study participants

As mentioned this interim report concentrates on 18 participants involved in the HDP study, six of whom have been followed to 91 days after discharge. This section of the report provides some detail on their characteristics, and briefly outlines their conditions and circumstances.

2.1. Characteristics

Of the 18 participants included in this interim analysis 16 are female and 2 are male. Their ages range from the early sixties up the nineties. Most participants (11) are over 80, and three are under 70. The men in the study are both in their seventies.

2.2. Reason in hospital

Although there were a variety of reasons why participants had been admitted to hospital including a knee replacement operation, a mastectomy, complications with a tooth infection and urine infections, by far the most common reason for participants in the study to be in hospital was as the result of a fall. In total eight participants had fallen, including falling out of bed or chair or had fallen on the doorstep. Some had experienced periods of falling more frequently which had finally resulted in them being taken into hospital. At least six participants who mentioned falling said they had previously been in and out of hospital.

Of the 18 participants included in this analysis four were readmitted to hospital within 91 days.

2.3. Characteristics

Of the 18 participants included in this interim analysis 16 are female and 2 are male. Their ages range from the early sixties up the nineties. Most participants (11) are over 80, and three are under 70. The men in the study are both in their seventies.

2.4. Reason in hospital

Although there were a variety of reasons why participants had been admitted to hospital including a knee replacement operation, a mastectomy, complications with a tooth infection and urine infections, by far the most common reason for participants in the study to be in hospital was as the result of a fall. In total eight participants had fallen, including falling out of bed or chair or had fallen on the doorstep. Some had experienced periods of falling more frequently which had finally resulted in them being taken into hospital. At least six participants who mentioned falling said they

had previously been in and out of hospital. Of the 18 participants included in this analysis, four were readmitted to hospital within 91 days.

2.5. Health conditions and vulnerability

Many participants were extremely frail due to age (>80) or chronic and acute health problems and often experienced multiple health problems. Participants' vulnerability was extreme and complex in nature. Participants were typically vulnerable because of their age, illness, lack of mobility, physical and mental health conditions, confusion, falls, social isolation, a lack of support, location, poor nutrition/hydration, and due to low income and/ or financial worries. Based on the data from this project it is possible to see how, because of their vulnerability, some participants would struggle to access appropriate services and understand the processes and decisions made along the HDP when they are navigating the health and care system.

Emerging findings and themes

This section of the report presents the emerging findings and themes from the analysis so far. It is based on data from 18 baseline interviews with participants, short catch ups and 91 day follow ups interviews with six of the participants. Given that the study is ongoing, these results should be treated with a degree of caution as some themes may change and new themes could emerge as the 'client journey' continues. Nevertheless, the data presented provides a picture of typical client experiences of the first 91 days from hospital discharge. At baseline we usually spoke to participants within two to three weeks of discharge (sometimes sooner and in a few cases longer). All the baseline interviews either took place at the participant's home (7) or at Positive Step (11). At the 91 day follow-up interviews some participants had moved back home or into care. A small number of 91 day case studies are presented in the Section 4 of the report.

3.1. 'A state of not knowing' what's happening and lack of awareness of services

A small number of vulnerable participants in the study were a little uncertain or confused about some of the details leading up to their hospital admission, what had happened to them, and reliant on family members to fill in the gaps.

R: Well according to my husband I had some kind of a seizure, he said I was sitting in the chair at the side of the fire and it was winter time and he said suddenly I waived one arm in the air and stretched my legs out and my body went rigid, so the doctor said I could possibly have had an epileptic fit but I haven't had one before so I don't know whether it was that or not.

(Participant 18, female aged 83, Positive Step)

And:

R: My daughter and she told me that I'd banged my head when I fell out of bed, my dressing table were there.

(Participant 15, female aged 83, Positive Step)

Some of the more vulnerable participants were also unsure of how and/or why they had been sent to a social care assessment unit.

I: Did you find out about this service at the hospital?

R: No not really, I just found myself here and I thought 'what's happening?'

I: But you don't remember?

R: I don't remember.

(Participant 7, female aged 80, Positive Step)

And:

I: You were saying you were dropped off here you didn't have any clue?

R: I didn't know anything about it, they didn't tell us anything just that it was all right, we'd be ok, but they wouldn't tell us anything that happened or what happened.

(Participant 9, female aged 68, Positive Step)

When researchers first spoke to participants many (particularly those who were at Positive Step) felt unsure about what was happening and what was going to happen next.

I: Have you got any idea about whether you'll go home or whether you'll be offered further support?

R: I don't know anything, they haven't said...

(Participant 5, female aged 88, Positive Step)

For some, the experience of being in a social care assessment unit or in hospital was new and they felt they needed more information to help them understand what was going to happen and who could help:

R: I don't know the titles, it's all new you see, care worker, social worker, I don't know all the titles.

I: Would you like to know that, would that information be important to you?

R: Yeah...titles for the people who can help you

(Participant 14, male aged 71, Positive Step)

Issues related to care were not something that a number of participants had thought about before, and it was not until they were in hospital or at Positive Step or receiving support through services like HFH that they had become aware of such services:

R: I didn't know anything about anything like this until I went in hospital.

I: Who told you about this service?

R: I heard in hospital but I don't know who told me or I just heard about it, I can't think who it was.

(Participant 9, female aged 68, Positive Step)

Given that baseline interviews were often within a few weeks of hospital discharge it might be expected that participants would be uncertain about what was going on, but it was evident that even those participants discharged for longer periods lacked awareness of what would happen next. Some participants did not know about other services and support which might be available to help them when they returned home:

I: What's going to happen next for you?

R: I go home on Thursday and I don't know what will happen then.

I: Have they talked to you about any support that might be available when you go home?

R: They said I may get some support when I go home as regarding managing and so on but I don't know what

(Participant 9, female aged 68, Positive Step)

And another:

I: When you go back home tomorrow will that care service start up again?

R: I was wondering if I could not get some [other] support somewhere, cos I'm sure there must be something somewhere.

(Participant 4, female aged 90, Positive Step)

Accessing information and finding out about services could be a matter of chance or luck and was generally more difficult for the socially isolated participants in the study. Information about services sometimes came via a family member or from other social connections and networks:

R: I think it would be nice if there was more information for the lay person, if it hadn't been for my daughter I wouldn't have known [about HFH]

(Participant 6, female aged 62, Home)

And:

R: I know nearly as much as they do through the church is excellent, being a member of the church, it's home from home... there's always... you're never lonely, there's always people there, always people popping in. I've found church very very helpful, and I'm happy there, there's everything I need.

Later in interview:

I: Do you feel you know what sort of help and support is available out there?

R: I do, I think that it can be given out a lot more, to tell people... I'm lucky cos I mix with the sort of people that know all these things, but there are some people that don't mix.

(Participant 7, female aged 80, Positive Step)

At baseline a small number of participants obtained additional information (and/or referral) from the services they were engaged with. For example, one participant mentioned finding out about a meal delivery service at Positive Step and was considering having meals delivered for the three days a week she would be alone at home when she left Positive Step. Another participant's son had found out about the HFH service via Doncaster's Carer's service. His mother, who was usually the main carer for his father, was in hospital and needed additional support when she was discharged. The HFH service put this participant in contact with additional services that could help her. As a result, she had accessed a laundry service, received information about chair based exercise which her and her husband were interested in, found out about Wiltshire Farm Foods, and the HFH service were looking into arranging door to door transport for her. The participant had also been trying to sort out the emergency contact scheme to provide short term emergency care cover to look after her husband should something happen to her again. She felt Age UK's involvement had helped to 'make things happen':

I: So their involvement has made some things happen?

R: Yes

I: And they've made you aware of some other services?

R: Definitely

I: And it seems you might take some of them up?

R: Yes

I: So now do you feel you're in a position where you know what help and support is available out there?

R: Oh yes a lot more.

(Participant 10, female aged 82, Home).

But, it was evident that many participants lacked awareness of the range of services available and did not always fully understand what particular services offered and how they could help.

I: Do you understand what this service is about? Why this service is in place?

R: Mainly what I've read on there, it's a pathway for people to get better, that's all I know.

(Participant 9, female aged 68, Positive Step)

At times participants were unsure about the range of help that services could offer and were unclear about which services were delivering help and care to them.

I: Did you understand what type of support Age UK were going to provide you with when they spoke to you at hospital. I've spoken to you before and you didn't expect somebody to come and help you to make the bed or clean the house?

R: That lady, I was shocked.

I: Cos when she helped to make the bed you actually asked her if she wanted payment?

R: Yes that's cos I knew I had to pay.

I: Through social services?

R: Yeah

I: Cos Age UK isn't social services.

R: No I know that now.

(Participant 1, female aged 70, Home)

At baseline many participants didn't really know what was going to happen next and were in what we have termed '**a state of not knowing**'. Participants did not report experiencing the 'discharge pathway' and in addition, had limited knowledge about any plans for their care that were being developed. Although some participants were content to see what would happen (or were resigned to waiting), "No "I've no idea. I'll see as it comes," typically participants in the study were unaware about what was going to happen to them next and about the sort of services which would offer them help and support.

3.2. Entitlement 'a state of not knowing and not asking'

As well as a lack of information about what would happen next and about the range and availability of services, it was apparent that participants did not know what support they were entitled to and what type of help they could expect.

R: I don't know anything cos we've always worked, we've never asked anybody for anything, we've earned our money and spent our money how we wanted, it's my own home, it's paid for, everything's paid for but that's a long time since. It's a big house for me, I have to keep it clean from top to bottom, how can you do it when you ain't got legs?

(Participant 11, female aged 89, Home).

And:

I: And it seems you're not fully aware of what you're entitled to?

R: Mm, somebody did say something about once going to a centre for something I don't know what it is.

(Participant 4, female aged 90, Positive Step)

Participants who were already (or had been) receiving care at home were sometimes unclear about what they were entitled to and what was and wasn't allowed as part of their care package.

Being unsure about entitlement, combined with a limited knowledge of the available services, resulted in some participants not knowing they could ask for certain things, or not wanting to ask for help, and to feeling guilty about 'having' to ask:

R: I honestly have not given it any thought. If they said to me 'this is on offer, that's on offer, that's on offer, which would you like?' I could say, but just to say 'I would like this, I would like that'...

I: But you would like to get out and about?

R: Yes

(Participant 9, female aged 68, Positive Step)

Participants who wanted to maintain as much independence as possible felt they should be doing things themselves and were reluctant to ask for help. One participant receiving support from the HFH service commented:

R: So yes it has helped me, but yesterday when the lady came I said to her 'I feel guilty you doing all this cos I thought I could do it' but it just takes that burden off you, so maybe I might try to have somebody come every so often, my sons want me to do that.

(Participant 10, female aged 82, Home)

Not feeling able to ask or feeling guilty about having to ask sometimes meant that participants' needs were not always being discussed or picked up. For example, one participant who was reliant on a wheelchair, and seemingly well informed and supported through her church connections, discussed how even though she was able to get out and about she didn't like having someone to push her wheelchair and felt 'terrified' of going out .

R: You need the support to go out. I'm terrified of going out, even though I've got a lot of support. I have a wheelchair but you don't like to think someone's going to push you, and I think how do I cope with that, now I'm saying it, I'll have to stay in I'm saying, but I know I won't but there are some people that will. How do you cope with this? I can't answer that myself, but I am frightened of going outside, I'm nervous, I think there ought to be more help out there.

On occasion a participant's reluctance to ask for help further limited the knowledge and understanding that the service(s) she was already engaged with had of her needs:

I: Have you told them about your loneliness?

R: I've told ones of them [other residents at Positive Step] that I was lonely; we've all said we were very lonely; we've all gone through falls and that.

R: What about staff here, have you told them about your feelings?

R: No

I: I guess if you did tell them about your feelings and your concern about going back [home] and being alone again, just to tell them about how low and tearful you've been feeling...

R: I don't want to burden them with it though.

I: It's their job.

R: No it's not, you go to a job to earn money to live on but you don't go...

I: But if they were aware of the problem they might be able to make some suggestions in terms of what options or opportunities there are out there for you to get out.

R: I hadn't thought of that.

(Participant 9, female aged 68, Positive Step)

It was noticeable that many participants wanted help to get out and about and some were worried about returning home and being alone again. Few participants seemed aware of the opportunities or support services available to help them start socialising again (see 3.3 Family, social networks and connections, below).

3.3. Family, social networks and connections

Social networks and connections were extremely important with family, friends, neighbours and other support networks often making the difference for participants in the study. Support from family members typically included being the participant's main carer, making meals, doing the housework, shopping and other household chores (like gardening and maintenance) and visiting the participant regularly. For example, a participant described how her son helped her:

R: He's good, he's hoovered through while I've been in hospital, he's made sure I've got all the old stuff chucked out of my fridge, cleaned my fridge out, restocked it with what I need. I'll not go hungry, I've got a cupboard full of tinned stuff, he's really good like that. He was out on a job this morning and he popped in 'hi ma, it's only me'....he come in and had a cup of tea and a sandwich cos it was break time and then 'I'll have to go, I'll see you tonight'. He always phones me up, tonight he comes to me and has a cup of tea but he'll go to his son's for his dinner about 6 o'clock.

(Participant 13, female aged 82, Home)

In a few cases family members were involved in helping a participant to sort out their care and /or provided information which enabled a participant to access support. For example, one participant only accessed help from the HFH service because her daughter, who works as a carer, knew about the service. Another participant's sister was supporting her and helping with discussions about care options:

R: People are listening, I'm getting somewhere at last.

I: Do you feel that?

R: I've made a start.

R (sister): I've spoken to the occupational therapist, the good thing is I've come today cos I've been away for the weekend, my sister went to the hospital on Friday and she'd just left so came at tea time here on Friday, I didn't get back till yesterday so it's a good job I'm here cos she does get confused and I'm trying to help out regarding what she's forgotten. I've just gone through quite a lot with the OT and she seems very helpful, she's also getting a CPN nurse involved, a social worker. So hopefully if you feel happy with what's happening that's positive isn't it?

R: Yeah

(Participant 2, female aged 70s, Positive Step).

There were often barriers to family support. Participants didn't always ask for help, didn't want to make a "fuss" or be a burden, recognising that family members often had other commitments such as work and children:

I: So you've got family support?

R: Yeah

I: Are your family busy?

R: Yes [daughter's name] has four little kids and [son's name] a night time lorry driver so biggest part of time he has to sleep in day.

I: So would you call on them if you needed something?

R: Well I haven't done.

(Participant 1, female aged 70, Home).

For some, family were supportive but lived far away and this limited the amount of practical support they could provide. There were also examples of family members regularly travelling some distances to help out and/or support other relatives who lived nearer to the participant and who had the main responsibility for the participant's care needs:

I: You say family and friends are busy?

R: Well they work, most of them, my daughter works, her husband works, not that he had a lot to do with me, he's all right but he's not that type to do things, and then there's my son, mind you he has more time hopefully but he's retiring this year, but they've a caravan which he'll be away at a lot and you've got to think about their life.

I: You say your daughter does the most for you, what sort of things would she do for you?

R: She does what she can.

I: who goes shopping for you?

R: My daughter usually. I have another daughter but she lives down south, near Norwich.

I: So she's far away, so I guess she can't help out much?

R: No, she comes once a month, she comes on the Friday and goes back Sunday.

(Participant 5, female aged 88, Positive Step)

In some instances (especially for elderly participants) family members were in poor health, or had become ill as well, which meant they could no longer help or could not help as much as they had done before:

I: So in terms of support and care it's not always going to be possible for your family to give you everything you need?

R: No, if [daughter's name] was to become poorly she'd have to stop at that end cos her daughters are at that end.

I: And [son's name] not been very well and you said before we started recording you ended up having to look after him?

R: I looked after him yeah.

I: And you're managing but...

R: If my daughter were to take poorly that would be another thing again.

(Participant 11, female aged 89, Home)

In some cases where family did help out, the amount of assistance that a participant needed could not be met by family support alone, and the participant needed and/or received additional care and/or practical support.

Some participants in the study had no family or other forms of support, or had emotionally distant family relationships. Family were sometimes unhelpful and in one or two cases were not very nice and could be regarded as part of the problem. One participant whose husband had died two years previously and who suffered with depression and felt extremely lonely talked about not getting out much and not seeing her daughter. Her daughter's attitude and lack of support were contributing to the participant's anxiety about going home:

I: Do you live in a very isolated...

R: No not really isolated but it is from shops, it's quite a walk from shops and I had a car but my daughter got rid of that and got one herself and I paid for that, she wanted one to do my shopping so she's got the car so I can't go anywhere now without she takes me but she won't take me.

I: And you don't get out and about at all?

R: No

Later in interview:

R: I thought I was happy at home, but now they're all saying 'yeah but you were this, you were that, you were useless' I'm not happy now about going home.

I: And that's cos family are saying that?

R: Mm, me daughter came the other day to a meeting and she says 'my mum's got to understand she hasn't got to keep ringing me if she wants something cos I'm busy' I thought 'I would be when you were little but I still brought you up and

did what you wanted' that really upset me, I thought 'I'm your mum, I had you and brought you up and even though I was busy I still saw to you'.

(Participant 9, female aged 68, Positive Step).

Loneliness and social isolation were prevalent amongst participants. A number of participants mentioned being or feeling like they were on their own "I'm always on my own", and many wanted to get out more and/or to take up activities they had once enjoyed. Participants were often reliant on family members to take them out and were unable to get out otherwise - many lacked awareness of other kinds of support that might be available to help them. A number of participants talked about how they didn't get out as much as they used to and missed socialising.

R: ... but I started going to bingo just at the top there, it's old folk, I don't drink and my daughter took me up there yesterday and you'd just think you'd gone into a family, it were lovely to see everybody, that's what I miss, I miss doing for other folk.

I: But you need someone to take you?

R: My daughter has to take me in the chair and she takes a book up and reads a book while I'm having a game of bingo but it got a bit too much for me and she had to finish off, cos I hadn't done it for such a long time and I got a bit overcome.

(Participant 11, female aged 89, Home)

And:

R (sister): This is where my brother came in, she used to meet him at the pub, I don't drink so it's not something I would do, especially in the afternoon it's the furthest thing from my mind, but they used to go down and socialise.

I: Do you miss that?

R: Yeah

(Participant 2, female aged 70s, Positive Step)

And:

I: Do you manage to get out, before going into hospital were you getting out?

R: The only time I got out was on a Friday when my daughter used to come, and if I felt well enough, she'd take me in the chair in the car but if not she just ... otherwise I don't get out at all.

NB: Would you like to?

R: Well yes. On a Thursday I go to the hairdressers in the next street and I get a taxi from the top of the street, he takes me, but apart from that...

(Participant 4, female aged 90, Positive Step)

One participant with mobility and other health problems had experienced particular difficulty and frustration getting out of his top floor flat. He was on a council waiting list for a ground floor flat but was concerned that he would leave Positive Step and have to go back to his old flat. A couple of other participants at Positive Step were concerned about going home and being alone and ending up how they were before.

Being in a social care assessment unit such as Positive Step or having carers or other services at home, provided much needed company and social interaction and many participants looked forward to their carer's visit:

R: In here you've got company with you all the time and that's good if you're like I was lonely

(Participant 9, female aged 68, Positive Step)

R: I like them who come now, we have a laugh and a joke, I love them who come now.

(Participant 3, female aged 70s, Home)

R: the girl's all right and she's good company, she knows the village so we get a bit of chat...

(Participant 11, female aged 89, Home)

A number of participants also emphasised the important role that care services in their home played in terms of providing a sense of security 'someone knowing I'm there'.

Although some participants had had discussions with service staff about opportunities which could help them or were starting to receive help to start socialising (for example through the HFH service), some (at least initially) were apprehensive about going out and socialising again and often faced practical and/or emotional (such as transport and confidence) barriers which they needed support to overcome.

R: People are saying that [about day centres] but I've got to go there, that's what...

I: So in terms of getting there would be a problem for you?

R: Well I don't [know] where it is and going.

I: If there was a service where you were picked up in the morning and then dropped off afterwards do you feel that sort of service...

R: Yeah that would be all right.

I: So it's not about you lacking the confidence to go, it's about the practical things that you need to get there?

R: Yes it is.

(Participant 9, female aged 68, Positive Step)

And:

I: How do you feel about going to the day centre?

R: All right.

I: Is it something you'd like to do?

R: I'm not looking forward to it but our [name] will help me.

I: Why are you not looking forward to it?

R: I don't know.

I: Are you a bit nervous?

R: Perhaps.

(Participant 3, female aged 70s, Home)

(Also see Mrs A case study in Section 4 of the report which highlights how support to go to the day centre helped the above participant).

3.4. Protecting independence and respecting autonomy

Participants valued their independence, and not surprisingly, wanted to maintain and/or regain as much independence as possible. For a couple of the younger participants in the study (one aged 62 who had had a knee replacement operation and another aged 69 who had had a mastectomy) it was a case of getting back to normal living as quickly as possible. For both respondents the HFH service was providing the necessary practical support (shopping, housework, helping arrange transport for appointments) they needed in order for them to regain their independence. For one of these participants, who had little other social support, the HFH service had sorted out many of the practicalities which enabled her to proceed with the operation (she was put in touch with the service by a Macmillan Nurse prior to hospital admission) and cancer treatment. For the other participant the service meant she had not had to rely on family too much.

R: ... I've always managed on my own, I'm an independent person, you've got to be, you can't keep relying on people, so until this happened I'd never thought about anyone helping me for anything, I manage everything on my own, you have to. So if it hadn't been for Age UK I would have been relying on the family again.

(Participant 6, female aged 62, Home).

Older participants and those with multiple health problems wanted to maintain or hold onto whatever independence they had. One participant who had suffered a serious stroke in her 40s and also had other health problems explained:

R: I said 'oh I'll be all right' I used to be slow but I used to, I still dress myself now.

I: So you'd rather do it yourself than ask somebody?

R: Yeah, I don't do it cos I'm showing off, I do it cos I feel... I want to try and keep like that.

(Participant 15, female aged 83, Positive Step).

Some participants were already receiving care at home, had cleaners, gardeners to do chores and/or received vital support from family, friends and neighbours which helped them to live independently as possible:

R: Yes I have them for four hours a day.

I: So they come in the morning?

R: And come back after evening meal.

I: What kind of support do they offer you, what do they do?

R: Mostly food of course and whatever I want them to do.

I: Is that a service that makes a difference to you?

R: Yes, I haven't been able to stand without support you can't stand at the sink and the cooker without support.

Later in interview:

I: Do you have others around you who can offer you help and support like family?

R: No

I: So you're very dependent on this service?

R: Yes

(Participant 4, female aged 90, Positive Step)

For some participants, changing circumstances meant the time had come when new and/or additional help and support was needed. The flexibility with which services could respond to such changing needs and preserve as much of a participant's independence as possible was an important issue. One participant, who had two carers three times a day and a cleaner every fortnight, was no longer sure if her current care package would be sufficient as she worried she would struggle to get herself out of bed and to her commode during the night:

I: Have you been managing at home then, just with carers?

R: Yeah cos I deteriorated, I got to the part where I could just get from my chair onto my commode and then the carers used to take me to my bed and in bed I could get out to the commode in the night with my walking frame, I could use my walking frame then.

I: So if you went back home again do you think the carers' support would be enough or would you need anything else?

R: I don't know really, it's getting out of bed really at night.

I: So if you need to use the toilet you would struggle to get out wouldn't you?

R: I would yeah.

(Participant 5, female aged 88, Positive Step).

For one participant, with lifelong mental health problems who was unable to administer her medication safely due to increasing confusion and who had previously lived independently with some housing support, the issue was about finding appropriate care which would enable her to maintain as much of her independence as possible, whilst at the same time accommodating her increasing needs. Her sister commented:

R: As far as finding somewhere where she can go, it's difficult because she has, mentally her health has got worse, this is the biggest thing now, what's going to be the place for her without taking her independence off her.

(Participant 2, female aged 70s, Positive Step)

At times there was a tension between how far services could enable participants to maintain independence whilst at the same time not becoming too dependent on these services, particularly if the availability of these services (as far as the participant was aware) might not be guaranteed. One participant, who had benefited from the HFH service and a care package being put in place (see Mrs A case study in Section 4 of the report), son explained:

R: She hasn't asked for the doctor, she hasn't asked for anything since they've been coming. The only down side of it is she hasn't been out of bed since they came, she'll go out, she'll get into the chair and go out for a walk but she hasn't been out of bed since they've come.

I: So you think she's getting dependent on them, the carers coming here?

R: Yeah

I: And bringing everything to her?

R: Yeah

I: Is that worrying for you, that she's losing her independence?

R: It won't worry me as long as these services are always available but you know how things change.

(Participant 3, female aged 70s, Home)

A common concern highlighted by participants in the study was the extent to which they were recognised as a 'person' and dealt with as an individual by the staff and services along the discharge pathway. A number of participants mentioned wanting to be treated with respect, the importance of being listened to and not talked down to, and needing professionals to take time and have the patience to talk and listen to them.

I: What does it feel like?

R: It's summat new like but I just wish they had more patience with you, they just say 'I'm doing something. I'm doing something'?

AH: Personalised, being a bit less busy and...

R: They could be more kind.

(Participant 14, male aged 71, Positive Step).

And:

I: ...so it's about being listened to and taking the time to actually understand that there's somebody in there?

R: Yeah cos they say 'I heard you' I say 'what did I say then?' [but] they carried on as if they're not taking any notice.

(Participant 16, male aged 79, Positive Step).

And:

R: ...as long as they're all right with me and I'll be all right with them and they give me respect and I give them respect, but I don't want anybody talking to me like I'm a kid, I hate it.

(Participant 15, female aged 83, Positive Step).

A few participants mentioned being extremely frustrated by how they felt they had been treated:

R: Them telling me what to do and I already know what they're going to say, they say when I'm walking down corridor they might say 'watch that thing, go straight' I know all that in my head, I'm a bit slow but I do know.

(Participant 16, male aged 79, Positive Step).

Generally participants wanted to be involved in decisions about their care and about what was going to happen next, but sometimes felt that their views and /or needs were being overlooked, or were not being taken into account:

R: To me sometimes they want me to do what they want. I think I know to a certain extent what's best for me and I am frightened to death of being on my own again.

(Participant 12, female aged 89, Positive Step).

Often participants' sense of identity and autonomy was bound up with their social activities and with getting out and about. Many participants talked about activities they had previously enjoyed and of needing additional help and support in order for them to maintain / and or regain their social life.

Some participants simply wanted someone to take them out now and then or wanted some company in order to feel less lonely and isolated.

R: So I don't need anything and staying in doesn't bother me in summer, it's winter when I'm locked in.

I: So during winter when you start to feel low would it help if you had people come to visit or would you want to get out?

R: I think just to have somebody say take me to Asda to do a bit of shopping, to look round the shops...

(Participant 13, female aged 82, Home).

Related to the above, and an issue identified by some participants in the study was that of boredom. A few participants felt that there was not much for them to do whilst they were recuperating at Positive Step, whilst others in the study had little to occupy them at home, and (as outlined above) were not getting out much. One participant felt there was little to do at Positive Step because the emphasis was on getting better and moving on:

I: What kind of things do you do here?

R: You don't do anything, that's the trouble, if you say anything they said they don't want it to become a sort of a home where you do things, it's just like a passing through place I suppose.

(Participant 5, female aged 88, Positive Step)

A couple of participants bemoaned a lack of activities other than watching television, "I don't want to sit watching telly all day", and wanted more stimulation:

R: Well this is another thing, I don't think we get enough stimulation. This morning it was lovely to go out in the garden but the occupational therapist isn't here as much.

I: So do you only go out if the occupational therapist is here?

R: Yes she takes us out there.

I: So you don't feel stimulated enough here?

R: No, I like to do word searches and things, I've got some of those myself and I like to do those and a few crosswords and I read quite a bit, there's hardly any books here. There's more on the other ward.

I: Do you watch telly from day to day?

R: I watch that sometimes yes, in the morning, they're not always programmes I want on but then again I've got to be [] ...there is other people besides me to consider.

I: So would you say you struggle with boredom while you're here?

R: Yes

I: Is that the main issue for you?

R: Yes that's why I go to sleep so much, it's boredom.

(Participant 18, female aged 83, Positive Step)

One of these participants mentioned that when she went into Positive Step the first time (she had been in there before) there were no books, but there were books when she went back in again:

R: ...there was nothing, there wasn't a book to read, there was the second time but not when I went in before, cos it was through me they got books and I asked if I could have dominos and things where say four of us could work together just to get rid of the boredom. We did nothing, just sit around in that lounge falling asleep, getting up for a cup of tea, back to sleep again.

(Participant 13, female aged 82, Home)

Some participants in the study enjoyed the company of a social care assessment unit environment. For a few participants in the study boredom was an issue. The lack of activities and the "sameness" of participants' days (whether at home or at Positive Step), as well as not being able to get out and socialise, compounded feelings of isolation and loneliness and the loss of independence they were experiencing:

I: What's making you feel fed up?

R: Well the sameness....thinking that you're going to be back on your feet, and that's what it's a bit beyond now

(Participant 17, female aged 95, Positive Step).

R: I do get a bit down sometimes when I'm just sitting here and dreaming and thinking about what I used to be able to do, I get a bit upset with it sometimes..

(Participant 18, female aged 83, Positive Step)

3.5. Person centred services and the ability to tailor care to meet clients' needs

When asked about what was important about the way care was delivered many participants did not really know how to respond to the question. Typically participants hadn't thought about it much before, didn't really know what to say, and/or had always done things themselves and managed on their own:

R: I don't know, I haven't thought about it, I just do it myself.

(Participant 1, female aged 70, Home).

R: I don't know, I haven't had that much for so long. I don't know"

(Participant 3, female aged 70s, Home)

Even if participants were receiving care it was apparent that the way in which care was delivered wasn't something they overly considered. For more vulnerable participants who already had care packages, regular often personal care delivered at home was very important:

R: Just to know that someone knows I'm there and need help

(Participant 4, female aged 90, Positive Step)

R: ...a different kind of care isn't it, cos if I wanted it here or if I wanted it at home, to sleep at home, I'd like to be at home to sleep

(Participant 5, female aged 88, Positive Step).

R: they come and clean me all up

(Participant 3, female aged 70s, Home).

Another participant whose experience of care at home was mixed and who was fearful of returning home wanted care delivered "somewhere I know I'm going to be safe."

Participants needed a degree of certainty about the delivery of care:

R (son): The main thing is to do what they say, if they say they're going to come out four times a day, as long as they stick to that then I'm happy, if it makes mum happy, cos the happier she gets the easier it gets for me, and it has got a lot easier.

(Participant 3, female aged 70s, Home)

Participants were usually appreciative of what carers did for them particularly if they felt that the service provided more or less what they needed:

I: What kind of support do they offer you, what do they do?

R: Mostly food of course and whatever I want them to do.

(Participant 4, female aged 90, Positive Step).

But in some instances, it was mentioned that what carers were able to do was limited by the time and resource available:

R: They do more or less whatever I ask but they've only got quarter of an hour to do it in, that is ridiculous so I do it myself, while I can I do it myself, open the curtains, pull the bedclothes back. This morning I were making a cup of tea and she said 'what are you doing? Go and sit down, I'll do it' so she made me a cup of tea.

(Participant 13, female aged 82, Home).

And:

I: I think you mentioned earlier that they do what they can with the people that work here, do you not think there's enough staff working here really?

R: No I don't, and they say the same.

I: Do you think they feel under pressure?

R: I should imagine they do yes. If everybody's buzzing at the same time to go to bed which they sometimes are.

(Participant 18, female aged 83, Positive Step)

The ability of services to respond flexibly to a client's care needs and to tailor the way in which care was delivered to meet those needs was valued:

R (son): It's for at least two hours a day and they do run over, they're not stuck to that half hour. I can tell sometimes when they've got time cos they will spend an extra quarter of an hour and just sit talking, or if mum doesn't need much

doing to her they'll spend the whole half hour just talking so it's good. Best thing so far I think.

(Participant 3, female aged 70s, Home)

Participants appreciated the flexibility offered by services such as HFH and often mentioned the benefits of such:

R: They said if you want anything phone up and we'll get it whatever you need, your needs will be met and they've made it clear my needs will be met.

(Participant 8, female aged 69, Home)

And:

I: Is it important that with Age UK you're able to contact them and change the times and days?

R: Yes it's fine cos I've been able to just ring and they've changed it.

(Participant 10, female aged 82, Home).

What services could or couldn't do or were willing to do to meet their client's needs was a common concern. One participant described how having to make a regular appointment of a time and day for a shower was sometimes difficult for her:

R: So really I suppose like others, I can't afford to give her a time on a day cos you'll never know what you'll feel like, there's many a time they want to come at 8 o'clock in the morning and I say 'I can't do that cos I can't get myself together' and being young they don't understand that as you get older you get slower, you haven't got the energy to move about. But no, it must happen to a lot of people.

This participant also described how one of her carers had managed to accommodate her need for an 'unscheduled' shower:

R: The one [carer] that came this morning, I shouldn't have done this; I'm supposed to have a regular appointment of a time, a day to have my shower but coming out of that place [Positive Step] they put patches on my back, pain patches so I'm scratching all over and I was supposed to have a shower in the morning cos I come home in the afternoon 'oh we've got the workmen in, you can't go in the shower' [referring to work going on in Positive Step] so I didn't get a shower so I've stuck it and I thought I can't stand this itching any more so I asked her [carer] this morning 'have you got time to give me a shower' 'well not just now but I'll come back at 10 o'clock and give you one' and she did bless her.

(Participant 13, female aged 82, Home)

Another participant's family explained how having found the participant on the floor the carer was unable to help:

I: That bit about the carer, you were saying when she had a fall some time ago the carer wasn't able to...

R: (son in law) Help, no, they're not allowed to pick her up, they've got to have an air assisted bed or cushion to bring her up and they've got to have two there.

(Participant 12, female aged 89, Positive Step).

The lack of flexibility in the way that some services were delivered or could respond to a client's needs didn't always make sense. For example, one participant's daughter explained how whilst her mother's finances and direct payments were being sorted and an agency was delivering her mother's care she had to ask them to do the washing:

R (daughter): I was doing all her washing and ironing and shopping and everything and taking her places, but cos I've got breast cancer I was taken out of it and the carers were supposed to look after her, they were supposed to do her daily washing, her clothes, which they say they don't do, I've asked them if as a favour if the bed's wet just to put that in so it doesn't smell and I'll do her personal clothes, but they're saying 'we don't wash up'.

(Participant 5, female aged 88, 91 day follow-up)

Whilst another participant, who needed a wet room because her shower was too small for her to get in and out safely, could not understand why her OT assessment wasn't undertaken at home:

R: A wet room, cos the shower's not very big, I haven't got a shower seat in there, that's why I was going to this place.

I: The occupational therapy service?

R: Yeah

I: So they can help you with that? Are they going to help you with it?

R: Yes as long as I get them phoned up again.

I: So have they been to assess your needs yet?

R: No I have to go there to have them assessed, to me that's stupid.

(Participant 1, female aged 70, Home).

3.6. Communication

As already discussed, participants in the study were often in a 'state of not knowing' about what was going to happen to them next, had limited knowledge of any plans for their care and were often unaware of the services available that could help them. In some instances, participants may have had conversations with service staff or received information about what was happening or discussed the various options for their care and the services available. However, our findings suggest that participants did not always understand the information they were receiving and it was sometimes insufficient for them to understand what was going on. Vulnerability including problems with memory and confusion obviously made it difficult for some participants to access appropriate services and understand the processes and decisions made along the HDP, but it was apparent that participants and their families needed better communication so that they felt better informed:

I: Have they talked to you about any support that might be available when you go home?

R: They said I may get some support when I go home as regarding managing and so on but I don't know what, they don't tell you enough to make you understand.

(Participant 9, female aged 68, Positive Step).

And:

I: Would you like to know that, would that information be important to you?

R Yeah if you write me a list of all the titles of people that can help

I: Do they introduce themselves when they come in?

R: Not really no, I wish they would do, if they do it properly [I'd know] what they do.

I: So when you get people coming in you want to know...

R Who they are and what they can do for me.

(Participant 14, male aged 71, Positive Step).

And:

R (daughter): Yesterday we had a meeting with the social workers for the very first time and she said 'you've already had a discussion with..' it was a bloke, and we'd never even heard of him. Apparently they've had a discussion with us and we've never heard of him.

(Participant 12, female aged 89, Positive Step)

Participants sometimes struggled to communicate with services or felt they were not being listened to, whilst a few participants felt services did not keep them informed about what was happening:

R:..they give me a new community nurse, I saw her once, haven't seen her since, I don't know if she's left or what, they don't give you any follow up information. They were going to come every two weeks, she come once, I've never heard from her since, that's the sort of thing that puzzles me.

(Participant 13, female aged 82, Home)

Others experienced difficulty in contacting services or finding out who the appropriate person was that they needed to speak to in order to get help. For example, the daughter of one participant who had been trying to sort out her mother's care arrangements and direct payments, as well as get oxygen for her mother at home explained:

R (daughter): ...even now I don't really know who the support worker is cos this gentleman at the hospital is part of the discharge team but he did come out, so I'm going to phone him cos I don't even know who the occupational therapist is...

For this participant's daughter, dealing with, and communicating with, various services and different parts of the system in order to get the situation sorted was taking a great deal of time and effort:

R (daughter) ...the thing I'm annoyed about, someone came to see me from the council regarding direct payments and then also I was ringing up trying to find care myself cos I wanted her home and I got in touch with this gentleman, he gets people to do care and that and he put feelers out and he'd got a couple of people who would be interested and willing to come ... but I've never had any paperwork, no copies of any assessments or anything and I've asked for it several times.

And was taking a toll on her particularly as she was ill herself:

R (daughter): I know I've got to carry on for my mum's sake but it does get me down, I get so frustrated I go every day and there's one thing or something else wrong and I have to ring somebody....

Such matters were compounded by the way different services or different parts of the system failed to communicate with each other about a participant's care:

R (daughter) ...it's like I rang the district nurses when she came out last time, I said 'have you got my mum on your list for a follow up?' 'no' I rang my GP and they hadn't got anything to come out and assess her.

(Participant 5, female aged 88, 91 day follow-up)

Issues with communication point to the need for services to look at the ways in which they communicate with clients and to consider options for doing things differently (and in more accessible ways) in order to help improve clients' understanding of what is happening and what services are available to help. Communication between different services and parts of the system also needs to be improved.

3.7. Impact on participants, carers and families

Generally, the impact of services on participants in the study was beneficial. Some participants praised the care and support they had received and appreciated the things that services were able to help with:

R: ... it's good, they've looked after me good and I like them all

(Participant 15, female aged 83, Positive Step)

R: Well I've been looked after.

I: Are you putting weight on again?

R: Yes, they do almost anything for you here, they've done more for me while I've been here.

(Participant 12, female aged 89, Positive Step)

A number of participants were dissatisfied with aspects of their care, whilst a few others recalled horrendous experiences of hospital and of home care. In one or two cases participants were not happy about the care they had received in hospital:

R: They were terrible in hospital.... I fell and broke my hip I said 'can I have a commode' cos I knew that was the key thing I can hang on to that and they refused, they said 'we've seen you walking to the toilet, you can walk it' just like that.

(Participant 14, male aged 71, Positive Step)

In one particular case a participant felt she had received very variable home care and support including carers not turning up when they were supposed to, not accurately recording care in the carers' logbook, not being able to pick up the participant after a fall and also a carer demanding money for changing a bed:

R (son in law): She had one lot of carers who actually wanted to charge her for changing her bed, she wanted the cash there and then to change the bed.

R: I've got a continental quilt which [...] you only have to change the one sheet at the bottom and they were charging me extra just to make the bed.

Later in interview:

R: I once had a carer, she worked for the council, she said to me 'you've got to do what I say' I said 'oh no you do what I want' and they sent me a man once to shower me, I think the poor man was embarrassed.

(Participant 12, female aged 89, Positive Step)

However, most participants in the study couldn't have managed without the short term intervention of services like Positive Step and the HFH service:

R: I couldn't have done it without them, I could not have managed without this [HFH service]

(Participant 8, female aged 69, Home)

Interventions like HFH provided invaluable support for a few participants in the study which helped them get back to normal:

I was grateful for it [HFH] but I was thankful when I could say 'thank you very much now I'm fine, I'm on my own again' so I was happy about that.

(Participant 8, female aged 69, 91 day follow-up).

Services often provided much needed company and interaction, and helped alleviate feelings of loneliness, with participants saying they looked forward to carers' visits.

R: ...I wouldn't have minded them [HFH service] just coming for a wee blether cos I thoroughly enjoyed their company, all the girls were really nice and we all got on well so I wouldn't have minded another week or two of somebody coming round for a wee blether

(Participant 8, female aged 69, 91 day follow-up)

One participant described how having company all the time at Positive Step had been good for her as she had been lonely at home, whilst another explained how her confidence had improved as a result of being at Positive Step and not being on her own so much:

R: I've been quite chatty, they're good listeners... I'm much better. I couldn't have sat down and talked to you like this, I've got a lot of confidence back, that's what they have given me, confidence...

(Participant 7, female aged 80, Positive Step).

Services gave reassurance to participants, to family members and carers and helped take the burden off participants and their families:

R: ... it's lovely that it's there [talking about the HFH support]

I: Is it reassuring?

R: Yes

(Participant 1, female aged 70, Home).

And:

R (son): It makes me feel a lot better, even if I go out I know there's somebody going to be... see I can go out, if they're due at 11 I might nip out at 10 and I'm expecting to be back at 12 so the most she has is an hour on her own and I like the way I know somebody's coming if I do have to go anywhere.

(Participant 3, female aged 70s, Home)

Once services became engaged with participants the impact on carers could be considerable. However, there were occasions when the amount of time and effort required to deal with services in order to sort out care was hard work for family carers and it was having a detrimental impact on them (see Section 4 case studies for more detail).

A common benefit for participants once they engaged with services was improved nutrition and hydration. Participants had often been struggling to eat properly and/or were losing weight when they were admitted to hospital. Services improved intake and provided vital support so that participants gained weight and felt much better:

R: Oh I've eaten, it took a while to get me on my feet but I've made it and all credit to them, they've done everything possible to get me going, to get me eating, the food is really good

(Participant 7, female aged 80, Positive Step).

And:

I: Do they take good care of you?

R: They do.

I: Cos you must have started eating again cos you're looking ever so healthy?

R: Yeah

I: Do they make sandwiches or do something for you, make you a cuppa or something?

R: Oh yeah.

I: So that's a really positive change isn't it?

R: It is.

(Participant 3, female aged 70's, Home)

Other benefits identified included improved mobility and there were also examples of participants linking with other services and social activities again through the HFH service.

The next section of the report presents case studies which provide detail about the impact of services on three participants in the first three months of their journey from hospital discharge.

Client case studies: the first 91 days

This section of the report details impact case studies at 91 days for three participants in the study. These case studies provide examples of the first three months of the 'client journey' from hospital discharge and illustrate many of the themes and findings discussed in the previous section of the report.

4.1 Mrs A's Journey (Participant 3)

Initial interview - February 2015

Mrs A is in her seventies, hard-of-hearing and is bedridden. She lives in a dilapidated mobile home with her son, who is her main carer. She was admitted to hospital numerous times before a lengthier stay of seven weeks around December 2014. During this time, attempts were made to rehabilitate her to walk again, but unsuccessfully, therefore, support was set up for Mrs A at home. Upon discharge, Age UK provided the HFH service in Mrs A's home, which although was initially for four weeks, was extended to six weeks. Age UK told them about other provision such as Day Care centres and also ordered a bed, bidet and a winch for Mrs A. Through the HFH service Mrs A had company and someone to talk to while her son went shopping. Whilst this company was welcomed, it was short-term and 'missed' by both Mrs A and her son when it ended.

Six weeks later

Fortunately, the carers at home service provided by Doncaster Council was put into place soon after, with half hour visits from carers four times daily, providing assistance with washing, companionship, and preparation of light meals and drinks. The social aspect was particularly valued by Mrs A, "*we have a laugh and a joke*", and her son felt reassured that his mother was not alone too long in his absence:

It makes me feel a lot better, even if I go out I know there's somebody going to be... see I can go out, if they're due at 11 I might nip out at 10 and I'm expecting to be back at 12 so the most she has is an hour on her own and I like the way I know somebody's coming if I do have to go anywhere.

There is flexibility in the carers' schedule and at times they stay on longer than half an hour to talk to Mrs A, freeing up her son to do essential tasks, such as household repairs. The respite care for two weeks was also set up by social services to give him a break from caring, but Mrs A struggled to settle and did not enjoy her stay and felt apprehensive about doing it again

Mrs A feels happier and healthier, she has gained weight, is sleeping better and consequently she hasn't needed to see her doctor, or go to hospital. Her son attributed this improvement to the assistance and companionship his mother receives from the carers service, but he also noted how her dependence on them has confined her to her bed:

She hasn't asked for the doctor, she hasn't asked for anything since they've been coming. The only down side of it is she hasn't been out of bed since they came

Should funding for this service be cut or withdrawn, he fears the repercussions for his mother due to her over reliance on the service, for example, if the carers' visits were reduced to two daily instead of four, in his view, this would have 'a big effect' on her. Being mainly bedridden, with very few visitors and only the television for company Mrs A appreciates having 'a laugh and a joke.....instead of just laying there'. According to Mrs A, the carers are the best people to provide the care that she needs.

Six weeks into the research, Mrs A hadn't seen her GP, or been to hospital. The only communication with her doctor was done over the phone to sort out medication. Her son explained, "*she's not wanted to go to hospital, she's not complained*". The family's social worker had provided extensive support including awareness of other services, completing paperwork and was arranging for a befriender to regularly visit and talk to Mrs A, because it is company that Mrs A wants more than anything else. In her son's view, social services have been very useful and met his needs too, '*I've got a lot more than I ever expected*'. They provided the household with a washer-dryer because her son was struggling to dry the blankets and sheets during winter because Mrs A requires clean blankets/sheets on a daily basis. The care and support was constantly improving; there were no gaps in service provision for the family at this stage.

91 days later

At three months, Mrs A hadn't visited her GP or been to hospital. She was attending the Day Care centre once every week. The Day Care centre accessed through Age UK includes pick up and drop off, a full-day of activities and a hot dinner. This service presents value for money, at £15 per session, '*it's worth it*', and is affordable due to the household being in receipt of Carers Allowance and Attendance Allowance. There were no complaints about the centre, except that Mrs A experienced discomfort sitting in her wheelchair all day. This was hoped to be resolved by moving Mrs A out of her wheelchair at the centre or by purchasing an adapted wheelchair offering more comfort. Valuable information was also picked up at the centre about products available for the household, e.g. a bin for hygiene waste disposal.

At this stage into Mrs A's journey since being discharged from hospital, she had a care and support package in place, including: carers at home four times daily; a befriender, arranged by social services, visiting once a week and providing companionship; and a regular visit to a Day Care centre each week. According to Mrs A and her son, all of these services played a part in maintaining her health and wellbeing, and consequently kept her out of hospital. Both social services and Age UK were seen as key in identifying the whole family needs and in putting services into place to meet their needs. Age UK, in particular, was helpful in providing information about a range of services that Mrs A and her son might benefit from.

Respite care was taken for a second time, but again Mrs A did not enjoy her short stay in the residential care home. Her son emphasised that she could try different care homes in the future to find one of preference, but it seemed that Mrs A struggled to cope with the upheaval of moving out of her home for temporary stays:

I don't want to go in a care home, I don't mind for a day but a day's like a week.

In terms of their awareness of services available to them, both felt they "*probably know too much.....sometimes it's too much all at once*". They explained that they found it helpful to receive this information from one person rather than through numerous people. The latter could lead to confusion. Queenie's son expressed frustration at having to go through long-drawn-out processes for repeat supplies, such as incontinence pads:

Cos mum went in hospital they know exactly how she is, what her toilet habits are, so they know she needs them cos they started it all, so why have to do it again? That's where it comes in with different departments, you've got to go through one and then you've got to do it again to go through somebody else

Her son discussed the possibility of arranging a holiday in a wheelchair adapted caravan, with their social worker which was met with some resistance from Mrs A. Essentially, she wanted to be cared for and supported at home, and felt the current package of care met her needs and those of her son, her carer, who reaffirmed:

Without the help the situation wouldn't be the same, my mum would be in a home cos she wouldn't be as well as she is now, she'd have gone further downhill.

4.2 Mrs B's Journey (Participant 2)

Initial interview - January 2015

Mrs B is in her seventies and has several health issues, including chest problems, depression and memory loss. Her health began to deteriorate after having a couple of operations; on her lung and her brain. A Community Psychiatric Nurse (CPN) is involved in her care. Last year, Mrs B was increasingly in and out of hospital, and in her sister's view, the hospital wasn't the right place for her rehabilitation and recuperation.

Most recently she was admitted to hospital after having a fall. At this stage, she was living independently in assisted accommodation with "*a restaurant downstairs, a hairdressers, chiropodist*" and could come and go as she pleased. Although nursing care was not provided, services included: help getting dressed; cooked meals; assistance taking her medication; a cleaner; and various activities were arranged for the residents. Her housing offered security, but when Mrs B stepped outside of this environment she was at her most vulnerable and at danger. She was often found wandering the streets "*lost and confused*", having lost her money or had her belongings stolen. Prior to this, she had a full, active life.

Mrs B smokes and likes to drink, but combined with her memory loss and state of confusion; both activities compromise her personal safety. At her family's request, social services stepped in to help her to manage her finances. Newly arrived at Positive Step, Social Care Assessment Unit, Mrs B was very unsure what her health and care needs were and she had no awareness of the various support services available in Doncaster, she only expressed that she would like her family to be involved in the delivery of her care. At Positive Step, Mrs B and her sisters have

already consulted with the Occupational Therapist, who is also getting a CPN involved, and a social worker. According to Mrs B, *"people are listening"*.

Mrs B has a very supportive family, including two sisters, who advocate on her behalf. They are committed to giving her choice and supporting her independence as far as possible, which is such a core part of Mrs B's identity. Her sisters repeatedly emphasised Mrs B's sociable character and free spirit; she enjoyed going out and meeting people, and would like to continue to get out and about. This concern with independence was balanced alongside the concern for Mrs B's safety when she was reminded a few times about the risks to her personal safety:

You fall asleep with a cigarette in your hand, these have been our concerns over the years, big concerns

Such concerns were raised with Mrs B's housing providers, who explained that residents were free to do as they pleased, and as independent adults they could come and go as they pleased. With constant admissions into A&E and fast deteriorating health, Mrs B's home was no longer considered a safe option to return to.

Six weeks later

After her initial interview, Mrs B was moved into residential care. Her family reported feeling under pressure from Positive Step and social services to move her out and into residential care. They had to look for somewhere permanent for Mrs B to move to. They were provided with a list of residential care homes, and felt *"pressured and pushed"* to find somewhere within the week. Before Mrs B had the opportunity to view the potential home that her sisters identified, on that very day, her bags were packed and she was sent in a taxi to the residential home, *"with nobody there to meet her"*.

Slowly adjusting to her new home, Mrs B shared that she would like to be taken out and that she would consider having a befriender because her days were very long with little to do. The family would also feel less pressure to constantly visit. She reported having more headaches, struggling to eat, and feeling tired all the time. However, she hadn't seen her doctor since being discharged from hospital or been re-admitted into hospital since then.

91 days later

Having settled somewhat and got to know a few people, Mrs B has had some good and some bad days in her new home; her sister noted that Mrs B wasn't getting dressed some days and that her low ebb might be due to there being so much to do at her supported housing compared to her previous the residential home:

There's just nothing, you come in and everyone's sat round the wall in a square which I don't think is good, everybody sits in the same place.

Mrs B also reiterated, *"They don't do anything here"*. And, when the family raised this they were told that volunteers were needed to support activities such as bingo, music, entertainment. Mrs B would like her family to take her out and she wants to go home, but she is confused about her whereabouts when her family take her out. She is reminded to take medication in the residential care home and she hasn't seen her GP since being discharged from hospital. A hairdresser provides a service at the care home, which Mrs B takes up weekly. Her family bring her whiskey and cigarettes regularly which she enjoys but she feels frustrated that the quantities are restricted by her family and staff, although her sister explained that the cigarette

supplies couldn't be increased until social services assessed her financial situation. Mrs B was struggling to understand the safety procedures at her new home and she expressed very strongly that others were taking her independence and control away from her.

4.3 Mrs C's Journey (Participant 5)

Initial interview November 2014

Mrs C is eighty-nine years old, and lives alone. She struggles with several health problems: a respiratory condition, arthritis, memory loss, and she has had mobility problems for some time. In November 2014 she went into hospital for treatment for an infected shoulder and got pneumonia while she was there. In total, Mrs C spent 21 weeks away from her home; over 11 weeks in hospital and 9 weeks at Positive Step, Social Care Assessment Unit. At home she was supported by carers, two of them visiting three times daily, which cost Mrs C £30 per day. They assisted with bathing, and heating her meals. A cleaner did the housework, fortnightly. Although Mrs C has a son and two daughters, only one daughter, who lives nearby, is mainly involved in her care.

Prior to her health deteriorating, Mrs C was part of a ladies fundraising circle at church, meeting fortnightly, and taking a lift from a friend to get there. She now requires a vehicle with wheelchair access to get from place to place, and is very dependent on others, but she desperately wants to go home. Mrs C's care preferences are clear, *"I'd like to be at home to sleep"*, but to return home would require round the clock support: to get out of bed, prepare meals, to go to the toilet and to have a bath. This is difficult due to limited access to care and support services in her area:

I think the trouble is if you're getting a person to come where we live, live in the outskirts of village and nobody wants to do it.

A few friends have been made at Positive Step, but there is little else to do, which leads to boredom. In Mrs C's view, they do not want their residents to get too comfortable, and to see the service as a *"temporary stop"*, so they don't provide any activities:

You don't do anything, that's the trouble, if you say anything they said they don't want it to become a sort of a home where you do things, it's just like a passing through place I suppose.

Ideally, Mrs C would like her family to be involved in the delivery of her care at home, but she appreciates that they all work and wouldn't want to burden them. Nevertheless, her daughter has continued to play a significant role in her mother's care; advocating on her behalf; washing and cleaning for her; and visiting her regularly at hospital and at Positive Step:

Yeah, my daughter's very good, I've been away months and she's only missed twice, she's been every day.

Six weeks later

Mrs C was discharged from Positive Step in late March and sent home; the family felt some pressure from Positive Step for Mrs C to return home after 9 weeks in their care. At home, she slipped into depression very quickly due to the isolation caused by her immobility. Her daughter explained:

She does spend quite a bit of time on her own.....She does like people, and she was very sociable as well, and she can't do obviously what she did.

Before going into hospital, Mrs C had two carers three times daily, but since returning home, she only occasionally has two carers, usually one, but four times daily instead of three. They "*transfer her to the commode, washing and dressing, shower three times a week, they prepare her breakfast*". And, an additional night time call was put in place, although the timing of that call wasn't working because by the morning call Mrs C had often wet herself. A nurse was due to visit to assess the situation. During this period of time, Mrs C's GP also visited her at home.

Her daughter, previously provided considerable support, but due to having an operation for cancer, was limited in the support that she was able to offer, although, she was still doing the shopping, ironing, and washing, as Mrs C's washing machine had broken down. There was limited awareness of the support services available, and the family were trying to provide care for Mrs C in her home believing she had very little time left. Her daughter was under enormous pressure coping with her own health problems whilst simultaneously supporting her mother, but she had a strong sense of responsibility to give her mother what she desperately wanted, which was to return home:

She was away from home for 21 weeks in total and I just think she wants to be home, she'd had enough being away from home. She was becoming institutionalised.

91 days later

Mrs C was re-admitted to hospital, so could not participate in an interview, so her daughter relayed her mother's experience, reaching back to the time when her health began to deteriorate.

Prior to her 21 week stretch in hospital and at Positive Step, Mrs C ended up in A&E on a monthly basis due to her respiratory condition. Once in hospital, while staff searched for a bed, Mrs C would recover, having topped up on oxygen again. Her daughter has been fighting for oxygen to be available at home since May/June last year (2014). In her view, the service provision is inadequate because Mrs C lives in a remote village that the carers cannot get to without incurring great expense:

A lot of the carers, I don't think they're allowed petrol allowance and she (Mrs C) wanted two carers and we really struggled, at the moment she's under STEPS (DMBC home care service) mainly cos we're in such a remote area, they can't get, they keep putting it out to tender to thirty odd different care agencies and nobody's taking it on.

At this stage, Mrs C's daughter didn't know which named professionals were involved in her mother's care, and she didn't appear to have a single point of contact that she could approach to discuss her mother's health and support needs:

Even now I don't really know who the support worker is cos this gentleman at the hospital is part of the discharge team but he did come out, so I'm going to phone him cos I don't even know who the Occupational Therapist is, even at home when she gets a shower, all the floor's getting flooded and she needs one of these soft cushions to sit on, we got her a donut but she's still a little bit sore.

The lack of flexibility of the carers was also raised as an issue, which was attributed to the carers' being recruited through an agency. When asked if they could help to wash up, they claimed that they were not permitted to do this task. This inflexibility

has taken its toll on Mrs C's daughter's health, who had the impression that the carers would assist with the household chores more than they actually could:

Cos I've got breast cancer I was taken out of it and the carers were supposed to look after her, they were supposed to do her daily washing, her clothes, which they say they don't do, I've asked them if as a favour if the bed's wet just to put that in so it doesn't smell and I'll do her personal clothes, but they're saying 'we don't wash up'.

Emerging implications and next steps

This report has summarised the interim findings from the HDP study being undertaken as part of the larger of evaluation Better Care Fund activities formerly those for the Supporting and Maintaining Independence Programme (SMIP) in Doncaster. The findings and themes which have emerged so far point to a number of implications for practice that DMBC may want to consider when planning for the health and wellbeing of adults in Doncaster. Some of the results also chime with recent recommendations made by NICE in their guidelines² on delivering home care and practical support to older people living in their own homes.

5.1 Improve practical help to get out and about, and provide additional support to (re)start socialising/activities

Almost all the participants in this study wanted to get out and about more and (re)engage with social activities. Many participants were unaware of the support which might be available to enable them to do this and needed more information about services and organisations which could help them. A common barrier highlighted was a lack of practical support to help participants get out. For many participants activities and socialising they previously enjoyed were part of their sense of identity and having the ability to socialise again would be very much welcomed. Exploring older people's aspirations to socialise and take up activities should be prioritised by relevant support services - the results in this study suggest there is considerable unmet (and unidentified) need in terms of older people doing what they want to do and going where they would like to go. Improved practical support and better community transport would obviously help combat problems of isolation and loneliness which were prevalent amongst participants in this study, and enable older people to stay independent at home and active in their local communities. Our results also highlight the importance and value of having someone to provide ongoing support to help overcome any fears and apprehension older and vulnerable people may have about re-engaging socially.

5.2 Re-examine routine ways of communicating with clients to improve their understanding of what is happening to them and the services they are receiving

This point is not only about providing more or better information, as it is apparent clients can feel overwhelmed by too much information all at once, but is about enhancing the understanding of the information received in order for clients, their

² NICE Guideline (2015) Home care: delivering personal care and practical support to older people living in their own homes [nice.org.uk/guidance/ng21](https://www.nice.org.uk/guidance/ng21)

families and carers to be more informed about what is happening to them. Better understanding of information would help alleviate the 'sense of not knowing' experienced by many participants in this study. Consideration of how and why information is communicated, the appropriateness and timing of information and also who is giving the information - is it lots of different people or one person? - is needed. Services should assess how they approach communication and contemplate the possibility of doing things differently in order to enhance clients' understanding of what is going on, the services available and what these services offer.

Things like service staff taking the time to introduce themselves properly and explaining what they do and how they can help, repeating messages, ensuring messages are communicated in tailored and accessible ways may help to promote understanding of services for clients and their families. As recommended by NICE providing clear concise written summaries of what has been discussed would be helpful. Services should ensure adequate and regular follow-up on the information and advice received by clients in order to respond to any questions and uncertainties about care and support.

5.3 Improving the ways in which a client's autonomy is respected and recognised by services and ensuring that care is person centred, flexible and holistic

Clients want to be recognised 'as people' by the services they are dealing with and also treated with dignity and respect. Services need to take the time to listen to clients' needs and show patience when dealing with users. The importance of maintaining and holding onto as much independence as possible was stressed by many participants in this study. Support services should aim to focus on enabling clients to do what they would like to do in order to maintain their independence. This may involve longer visits for those receiving home care (as recommended by NICE), and demands much more flexible and holistic approaches to the way services are delivered in order to fully meet clients' needs and aspirations for their support and care.

NICE recommends that clients, carers and families should be involved in all decisions about care and support and the results from this study would support such an ambition. Crucially clients need to feel that what they are saying is being respected, adequately considered and taken on board and is not being overlooked. Clear and mutually agreed expectations of what support services will deliver at the outset would help avoid the uncertainty experienced by some participants in this study when it came to knowing what they could expect and ask for from the care and support services they were dealing with.

5.4 Next Steps

We will continue to collect data for the HDP study during the rest of 2015 and into early 2016. As far as is practicable participants in the study will be followed for up to one year, although some participants will be followed for around six or nine months. Continuing 'the client journey' with participants in this study will provide a unique insight into the experience of going through the Doncaster Hospital Discharge Pathway and associated pathway services. It is anticipated that the study will provide vital evidence on how well clients are coping once they leave hospital and highlight the circumstances which may lead to a further hospital admission or which may act to prevent further harm and readmission. Most importantly the study gives clients a much needed voice to talk about their experience and to discuss in detail their perspectives on the care and support they are receiving.

The final report for the HDP study will be produced in Spring/Summer 2016, and it is hoped that a feedback event which will include relevant staff and commissioners as well as the study participants and their families and carers will be organised around this time.