

Doncaster Hospital Discharge Pathway Study: *Final Report*

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

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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 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.

This report updates an earlier interim report submitted to Doncaster Metropolitan Borough Council (DMBC) in October 2015. The current report is based on all interviews conducted with 22 participants recruited to the study between November 2014 and July 2015.

Semi-structured interviews with participants took 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.

22 participants (19 women and three men) were recruited to the study and around half of the participants were aged over 80. Many participants were extremely frail due to age or chronic and acute health problems and often experienced multiple health problems. Participants' vulnerability was extreme and complex in nature.

Although there were a variety of reasons why people were in hospital, the most common reason for participants to be in hospital was as the result of a fall. Eleven participants were in hospital because of a fall. Six of 21 participants (one participant withdrew from the study after the first interview) were readmitted to hospital within 91 days.

This report presents the main outputs from the evaluation, the detailed Client Case Studies and Client Timelines which illustrate many of the key findings and themes to emerge from the study. It is envisaged that these timelines and case studies will be useful learning resources for a range of health and social care professionals and voluntary and community organisations involved in commissioning and/or delivering care services.

The study gives an indication of how challenging it is to provide support in a home environment in an integrated way. The findings and themes outlined here and in the earlier interim report point to a number recommendations for practice that DMBC may want to consider when planning for the health and wellbeing of adults in Doncaster. Some of our findings chime with the recent NICE recommendations on delivering home care and practical support to older people living in their own homes. The study indicates that the following points are important in improving the experience and outcomes of clients on hospital discharge pathways and include:

- Improving practical help to get out and about and providing additional support to (re)start socialising / activities.
- Ensuring that all clients being discharged from hospital, rehabilitation and social care assessment settings are made aware of, and know how to access befriending services that could provide much needed social contact and support.

- Re-examining routine ways of communicating with clients to improve client understanding of what is happening to them and the services they are receiving.
- Involving clients and families in decisions about care and better integrating the needs and abilities of clients and their families in the assessment, planning and management of discharge pathway services and care packages.
- 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.
- Enabling adequate consideration, better ongoing support and review of carers' emotional wellbeing needs when discharge planning and developing care packages.
- Ensuring that those who are at risk of falling are referred to the Falls Service and increasing the awareness of professionals visiting clients' homes that many falls go unreported by vulnerable older people.
- Reiterating the requirement for all relevant professionals to identify any opportunities for early intervention and prevention in order to improve health outcomes and Make Every Contact Count (MECC).
- Providing home carers the necessary knowledge and skills to recognise and respond to signs of deterioration and ensuring that care workers feel confident to report such issues and/or intervene as appropriate.
- Commissioning and encouraging health and social care services that develop ways of working which enable care workers and other professionals to respond more flexibly to clients' needs and aspirations for their care.

It is hoped that the findings and suggested recommendations in this study provide material for discussion to help DMBC and its partners to identify strategies and solutions for better health and social care services so that services can work in a more streamlined and accessible way and deliver better outcomes for clients and their families.

Introduction

This report provides an overview of the independent evaluation of the Doncaster Discharge Pathway and Associated Discharge Services. The evaluation was undertaken by the Centre for Regional Economic and Social Research (CRESR) at Sheffield Hallam University with the School for Health and Related Research (SchHARR) at the University of Sheffield. The report outlines the research undertaken for the evaluation, provides a profile of the participants involved in the study and discusses some of the key findings from the study. The report includes the other final outputs from the study, the in-depth Client Case Studies and the Client Timelines, which have been developed to help inform future service commissioning and delivery. An earlier interim report produced for DMBC in October 2015 provided a thorough analysis of the baseline position of most of the participants in the study. The interim report highlighted emergent themes, provided insight into the first 91 days of the client journey from hospital discharge and discussed implications for practice.

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 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. It should be noted that the purpose of this study is not to 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 ended in Spring 2016. Evidence from the HDP evaluation interim findings has already fed into the Intermediate Care Review NHS Doncaster CCG and DMBC are currently undertaking. NHS Doncaster CCG has developed a case for change report which will inform the redesign of intermediate care services and the service response to meet patients' needs. The findings of this study deliver valuable evidence for such a review of services.

1.1. About this report

The rest of this report is structured as follows:

- Section 2 Research Process and Methods
- Section 3 The Study Participants and the Research Journey
- Section 4 Client Case Studies: Six Months and Beyond
- Section 5 Discussion and Recommendations
- Appendix 1 Glossary and Client Timelines.

Research Process and Methods

This section of the report discusses recruitment to the study and the research approach adopted. It details the issues researchers faced getting the study off the ground and highlights the challenges of such an in depth qualitative study following a cohort of patients recently discharged from hospital.

2.1. Recruitment and Sampling

A total of 22 participants were recruited to the study between November 2014 and July 2015. Initially 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 researchers 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 worked closely with DMBC exploring various options for approaching participants and engaged the Home from Hospital (HFH) service and the Social Care Assessment Unit, Positive Step, 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 their service and provided advice regarding clients' potential eligibility. Staff discussed the project with the client, provided an information sheet and elicited agreement for researcher contact. 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 meant it was not possible to recruit two distinct cohorts of participants (summer and winter) to the study and follow all of the participants for 12 months. Some participants were followed for around 6 months rather than 9 or 12 months.

2.2. Data Collection and Analysis

Following consent, first interviews took place in the participant's home or care facility as appropriate and in accordance with the participant's wishes. Interviews with participants took 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 research team maintained 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 2.1: Study Flowchart below). The purpose of the telephone contacts was:

- To track the persons 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.

However, for a number of participants telephone contacts were inappropriate and some catch ups were undertaken face to face (see Challenges below). Participants' circumstances and preferences dictated the frequency and method of catch ups and researchers used their judgement and sensitivity in order to maintain contact.

Throughout the study the research team also kept in contact with up to two key stakeholders (as appropriate) involved in the participant's care. In most instances this was a family member but other examples included social workers, other carers and staff at care homes. Including family, carer and other perspectives helped insight if the participant had poor recall or memory. Telephone contact was also made with the key stakeholders in between interviews, as with the main participant.

Interviews were semi-structured and conducted using a topic guide developed from relevant literature and through discussion with the project team. Interviews were audio recorded transcribed and all identifying details removed to protect anonymity. The research team read through transcripts and met to regularly review evidence and discuss emerging issues and themes. A thematic coding framework was developed and data entered onto QSR NVIVO for storage, management and analysis.

Analysed interviews and emergent themes formed the basis of the Client Timelines and the detailed Client Case Studies (see Section 3.5 and 3.6).

2.3. Challenges

Following a cohort of patients recently discharged from hospital for up to 12 months has been challenging. Continued involvement in the study required a great deal of commitment from both participants and researchers and was often an emotional, sometimes upsetting, but ultimately rewarding experience for the parties involved. Over the course of the study researchers and participants developed close relationships with participants often looking forward to researcher contact.

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 the HDP study took time and initial recruitment through the IDT was slow. One of the main reasons why recruitment was low initially was that staff kept forgetting to ask patients whether they

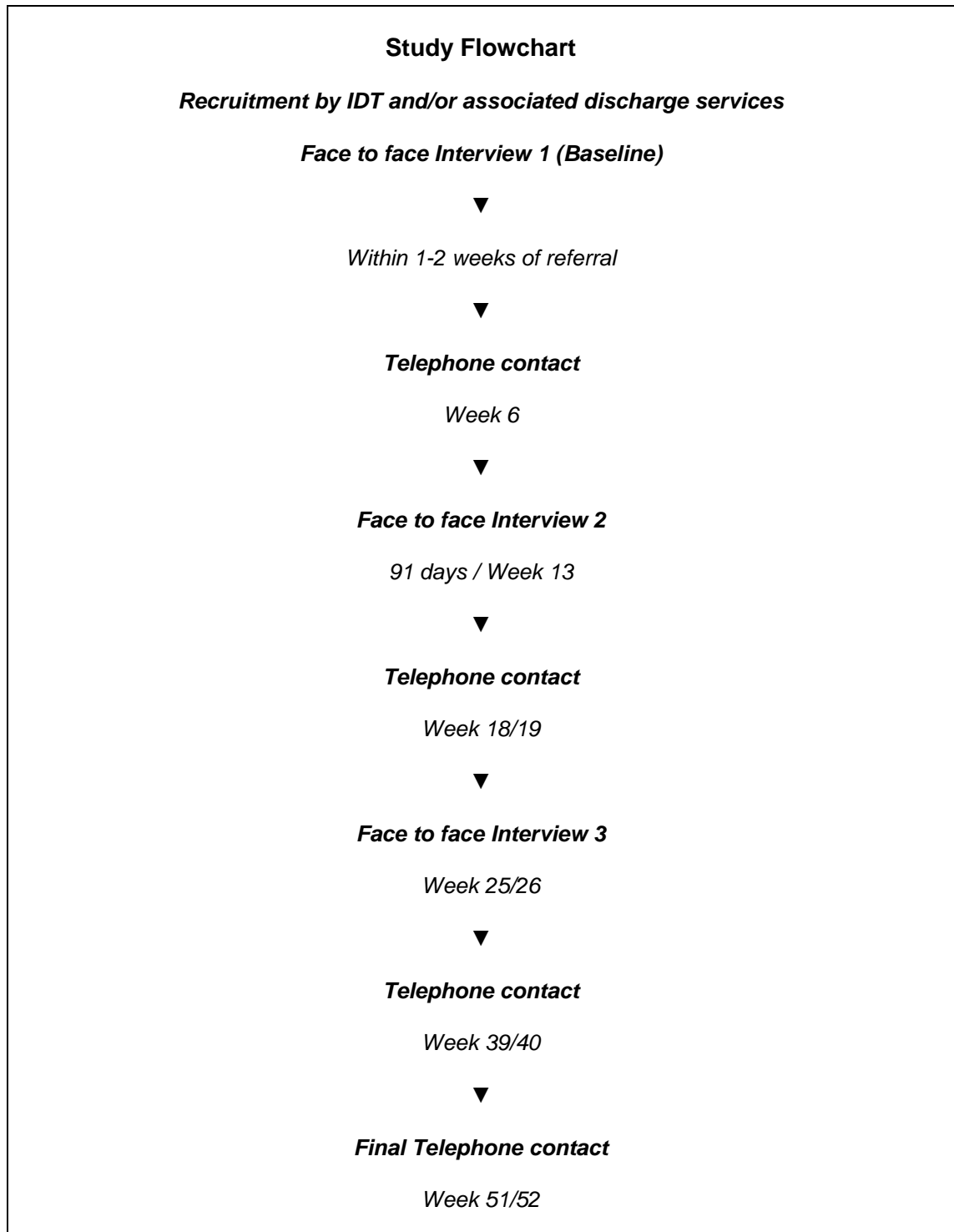
would be interested in taking part in the study. There was also some reluctance to ask clients about taking part in the study, and perhaps most significantly, intense seasonal pressures on the IDT at the time. Subsequently researchers attended the IDT monthly meeting to inform more staff about the study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

To overcome these problems of low recruitment 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 extremely 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) meant telephone catch-ups could be difficult and a large number of planned telephone catch-ups were conducted face to face. Arranging any catch-up either by telephone or face to face took time and usually involved contacting a carer/family member to find the whereabouts and check the circumstances of the participant and whether it was okay to contact them. A carer/family member (with prior permission from participant) often provided further information about the participant's care, which then had to be written up in addition to the catch-ups. The task of locating a participant (particularly those without family or carer) at any point during study could be time consuming and the geographical spread of participants' locations made it difficult to visit more than two or three participants in a day. Given that face-to-face catch-ups were often the most viable option for keeping in touch short catch ups proved especially demanding of resources.

In light of these challenges 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) has enabled the project to broadly keep to the original project timeline.

Figure 2.1: HDP study flowchart



The Study Participants and the Research Journey

This section of the report details the characteristics of the participants in the study and the reasons why they were first admitted to hospital. Details of the participant research journey, the number of research contacts and the length of time each participant was followed is outlined. Information about the Client Timelines and Client Case Studies produced as the other main outputs from the study is also provided.

3.1. The Participants

There were 19 women and three men in the study and around half of the participants were aged over 80. Each participant in the study was given a participant number and pseudonym and their demographic details are provided in Table 3.1 below.

3.2. Health conditions

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 that 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.

3.3. Hospital Admissions

Although there were a variety of reasons why participants were admitted to hospital (see Table 3.1) including a knee replacement operation, a mastectomy, complications with a tooth infection and urine infections, by far the most common reason for participants to be in hospital was as the result of a fall. In total eleven participants had fallen, including falling out of bed or chair or 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.

Six of 21 participants (one participant Erica withdrew from the study after her first interview) were readmitted to hospital within 91 days (see Josie, Jane, Molly, Jean, George and Norma timelines). Three participants went back to hospital because of a fall (see Molly, Jean and George timelines) one participant, Norma, was readmitted because of a urinary tract infection (UTI) and Jane was readmitted with respiratory

problems. After her admission to hospital Josie was withdrawn from the study due to diminished mental capacity. Almost half of all the participants (9) were readmitted to hospital during the study with some participants being readmitted a number of times.

Table 3.1: The Study Participants

Number	Participant Pseudonym	Age	Sex	Reason in hospital
1	Betty	70	F	Water infection and temperature
2	Pearl	79	F	Had a fall and bump on head that would not go down
3	Queenie	70s	F	Stopped eating and was losing weight. Had suffered a number of falls
4	Josie	90	F	Wasn't very well because of problems with insulin dosage
5	Jane	88	F	An old injury, fractured shoulder became infected
6	Elizabeth	62	F	Knee replacement operation / arthritis
7	Audrey	80	F	Was having lots of falls and injured her back
8	Kathleen	69	F	Mastectomy
9	Annie	68	F	Fell and broke both arms
10	Kate	82	F	Infected tooth
11	Martha	89	F	Fell from chair
12	Jean	89	F	Wasn't eating properly and had a water infection
13	Sheila	82	F	Fell out of bed and broke bones in back and shoulder
14	Mavis	83	F	Fell out of bed and banged her head, some bleeding on brain and suffered three seizures in hospital
15	Bert	71	M	Struggling with breathing problems and bronchitis. Also had a fall
16	George	79	M	Fall
17	Erica	95	F	Falls
18	Geraldine	83	F	Seizure resulting in a fall
19	Frank	79	M	Onset of Heart Failure
20	Beryl	92	F	Viral pneumonia
21	Norma	78	F	Suspected heart attack
22	Molly	77	F	Water infection and confusion

3.4. Research Journey

First interviews usually took place within a couple of weeks of hospital discharge and were conducted either at the participant's home or at Positive Step. Although the number of contacts varied, most participants (17) were tracked for period of 6 to 12 months, with six of these participants being followed for around a year. Three participants were involved in the study for just less than six months and two participants were interviewed only once. Both these participants left the study, one

because they no longer wished to continue (Erica) and the other (Josie) was readmitted to hospital shortly after the first interview and withdrawn from the study due to diminished mental capacity. Table 3.2 details the length of each participant's journey, the number of interviews conducted with the participant and the reason for the length of follow-up.

It is worth noting that the participant research journey was influenced by a number of factors including project resource and research capacity, the project timeframe, research team judgement and participant preference. In some cases the research team, in consultation with the participant, made the decision to complete the journey earlier because carrying on would go beyond the end of the project timeframe and project resource was an issue. In one or two instances participants moved away out of area. For others their health condition and circumstances were stable so a decision was taken to concentrate efforts elsewhere. In a couple of instances the research team lost contact with participants and unfortunately three participants died during the study.

Table 3.2: The Participant Journey

Number	Participant Pseudonym	Followed for:	No of contacts	Reason for follow- up period
1	Betty	8 months (17/12/2014 - 17/08/2015)	5	Lost contact
2	Pearl	13 months (27/01/2015 - 03/03/16)	7	Completed
3	Queenie	8 months (03/02/2014 - 05/10/2015)	6	Participant died
4	Josie	One contact made	1	Withdrawn from study due to diminished mental capacity
5	Jane	6 months (20/02/2015 - 10/08/15)	4	Participant died
6	Elizabeth	11 months (24/02/2015 - 19/01/2015)	6	Agreement to complete earlier
7	Audrey	12 months (24/02/2015 - 04/02/2016)	6	Completed
8	Kathleen	11 months (24/02/2015 - 19/01/2015)	6	Agreement to complete earlier
9	Annie	4 months (09/03/2015 - 16/07/2015)	3	Lost contact
10	Kate	11 months (21/04/2015 - 15/03/2015)	6	Completed
11	Martha	11 months (21/04/2015 - 03/03/2015)	6	Completed
12	Jean	5 months (06/05/2015 - 05/10/2015)	4	Participant died
13	Sheila	10 months (06/05/2015 - 18/03/2016)	6	Completed
14	Mavis	6 months (14/05/2015 - 17/11/2015)	5	Agreement to complete earlier
15	Bert	8 months (14/05/2015 - 12/01/2016)	4	Agreement to complete earlier
16	George	6 months (20/05/2015 - 02/11/2015)	5	Participant moved out of area
17	Erica	One contact made	1	Participant did not want to continue
18	Geraldine	8 months (11/06/2015 - 13/02/2016)	10	Agreement to complete earlier
19	Frank	4 months (16/07/2015 - 26/11/2015)	4	Agreement to complete earlier
20	Beryl	6 months (16/07/2015 - 08/01/2016)	5	Agreement to complete earlier
21	Norma	6 months (16/07/2015 - 12/01/2016)	5	Agreement to complete earlier
22	Molly	6 months (14/07/2015 - 13/01/2015)	5	Agreement to complete earlier

3.5. Client Timelines

All interviews were analysed and translated into a Client Timeline for each participant. A Client Timeline is a visual representation of each participant's research and health and social care journey during the study. Timelines summarise the main research contacts and health and social care developments. They are enhanced using illustrative quotes from interviews undertaken with participants and/ or their families or other stakeholders involved in their care. These quotes illuminate the participant's feelings and provide valuable insight into the context of the participant's experience and help to highlight what the main concerns were for the participant and their families. Each timeline has a detailed key message which points to possible implications for the planning and delivery of health and social care services.

All the participants in the study have a Client Timeline apart from Erica who decided she didn't wish to continue with the study after her first interview. The Client Timelines can be found in Appendix 1 of the report.

3.6. Client Case Studies

As well as timelines we have developed detailed Client Case Studies for five of the study participants.

Three Client Case Studies at 91 days were presented in the interim report for Queenie (detailed as Participant A in the interim report), Pearl (Participant B) and Jane (Participant C). These case studies provided examples of the first three months of the 'client journey' from hospital discharge and illustrated many of the themes and findings in the interim report. We have continued to develop these case studies so that they now detail their entire journeys to six months and beyond. Case studies for the journeys of two other participants, Geraldine and Beryl, have also been produced.

The Client Case Studies are presented in the next section of the report.

It is envisaged that the timelines and case studies will be useful learning resources for a range of health and social care professionals and voluntary and community organisations involved in commissioning and/or delivering care services.

Client case studies: Six months and beyond

This section of the report presents impact case studies for the entire client journey for five participants in the study. The case studies illustrate many of the key findings and themes to emerge from the study. The issues raised are common to many of the participants and their families. For instance, Queenie's journey highlights the importance of holistic care flexibly delivered which not only meets practical and physical needs, but satisfies the emotional need for social contact and companionship of many old and vulnerable clients. It shows that continuity is important and dealing with one person in the system, such as a Social Worker, makes negotiating the health and social care system a lot easier. Appropriate information and communication with clients and their families is vital, as having to deal with information from different sources can be overwhelming at times and difficult to remember. Queenie's story also provides an example of the important caring role that many family members play, the impact and toll caring can take and the importance of ongoing emotional support for carers as well as clients.

The client journeys for all participants are summarised in the Client Timelines in Appendix 1.

4.1. Queenie's Journey

Initial interview - February 2015

Queenie is 79 years old, 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 Queenie at home. Upon discharge, Age UK provided the Home from Hospital service in Queenie's home, which although was initially for four weeks, was extended to six weeks. Age UK told Queenie and her son about other provision such as day care centres and also ordered a bed, bidet and a winch for Queenie. Through the Home from Hospital service Queenie 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 Queenie 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 Queenie, *"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 Queenie, 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 Queenie's son a break from caring, but Queenie struggled to settle and did not enjoy her stay and felt apprehensive about doing it again.

Queenie feels happier and healthier, having gained weight and she is sleeping better, thus consequently not needing to see her doctor, or go to hospital. Her son attributed this 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 because of her 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, she appreciates having *"a laugh and a joke.....instead of just laying there"*, with very few visitors and only the television for company. According to Queenie, the carers are the best people to provide the care that she needs.

Six weeks into the research, Queenie 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; awareness of other services; completing paperwork; and was arranging for a befriender to regularly visit and talk to Queenie, because it is company that Queenie 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 Queenie 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

At three months, Queenie 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 was seen as value for money, at £15 per session, *"it's worth it"*. It was affordable because the household was in receipt of Carers Allowance and Attendance Allowance. There were no complaints about the Centre, except that Queenie experienced discomfort sitting in her wheelchair all day. This was hoped to be resolved by moving Queenie 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 Queenie'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 Queenie 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 played a key role 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 Queenie and her son might benefit from.

Respite care was taken for a second time, but again, Queenie 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 Queenie 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 Queenie. 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.

Week 18/19

In recent weeks, Queenie saw her doctor for stronger pain killers for the pain in her knees and she saw an out-of-hours doctor for antibiotics for a water infection. She hadn't been to hospital or asked to go there, and this was attributed to the gap the carers had filled in her life through their four daily visits:

She's not mentioned about going to the hospital, before it was every other day, now it's never...without them (the carers) coming she'd be exactly the same now or even worse.

Queenie was attending the Day Care centre weekly, but the discomfort of sitting in a wheelchair throughout the day was still unresolved. Her son continued to save up for a more suitable chair. Whilst acknowledging that Social Services could provide financial support he felt it would be too lengthy a process to acquire one through this route:

By the time we go through them and get things it'll be another three or four months without one.

Interview at six months

Queenie was admitted to hospital with a urine infection in early October for four days. Her son also reported that although undetected at the time, his mother had suffered a minor stroke two/three months prior. The carers were continuing to provide support. In a separate interview he noted a decline in his mother's general well-being; she wasn't in good spirits and was struggling to feed herself. Queenie had also stopped attending the Day Care centre due to the travelling involved and her lack of motivation to socialise. Her son felt 'tied' down as a result of this change coupled with having to feed his mother her meals.

As the Social Worker now had minimal involvement in his mother's care he independently found two carers to provide her company for one-two hours per day four days per week. Although in its early days, this arrangement seemed to be working:

My mum likes it, it's just company for her, she gets what she needs out of it I think.

He had also made an appointment at Tickhill hospital to find a more suitable wheelchair which provided more comfort and prevented her sliding around.

Week 39/40

During a catch-up by telephone, Queenie's son informed the researcher that his mother had passed away just before Christmas 2015. He requested a home visit. The following day the researcher visited him at home and learnt the following.

Queenie was hospitalised again in October, and again in November 2015. By this time she was struggling to swallow food. Her rapidly changing health indicated that she had several strokes leading up to her death.

Having reflected on his experiences as the main carer for his mother, Queenie's son felt that although they were both well supported by DMBC, he needed more emotional support in his role as a carer. Whilst he was given telephone numbers for other services, he was not provided with any contact details for support services to meet his mental health needs during a particularly challenging time.

4.2. Pearl's Journey

Initial interview - January 2015

Pearl 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, Pearl 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". She 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 Pearl 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 her belongings stolen. Prior to this, she had a full, active life.

Pearl 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, Pearl 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 Steps, Pearl and her sisters have already consulted with the Occupational Therapist, who is also getting a CPN involved, and a social worker. According to Pearl, *"people are listening"*.

Pearl 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 Pearl's identity. Her sisters repeatedly emphasised Pearl'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 Pearl'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 Pearl'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, Pearl's home was no longer considered a safe option to return to.

Six weeks later

After her initial interview, Pearl 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 Pearl to move to. They were provided with a list of residential care homes, and *"pressured and pushed"* to find somewhere within the week. Before Pearl 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, Pearl 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

Having settled somewhat and got to know a few people, Pearl has had some good and some bad days in her new home. Her sister noted that Pearl wasn't getting dressed some days and that her low ebb might be due to there being so much more to do at her supported housing compared to 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.

Pearl also reiterated, *"They don't do anything here"*. When the family raised this they were told that volunteers were needed to support activities such as bingo, music, entertainment Pearl 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 Pearl 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. Pearl was struggling to understand the safety procedures at her new home. She expressed very strongly that she thought others were taking her independence and control away from her.

Week 18/19

Pearl hasn't been well recently; her legs are swollen and she has been feeling low. The GP has seen her. Her sister reported, *"she's just up and down; one day she's happy to be there (at the care home), another day she's not"*. The family have moved some of Pearl's belongings into her room to make it feel more like home. On the whole, she seems to be settling in, she has got to know staff, and her memory seems to have improved.

Having lived a sociable, full and independent life, Pearl's family are frustrated that there is very little for residents to do at the care home and limited opportunities for outings. Pearl's family approached her Social Worker about the possibility of arranging for someone to take her out, but this was not agreed as part of Pearl's care plan.

Part of Pearl's care plan now includes that a small amount of alcohol can be consumed in the afternoon and a small amount in the evening. She also smokes more now, but is frustrated staff control how many cigarettes she can have daily.

Interview at six months

Pearl was unwell and unable to be interviewed and therefore her sister provided an update. She reported that Pearl has recently had a number of water infections, which she felt were due to an underlying health problem. The increase in chest infections was attributed to starting smoking again.

The limited opportunities for residents at the care home to get out and about were raised again. Apart from her family taking her out, and on one occasion a member of staff taking her round town on a voluntary basis, Pearl has been restricted to the environment of the care home permanently. The difficulty in balancing the ongoing responsibility of taking Pearl out with other family commitments was expressed by her sister:

'It does get a bit tiring knowing that this commitment is ongoing cos everybody's got busy lives'.

Staff at the care home were developing an understanding and cooperating with the family in meeting Pearl's requests for cigarettes and alcohol, her *"only pleasure"* in life, but at the same time monitoring the quantities for health and safety purposes.

Telephone catch-up week 39/40

Pearl has seen her doctor recently. She is retaining water in her legs and had a few chest infections. Her family are actively involved in her care; taking turns to visit her throughout the week. However, they continue to be concerned about her lack of stimulation at the care home. The home seems to be understaffed, so various plans have not happened. Nevertheless, Pearl has settled well at the residential care home. Staff are listening and have shown flexibility in meeting some of her needs, for example, they understand not to let her be without any cigarettes because she gets anxious.

4.3. Jane's Journey

Initial interview November 2014

Jane 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, Jane spent twenty-one weeks away from her home; over eleven weeks in hospital and nine weeks at Positive Step, Social Care Assessment unit. At home she was supported by carers, two of them visiting three times daily, which cost Jane £30 per day. They assisted with bathing, and heating her meals. A cleaner did the housework, fortnightly. Although Jane has a son and two daughters, only one daughter, who lives nearby, is mainly involved in her care.

Prior to her health deteriorating, Jane was a member 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. Jane'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 Jane's view, they do not want their residents to get too comfortable as the service is 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, Jane 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 Marian 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

Jane was discharged from Positive Step in late March and sent home; the family felt some pressure from Positive Step for Jane 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, Jane had two carers three times daily, but since returning home, she only occasionally has two carers. Usually there is one carer, 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"*. An additional night time call was put in place, although the timing of that call wasn't working because by the morning call Jane had been incontinent of urine. A nurse was due to visit to assess the situation. During this period of time, Jane's GP also visited her at home.

Marian previously provided considerable support. However, Marian was due to have an operation for cancer, and so was limited in the support that she was able to offer. Despite this, she was still doing the shopping, ironing, and washing, as Jane's washing machine had broken down. Jane and Marian had limited awareness of the support services available. The family were trying to provide care for Jane 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. However, 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

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

Prior to her twenty-one week stretch in hospital and at Positive Step, Jane ended up in A&E on a monthly basis due to her respiratory condition. Once in hospital, while staff searched for a bed, Jane 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 Jane 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 (Jane) 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, Marian 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 who 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 Marian'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'.

Week 18/19

Jane was readmitted into hospital at the end of June and this time the need for oxygen at home was identified. However, she was unable to return home because of the difficulty in finding carers who cover the area where she lives. During her recent five week stay in hospital, Jane has been moved to three different wards, which disorientated her greatly. Marian recalled:

It was very late when they moved her, I think that threw her. She didn't know what were happening.....that upset her. For a couple of days she were disorientated.

Marian visited her at hospital every day and advocated on her behalf. She explained, "when we went to look at the (care) home they suggested I just said no, she deserves better than that.....there was quite a lot of people with dementia". She also fought to get her mother the foods that she enjoyed because she was put on a strict soft diet. There was no flexibility in the soft diet, so for example, toast was withdrawn from Jane's diet, even though she was able to eat this without any problem.

Two other issues were raised: firstly, that Doncaster Council previously paying 24 per cent towards Jane's care were now proposing that she cover the full costs. Secondly, Marian was disappointed that the discharge team responsible for her mother's continuous healthcare assessment (undertaken at the beginning of June) didn't get back to the family, even though this was supposed to happen within 28 days.

Six months

Jane passed away around this time.

4.4. Geraldine's Journey

Initial interview – 11/06/2015

Geraldine is 84 years old and has several health issues – osteoporosis, tiredness and difficulties with walking, sleeping and incontinence. Geraldine has been readmitted to hospital several times due to falls, the first of which occurred after a '*bit of a mental breakdown*'. She fell backwards, landing on the concrete outside of her house and fractured her pelvis. After her latest fall - this time fracturing her pelvis, clavicle and also injuring her arm - she was again readmitted to hospital between March and April 2015.

Before her latest hospital admission Geraldine lived home with her husband of 60 years with the support of two carers, a cleaner and a gardener, and since her discharge has been moved to Positive Step, where she currently resides. Her husband has suffered with many health problems over the years which has meant that she was unable to return home after hospital for rehabilitation.

The Positive Step staff are friendly and a nurse helps her with regular injections for her osteoporosis. However she gets very bored and wishes for more support during the evenings. She often needs the toilet and finds it difficult to get in and out of bed and to walk down the long corridors. For entertainment she does word searches, cross words and reads but often sleeps due to boredom. She likes the outdoors and enjoys sitting outside in the sun when the occupational therapist is around.

Prior to her health problems Geraldine led an active life. She and her husband enjoyed regular walks in Derbyshire with the children, gardening, planting fruit and vegetables and making their own Gin. She often gets upset in Positive Step recollecting past memories:

I do get a bit down sometimes when I'm just sitting here and dreaming and thinking about all the things I used to be able to do, I get a bit upset with it sometimes but I tell myself carry on, you've got to do it... but I feel apprehensive.

Often being bored and confined indoors, Geraldine appreciates the visits she has from family members, although her husband cannot visit as often as she would like due to travel costs (£20 taxi fares). She wants to return home to him instead of moving to a care home or other accommodation, but acknowledges that it 'is impossible at the moment' due to their combined health conditions.

Six weeks later

A month ago Geraldine's social worker arranged for her to move from Positive Step to Rose House. She is due to stay in the care home until the 7th of August before moving back home to be reunited with her husband, who has been in hospital for an operation on his hip and knee. He is also due home on the same day.

The facilities are not as good in Rose House as they were in Positive Step. The beds give inadequate support and she is having trouble sleeping again. The staff are gradually trying to increase her independence which has meant there is less support available. Thankfully this hasn't been too much of an issue for Geraldine as she acknowledges the need to get back on her feet again. Six weeks into the research Geraldine has not visited her GP or been back into hospital.

Moving accommodation has been difficult for Geraldine and she is looking forward to being reunited with her husband after months of being apart. However, the move back home makes her anxious and she worries that with their combined health issues they will 'struggle to cope' without regular support. The pain in her arm, shoulder and pelvis is still a problem and her mobility is worsening. Should the move prove difficult their care package will be reassessed to determine whether it is adequately meeting needs. They will continue with the regular cleaner, gardener and two carers as a starting point.

91 days

At three months Geraldine and her husband Roger have returned home. She is suffering with constipation and pain in her shoulder and arm, but otherwise feels 'alright'. She administers her own injections is taking regular statins and painkillers.

Both are glad to be home and together again. Geraldine's initial apprehension about moving home was due to worries she would fall again and concerns for her husband's health. She was '*thinking he would have to do more*' but Roger stated that they are getting along fine with the support of two '*excellent carers*' that come in four times a day. They support the couple to dress, empty the commodes, serve up meals and undress in the evening. The couple appear to be satisfied with the level of care and support they are receiving at this stage.

Discussing her worsening mobility and urinary problems, Geraldine noted the negative impact this is having on her ability to engage in activities. Trips to shops have now been abandoned, leaving her feeling '*frustrated*'. In an ideal world she would like to be able to have dinner at the community hall but she has not yet felt well enough to do so. The couple attempted to attend a fortnightly dinner at their local church but Geraldine was unable to get into the taxi, leaving Roger to go alone. Geraldine encourages her husband to attend these events despite his trepidation of leaving her on her own, stating she has now got used to her own company. Geraldine's mood is lower and she seems tired.

Week 18/19

In early November Geraldine suffered a serious fall and has been in hospital ever since, first in Doncaster Royal Infirmary before moving to a rehabilitation ward at Mexborough Hospital. She was taken to A&E after falling down the stairs and hitting her head against the banister. Due to the severity of the fall it is unclear when she will be returning home. Her husband remains at home with the support of carers.

Roger discussed how Geraldine '*has not been herself*' in recent weeks and that her mind had been deteriorating. Roger is '*coping just about*' with the support of family despite some problems with his mobility. He hopes for his wife's recovery.

Interview at 6 months

Geraldine has been in Mexborough Hospital for two months and '*progress is slow*'. Although the pain has improved she is very tired, often confused, and has decreased mobility. She spent the Christmas Holidays in hospital but had a nice time filled with activities such as quizzes and baking. Roger visits when he is able using a door to door pick up service, but his mobility is worsening.

Geraldine is due a home visit soon to assess her condition. If deemed well enough she will return home and will be closely monitored for three to four weeks, with the possibility of moving her to other accommodation if she is not coping. Roger misses his wife and hopes that the home visit will be positive. This year has been a particularly difficult one for the couple; who have spent six months apart from each other through hospital admissions and Geraldine's time in Positive Step. After being married for 60 years and spending every day together, this time apart has been testing, a stressful situation compounded by their health problems.

Although Roger is excited to be reunited with his wife he admits how this also fills him with apprehension. Since Geraldine's fall her health issues have become more challenging, and he worries that he will not be able to cope whilst also dealing with his own mobility problems. Before her admission to hospital he reported that Geraldine's mind had deteriorated and she had started wandering. The council fitted a door alarm to prevent her leaving the house but the danger worries him. The hospital suspect the cause of this could be due to a bladder infection but diagnosis remains uncertain.

Roger has been considering options to help the couple to cope, including moving to a smaller bungalow to try and prevent further falls. Roger acknowledged that the move would be the best thing to do for his wife's safety, but after 15 years living in their home they have a lot of shared memories and he would miss living there. During his wife's absence he spends quite a lot of time thinking about the future, 'wondering what will happen to them,' and 'how they will cope'. They will tackle one day at a time, first with the home visit. It is a particularly 'traumatic' and 'stressful' time.

2 weeks later

Geraldine's home visit went well and she should be returning home in the next few weeks. Although Roger looks forward to her return he still remains apprehensive.

Two carers will come in morning and evening but Roger is unsure whether this will be sufficient support. It will take a few weeks to settle into a routine.

Interview at 8 months

Geraldine has returned home after spending over three months in hospital. Overall, she was happy with the care she received, despite some 'bullying' nurses who would not allow her to go to the toilet during the night. After a long period of time in hospital and away from her husband, she was ready to come home.

The couple described the trauma of Geraldine's most recent fall and the shock it caused Roger to find her that way; '*it was a sight I didn't want to see, propped up on the stairs with blood on her head*'. She had 38 clips in her head and further damaged her fractured clavicle and arm, restricting her movement. While she was in the rehabilitation ward Geraldine was diagnosed with vascular dementia, a diagnosis she refutes as '*her memory's still very good*'. Over-all she is in less pain than she was expecting, and is happy with her progress. Roger is still having some issues with his mobility and is awaiting an operation for a hernia.

A doctor at Mexborough Hospital, social services and Geraldine's care providers will assess her health and social care package in three weeks. Extra support is in the place for the next five weeks, with five carers coming in at three or four am, morning, mid-morning, lunchtime and evening specifically for Geraldine (Roger has two carers, morning and evening). Geraldine feels adequately supported with the care she is currently receiving. However, at the end of the monitoring period the care package is likely to decrease.

Instead of moving to a bungalow the couple are applying for planning permission to build a new home on the half acre of land in their back garden. If their plans are rejected, they will adapt their current home in order to avoid the '*big trauma*' that moving after '*all these years*' would cause. Geraldine is currently sleeping downstairs as Roger is very anxious about her safety:

I'm frightened if she went upstairs... you can't get up out of bed very well now but before when she got up she had a fall in the bedroom so I am frightened of the stairs and her falling.

Leaving the house has also been difficult due to Geraldine's urinary problems and her associated embarrassment. Geraldine now has a catheter fitted and with this in place the couple hope that she will be able to go to a Day Care centre once a week arranged by her social worker. As Geraldine has frequently felt frustrated in recent months, the possibility of the Day Care centre is something that she values: '*...it gets*

me out of the house and you meet different people and make friends'. They will find out in the next week if there is space for her.

The last year has been a great period of change for the couple. After Geraldine's latest fall Roger has had a lot of thoughts about the future and '*what to do for the best*'. Geraldine's health deteriorated considerably since the research began and her husband has health problems of his own. At different times throughout the research the couple have worried that they are failing to give the other sufficient support. Yet despite everything, they remain stoical, a long-married couple expressing a determination to face an uncertain future together.

4.5. Beryl's Journey

Initial interview July 2015

Beryl is 92 years old and lives alone. She has never married and has no family close by. She was admitted to hospital with viral pneumonia and placed on a ward overnight. The following day she was transferred to Tickhill Hospital where she spent four weeks. Upon discharge, Age UK provided the Home from Hospital service in Beryl's home for the standard four week period. Beryl is a very independent lady and primarily used the Home from Hospital service to take her to the bank so she could sort out her finances. She refused further domestic help stating:

I told Age Concern that I didn't want somebody coming in every week, I thought I should be able to cope...and I also consider that some domestic chores are good for people, sitting in a chair is not good for you, you need to move about.

In addition to the support provided by Age UK, she pays for a gardener and has had hand grips fitted on the stairs and outside the back door by a local builder, whom she relies on to do jobs around the house. The Local Authority has provided a commode, a toilet seat, shower board and chair for the bathroom. She has a pendant alarm, for which she pays £80 per year. Her neighbour currently does her shopping for her, but is moving out of the area shortly, so will no longer be available. She does not know how she will cope without this support:

I don't know what I'm going to do when she is no longer there.

6 weeks later

Beryl has had no further health problems and is now attending a Falls Clinic at Tickhill Hospital. She uses taxis to get into town and can walk with the aid of a stick, but prefers not to walk outside on her own as the pavements are very uneven.

91 days

Beryl is still attending the Falls Clinic. She is not getting out much on her own and uses Leger Transport or relies on taxis to take her into town. However, taxis can prove expensive:

The taxis all decided they wanted a basic fare so it's £3.50 even if you only want to go to the next road. I think it's most unfair to pensioners.

Her neighbour has now moved house, so her builder is bringing in essentials such as bread, milk, cheese and butter. This is in return for allowing him to use her garage as a storage space for his equipment. She also has meals delivered by Wiltshire Farm Foods. She has been without hot water since her new immersion heater broke down shortly after it was fitted. As a result, the bathroom was very cold so Beryl was

avoiding going upstairs to use the toilet during the day and was forced to boil water from the kettle to have a wash. Following this interview, the researcher referred Beryl to the Community Well Being Officer (CWO) team, who agreed to call out to see her that day regarding the heating and hot water.

Week 18/19

Beryl has just returned from a holiday in Scotland, visiting relatives. She reported that following our previous interview, the CWO had contacted her and supplied her with blankets and heaters. Her immersion heater has also been fixed, so she has hot water:

[The CWO] got me that fire and a little fire that I can put on in the bathroom and she gave me two blankets, so I have one on my bed and I've kept one downstairs as they are lovely and warm.

Interview at 6 months

Beryl has now completed the allocated sessions at the Falls Clinic. She has been provided with a 'rollator', to use outside, which has four wheels and is therefore better on the uneven pavements. She misses the social aspect to the Falls Clinic and would like to have more of a social aspect to her life. She mentioned a group she used to attend, which no longer runs due to lack of funding:

You do miss people. I've gone week after week and never really spoken to anyone.

Following on from this, she reported that the most help and care she had received was from Age Concern, and would have taken up Age UK Day Centres had the service not been so expensive:

If the charges had been a little less I would have phoned Age Concern and said 'have you got a sewing class' or 'have you got a listening to music class', because they can be quite enjoyable.

She discussed how the local Citizens' Advice Bureau in town had closed, which had upset her as she had used them in the past and was now unsure where she would go if she needed advice. Her builder had stepped in when she was pressured to leave her phone provider by a rival company and ensured she was able to stay with the original company. This situation indicates how vulnerable older people can be who live alone and have no family support. Beryl had also received a visit from a person from the Council to help with household tasks such as replacing light bulbs. She is unsure exactly where this support came from, but remembers picking up a leaflet 'somewhere.'

Following this interview, the researcher called the CWO team regarding the wiring of Beryl's telecare unit as she had mentioned during the interview that the exposed wires had caused her to trip on several occasions. The team arranged for an engineer to visit to attend to the wiring. This case study highlights that on two occasions, the researcher had to intervene and arrange for support. If the reported problems had not been rectified they may have led to an emergency hospital admission. The fact that Beryl lives alone and is socially isolated also increases the likelihood of this occurring.

Discussion and Recommendations

This report has summarised the HDP study undertaken as part of the larger of evaluation of Better Care Fund activities, formerly those for the Supporting and Maintaining Independence Programme (SMIP), in Doncaster. Whilst the study was being conducted NICE released their guidelines¹ on delivering home care and practical support to older people living in their own homes. Recent reports by the Parliamentary and Health Service Ombudsmen on hospital discharge² and from Age UK on the growing number of older carers and the increasing demands on them³ and carers more generally, highlight some of the current challenges facing those delivering HDP services nationally.

Overcoming such challenges is not easy, particularly in light of growing demographic pressures, the increasing numbers of complex cases and the financial burden on the NHS of undue hospital admissions and delayed transfers of care from hospital. The Parliamentary and Health Ombudsmen report states: *‘that structural and systemic barriers to effective discharge planning are long standing and cannot be fixed overnight’* and identifies the *‘need for better integration and joint working of health and social care services’*.

In this study the impact of services is generally beneficial. Most participants couldn’t have managed without the short term intervention of services. 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 is improved nutrition and hydration.

There are also some good examples of services supporting people at home and a small number of instances of them helping to prevent or delay GP consultations and hospital admissions. It is apparent however, that meeting support needs at home is challenging. The provision of support at home is not always adequate and at times support services are moving things round the health and social care system and problems of bed blocking and hospital admissions are still occurring.

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](http://www.nice.org.uk/guidance/ng21) (last accessed: 25/5/2016)

² Parliamentary and Health Service Ombudsmen (2016) A report into investigations of unsafe discharge from hospital http://www.ombudsman.org.uk/_data/assets/pdf_file/0005/36698/A_report_of_investigations_into_unsafe_discharge_from_hospital.pdf (last accessed: 25/5/2016)

³ <http://www.bbc.co.uk/news/health-36310617> (last accessed: 25/5/2016)

Our findings identify a range of factors relating to discharge care pathways that need to be considered in order to better meet the NICE guidance and improve client outcomes such as those measured by ASCOF 2b. These issues are summarised below and are evidenced by the Client Timelines in Appendix 1 and the detailed Client Case Studies in Section 4 of this report.

5.1. Communication

The earlier interim report highlighted how many study participants were 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. 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.

Participants sometimes struggled to communicate with services and didn't always feel listened to or informed about what was happening. Some experienced difficulty in contacting services, or finding out who the appropriate person who they needed to speak to in order to get help. In some cases participants were frustrated by the lack of communication between different services. There was a lack of coordination within and between services and different parts of the system didn't link up effectively or get back to clients and/or their families when they said they would.

The interim report recommended that services needed to re-examine and improve routine ways of communicating with clients in order to improve client understanding of what is happening to them and the services they are receiving. Importantly, this point doesn't necessarily relate to providing *more* information as our results suggest that too much information all at once can be overwhelming, but is about enhancing the understanding of information received in order for clients, their families and carers to feel informed about what is happening to them. Better understanding of information would help alleviate the sense of not knowing identified in the 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 about what services offer.

Our findings show that 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.

It is also apparent that dealing with one named person would be helpful for many clients and their families. Clients and their carers would benefit from the assistance of a key worker who could: help them navigate the health and social care system; deal with information and queries; and assist with communication and planning.

5.2. The importance of family support and involving clients and families in decisions about care

Without family many of the participants in the study would be in a much worse position. When participants had family and their family were in a position to contribute to and complement care, participants seemed to progress better. Those who were alone or who had family who couldn't help were more likely to struggle. Where family did contribute to care this didn't always appear to be planned or integrated into the assessment or management of the discharge planning and care package. In some cases it was evident family members were filling in the gaps of service provision. In one or two cases participants felt they might have got more help and support if they didn't have family.

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.

Effective involvement of clients and families and better integration of family members who want and are able to contribute to care in the assessment, planning and management of discharge pathway services and care packages, might help avoid situations where families feel they are taking up the shortfall of service provision, and may help relieve some of the burden they feel. Integrating the client and family in such a way provides an opportunity for all parties to set expectations and agree proper arrangements of what services will provide; what families are able to contribute; and promotes better understanding of the limits of both. 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 were entitled to and could ask for from the care and support services they were dealing with.

5.3. Consideration of carers' needs and support for carers' emotional wellbeing

Caring for others should not be to the detriment of the carer's own health and wellbeing. Carers are entitled to support and can receive support in a number of ways including from: social services; the voluntary and community sector; the NHS; the benefit system. Although clients were being supported it was evident that in some cases the needs of carers were not prioritised or were being missed. Some carers in the study were struggling with caring responsibilities which were taking their toll. Carers did benefit from respite care and other practical help but our study suggests carers' ongoing mental and emotional needs require better attention and support. Carers' needs and emotional wellbeing should be a consideration and integrated appropriately into discharge planning and care packages. Carers also need to know about what services are available to help them and how to access them.

5.4. Loneliness and social isolation: The importance of practical and social support to (re)engage in social activities and get out and about

Loneliness and social isolation are prevalent amongst participants in the study. Participants were often reliant on family members to take them out and were unable to get out otherwise. It was evident that a lack of social contact has a big impact on the quality of life and wellbeing of study participants and possibly triggers deterioration for some people. Given that the problems of social isolation and loneliness in older people are so widespread and well recognised, it is surprising that

these issues were sometimes being missed or not effectively dealt with by services. Some participants benefited from befriending services and HFH referrals sometimes helped people to access these services. However, many more of the participants could have benefited from such interventions if they had known about them and how to access them. For instance, the most frail and lonely participants in our study were frequently discharged from hospital to Positive Step as they needed social care assessment and support. When these participants returned home and their care packages were sorted they were not always accessing social support or befriending services which appeared to be more routinely offered through the HFH service.

Boredom is a concern. A number of participants at Positive Step, in residential care and living in their own homes didn't have many things to do. It appeared that facilities like Positive Step and residential care homes didn't always have the resources or available staff or sufficient volunteer support to accommodate clients' wishes to go out and socialise and/or engage in other activities. It was evident that when participants were able to go out and engage in a variety of activities they felt much happier and healthier.

Our interim report stressed the importance of practical help to get out and about, and additional support for clients to (re)start social activities. Almost all participants in the study expressed a desire to get out and about more and/or (re)engage in social activities. A common barrier identified by participants was a lack of practical support to help them 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 and/or engage in meaningful activity 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 will obviously help combat problems of isolation and loneliness 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.

5.5. Respecting client autonomy and ensuring person centred flexible and holistic care

The importance of maintaining and holding on to as much independence as possible was stressed by many participants in this study. Clients want to be recognised 'as a person' by the services they are dealing with and treated with dignity and respect. A number of participants in our study expressed a desire for staff in homecare, residential care and assessment unit settings to '*just sit and talk*'. Services need to take the time to listen to clients' needs and show patience when dealing with users. Wherever possible the focus of services should be on enabling clients to do what they would like to do in order to maintain their independence. According to the NICE guidelines this may require longer visits for those receiving home care. It also 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.

Participants in this study were usually appreciative of what carers did for them particularly if they felt that the service provided more or less what they needed. Our findings demonstrate some of the benefits of flexible and holistic homecare but also highlight some concerns in the way that homecare services were being delivered.

For some participants early opportunities for intervention and prevention were missed and signs of deterioration and decline were not picked up by services. Care workers were visiting homes and carrying out what they had to do but were not always picking up on these warning signs. In some cases this was because care packages weren't always flexible enough or weren't reassessed in order for carers to make a difference.

Some participants (clients and family members) described concerns and instances where care services delivered a package precisely and inflexibly. In some of these situations this inflexibility meant risk hazards and hygiene needs were left unaddressed, examples included: soiled continence pads being left around the house; food debris and washing up being left; falls hazards.

Guaranteeing home care workers are able to recognise and respond to deterioration in someone's health or circumstances, ensuring that they have the knowledge and skills needed to perform their duties safely and are able respond to risks and concerns of self-neglect are outlined in the NICE guidelines.

Our findings show that when carers were more flexible and able to support social needs as well as other needs, or the service was more responsive, this increased the quality of life of participants and people were happier and more content. The HFH service provides some good examples of responsive care.

While some participants had been referred to the Falls Service, for many it wasn't apparent and many people fell after discharge. Some participants were not reporting falls or deterioration because they did not want to experience the uncertainty that they had encountered after a previous hospital admission/discharge. Participants didn't want to cause a fuss or be a bother to services and family.

5.6. Recommendations for practice

The study gives an indication of how challenging it is to provide support in a home environment in an integrated way. The findings and themes outlined here and in the earlier interim report point to a number recommendations for practice that DMBC may want to consider the when planning for the health and wellbeing of adults in Doncaster. Some of our findings chime with the NICE recommendations on delivering home care and practical support to older people living in their own homes. The study indicates that the following points are important in improving the experience and outcomes of clients on hospital discharge pathways and include:

- Improving practical help to get out and about and providing additional support to (re)start socialising / activities.
- Ensuring that all clients being discharged from hospital, rehabilitation and social care assessment settings are made aware of, and know how to access befriending services that could provide much needed social contact and support.
- Re-examining routine ways of communicating with clients to improve client understanding of what is happening to them and the services they are receiving.
- Involving clients and families in decisions about care and better integrating the needs and abilities of clients and their families in the assessment, planning and management of discharge pathway services and care packages.
- 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.

- Enabling adequate consideration, better ongoing support and review of carers' emotional wellbeing needs when discharge planning and developing care packages.
- Ensuring that those who are at risk of falling are referred to the Falls Service and increasing the awareness of professionals visiting clients' homes that many falls go unreported by vulnerable older people.
- Reiterating the requirement for all relevant professionals to identify any opportunities for early intervention and prevention in order to improve health outcomes and Make Every Contact Count (MECC).
- Providing home carers the necessary knowledge and skills to recognise and respond to signs of deterioration and ensuring that care workers feel confident to report such issues and/or intervene as appropriate.
- Commissioning and encouraging health and social care services that develop ways of working which enable care workers and other professionals to respond more flexibly to clients' needs and aspirations for their care.

It is hoped that the findings and suggested recommendations in this study provide material for discussion to help DMBC and its partners to identify strategies and solutions for better health and social care services so that services can work in a more streamlined and accessible way and deliver better outcomes for clients and their families.

Appendix 1: Glossary and Client Timelines

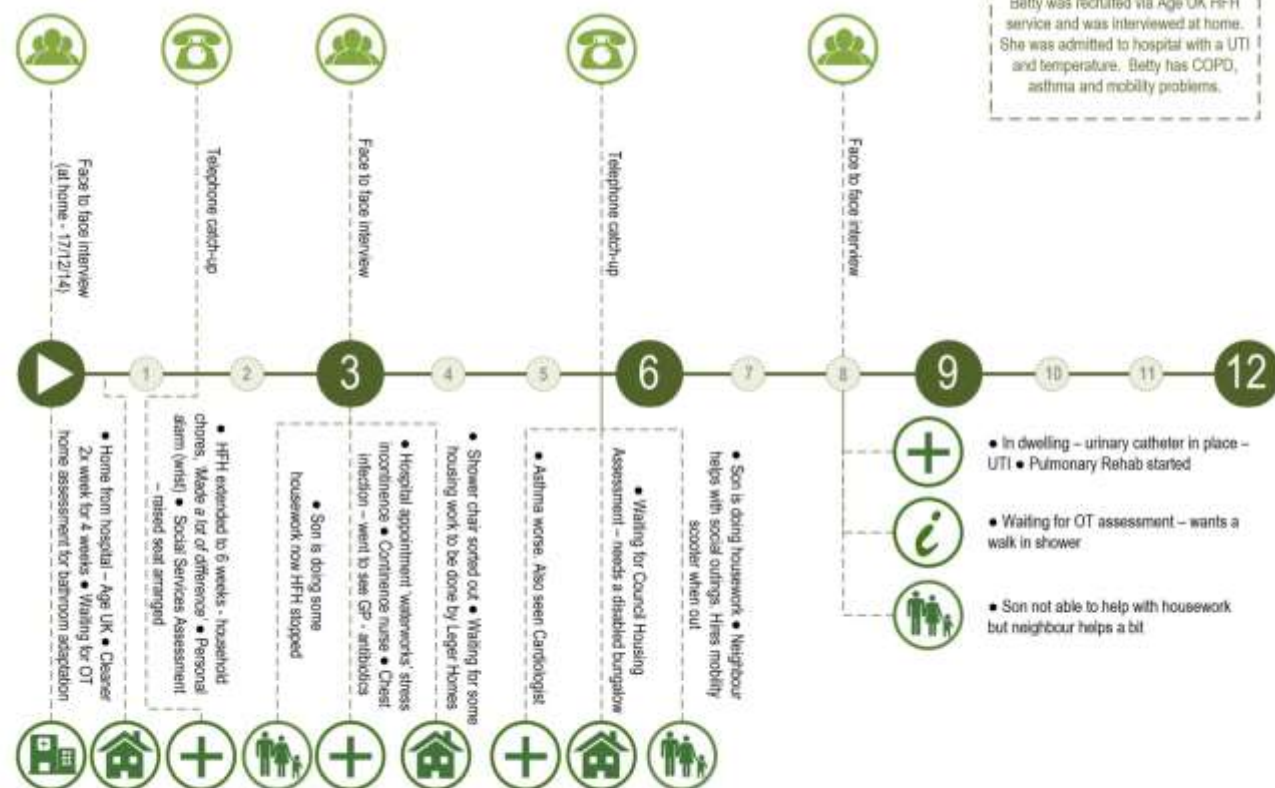
AA	Attendance Allowance
COPD	Chronic Obstructive Pulmonary Disease
CPN	Community Psychiatric Nurse
CWO	Community Wellbeing Officer
DRI	Doncaster Royal Infirmary
HFH	Home from Hospital Service
GP	General Practitioner
IBS	Irritable Bowel Syndrome
OPD	Out Patient Department
OT	Occupational Therapist
PS	Positive Step (Social Care Assessment Unit)
TD	Thornedene residential care home
TIA	Transient Ischaemic Attack (mini-stroke)

CLIENT TIMELINE: BETTY

Key Message

Betty is independent but is relying on family, friends and neighbours a lot more. This support is making all the difference to Betty but she struggles with housework if her family are unable to help her. HFH provides Betty with much needed flexible household support and company and when the service ends she misses it. After the HFH service finishes Betty goes without help with the housework for nine weeks because her son is very busy. Apart from the HFH service Betty seems unaware of what other support might be available to help. Although Betty receives some aids she would like a wet room and her housing is unsuitable for her needs. The lack of follow-up from services and poor communication puts Betty off and leaves her not knowing what is happening and waiting for services to respond, she mentions chasing services and waiting for people to get back to her.

Research Timeline



Health and Social Care Timeline

Quotes

Yeah, I've always been independent but the time has come where I need help and they [her family] can't always provide it

I think it would be lovely, especially if it was one of them days where I thought to myself I can't do with going out. I think it would be nice, but it would be hard to accept with always being independent but it's lovely that it's there [the HFH service]

She [HFH worker] has done [made the bed] and she washed up and took Christmas decorations down...she went to the shop for me

I've [incontinence] nurse come here and she sent me some samples and stuff to use which were all right, I couldn't find the telephone number to tell her and when I rung the community centre they wanted you to phone here, there and everywhere, I thought no

...she come out and what I asked for I'm still waiting to hear and that's got to be three months ago but there's an occupational therapist, I'm going to ring her and see if she can do owt for me

They've not been able to cos they're busy but he's coming back to do it [talking about housework] this next week, it's been a right mess

Interviewer: I wonder what you'd do without that support from [neighbour's name] and your son?

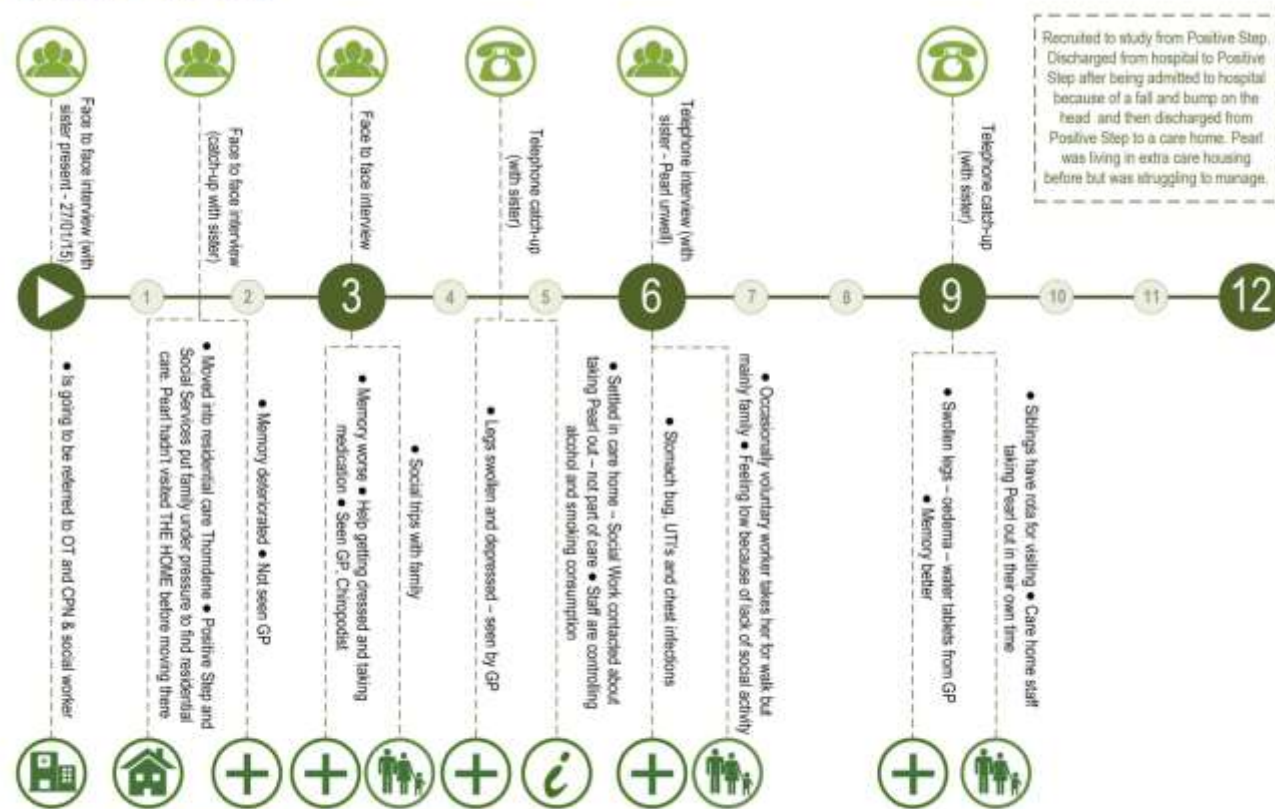
Betty: I don't know, I dread to think

CLIENT TIMELINE: PEARL

Key Message

Pearl is struggling to manage at the extra care housing where she lives due to increasing problems with confusion and wandering. Pearl has always been independent despite her mental and physical health problems but her current housing is no longer considered a safe option for her. Pearl has two sisters who advocate on her behalf who visit and take her out regularly. Without her family Pearl would hardly go out and would have nobody to represent her interests. The lack of opportunity to go out and socialise once Pearl is at the care home causes her family concern and at times puts pressure on family members who have a rota for visiting. Not being able to go out as much is making Pearl miserable. Greater service flexibility is needed to help Pearl maintain her identity and independence and meet her needs to go out, socialise and enjoy herself. Pearl's family are told that her care plan doesn't allow for someone to take her out.

Research Timeline



Quotes

Sister: The answer was they're looking for volunteers for things like putting bingo on, music, entertainment, anything, 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

Sister: There's been times when they've said they were going to organise a bingo trip, take her to the bingo which she used to like and nothing's happened about that

Sister: I'm not there all the time and they do say that they have people coming in and sometimes Pearl's not always bothered about getting involved so there's that as well, I think Pearl just wants to get out of the place, she doesn't want to be sat there throwing a ball round a room, that's not Pearl

Sister: She manages to get five cigarettes in a morning and five in an afternoon simply cos, and I do agree with what they say, that if you gave her 20 or 10 in one go she'd smoke them all so if visitors go we have got some cigarettes that Pearl doesn't know about in her room and we just give her the odd couple

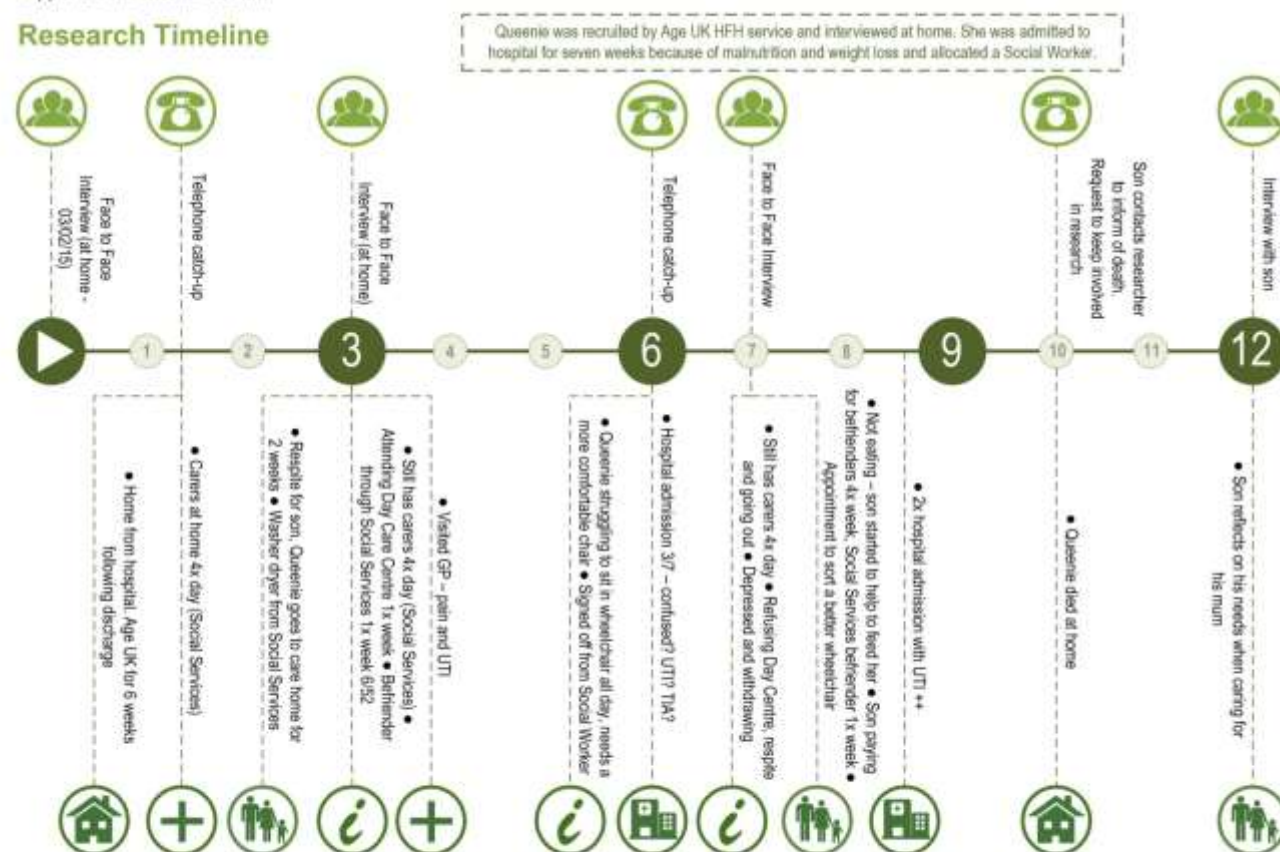
Sister: It does get a bit tiring knowing that this commitment is ongoing cos everybody's got busy lives but we do what we can

CLIENT TIMELINE: QUEENIE

Key Message

When Queenie returns home she receives HFH support and a care package is put in place. Both have a major impact on Queenie and her son who she lives with and who cares for Queenie. Befriending is pivotal to Queenie's care - carers and regular befriending support provide her with much needed company which is making her feel better and happier and makes things easier for her son. The comprehensive support meets Queenie's physical and emotional needs and reduces her use of health services. Queenie's son feels well informed but having to deal with information from different sources can be overwhelming and difficult to remember. Although well supported by DMBC Queenie's son feels there is a need for better emotional support for carers. He was given numbers for other services, but no contact details for services that might have supported his mental health.

Research Timeline



Health and Social Care Timeline

Quotes

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

Queenie: I like them who come now, we have a laugh and a joke, I love them who come now...they come and we have a laugh and a joke, they play jokes on me, I play jokes on them, it makes it, instead of just laying there

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

Son: She's not mentioned about going to the hospital, before it was every other day, now it's never...without them [the carers] coming she'd be exactly the same now or even worse

Son: remembering half of it [information about other services], remembering who to deal with...there's too many departments, too many different people to talk to - the pads is one department, asking for a wheelchair is a different department, and if you want a ramp it's a different department

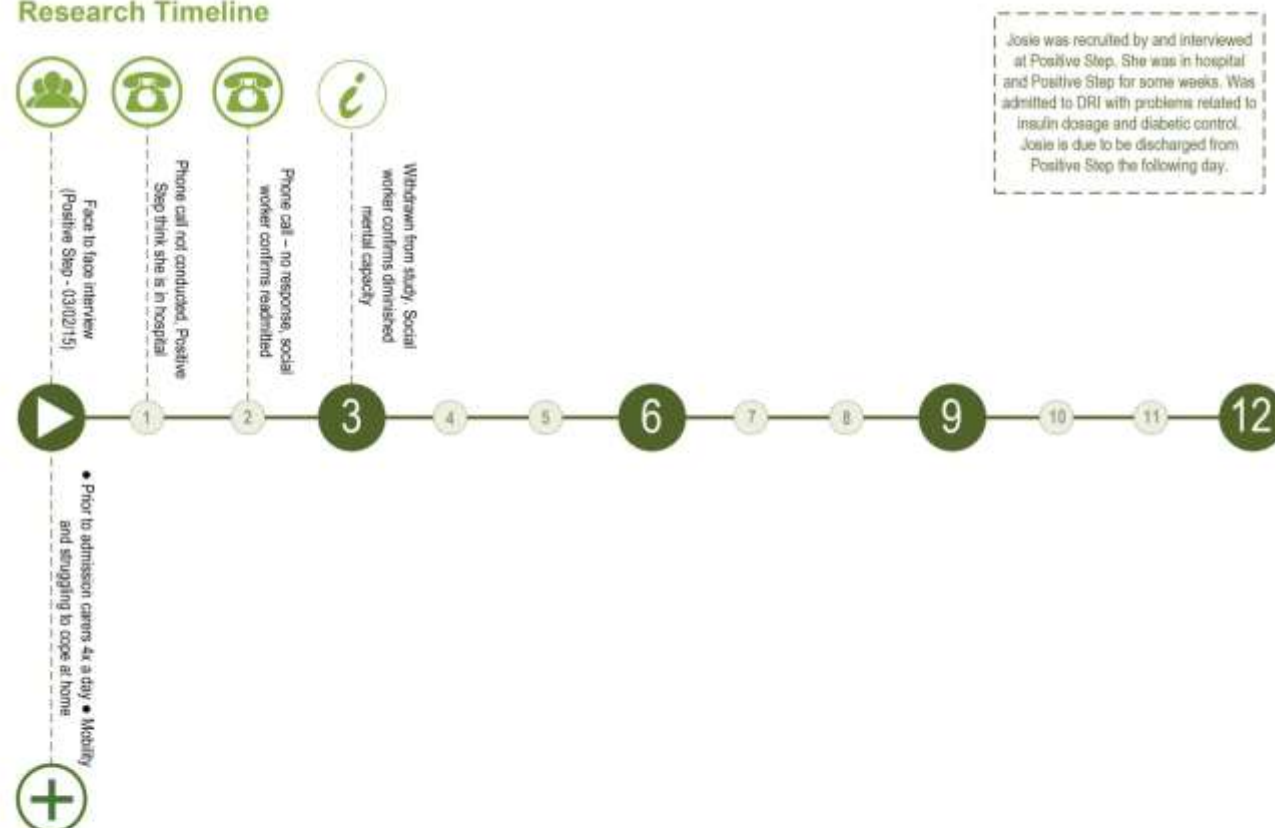
Son: Sometimes yeah, sometimes it's too much all at once, it would be nice if everything was just one person

CLIENT TIMELINE: JOSIE

Key Message

Although Josie already has care in place she leaves Positive Step without knowing about other services that might help and support her. Josie has no significant family support, although Josie's daughter takes her out occasionally. Josie has carers four times a day at home but is not accessing any other support. Josie cannot stand without help and is reliant on carers for her cooking and personal needs. Regular care is extremely important to Josie and provides her with security. Finance is a concern. Josie says she pays for the carers herself and is happy to do so but is unsure of what she might be entitled to.

Research Timeline



Health and Social Care Timeline

Quotes

[The carers are] very important. I know they're expensive but you might as well

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

Well neighbours don't want to know so that's out and I haven't any friends that live round [here] so it's got to be these people [carers] who can come and support

I was wondering if I could not get some support somewhere, cos I'm sure there must be something somewhere

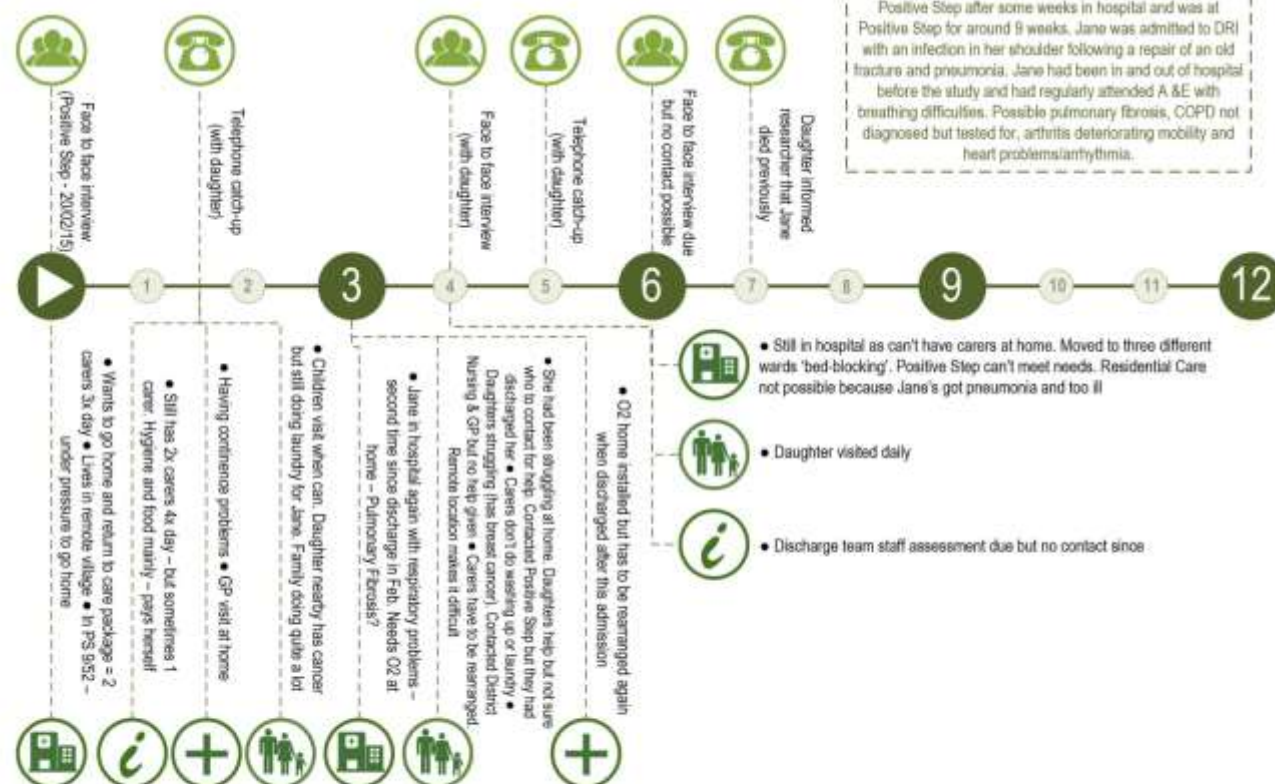
Mm, somebody did say something about once going to a centre for something, I don't know what it is

CLIENT TIMELINE: JANE

Key Message

Jane is unsure about what is going to happen to her. Jane wants to maintain as much independence as possible, she wants to sleep at home, and does not want to go into a care home. Jane's family want her to be at home as they feel she is coming to the end of her life. But Jane is isolated and lives in a remote village and spends a lot of time on her own. Jane's family help a lot and she is particularly close to her daughter who advocates for her and lives nearby. Jane's daughter is increasingly struggling as she has just had an operation for breast cancer. Every time Jane goes into hospital care has to be reorganised and after a hospital admission she cannot return home because there are no carers to cover the area where she lives. The family also struggle for some months to get oxygen for Jane at home. Dealing with and communicating with various services across the system is taking Jane's daughter a great deal of time and effort and is taking its toll on her. Jane's daughter's needs as a carer are being overlooked and she has not received any advice or support about services which might be available to help her.

Research Timeline



Health and Social Care Timeline

Quotes

I don't really know, I just want to be able to keep active, go into town, keep my marbles It's a different kind of care isn't it, cos if I wanted it here [Positive Step] or if I wanted it at home, to sleep at home, I'd like to be at home to sleep

Daughter: 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

Daughter: This is what I've been fighting for the oxygen for cos by the time they'd found her a bed in hospital she'd picked up cos she had the oxygen.... No she still hasn't got it now, this is why, this time she's gone in [hospital] they're hoping to get her some oxygen at home

Daughter: Because we live in such a remote village and a lot of the carers and she wanted two carers and we really struggled, at the moment she's under Steps mainly cos we're in such a remote area, they can't get, they keep putting it out to tender and nobody's taking it on

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

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

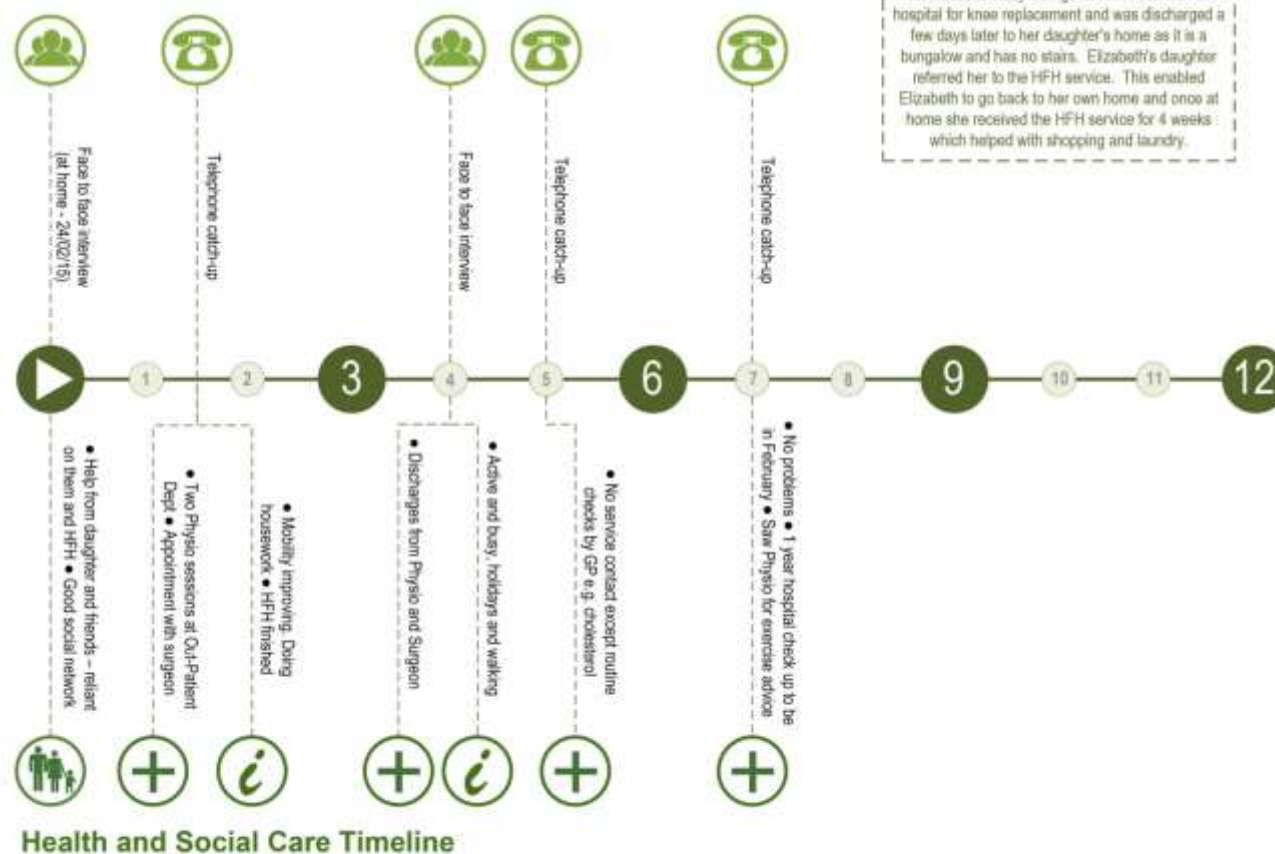
Daughter: I know I've got to carry on for my mum's sake but it does get me down, I get so frustrated I go every day and there's one thing or something else wrong and I have to ring somebody...

CLIENT TIMELINE: ELIZABETH

Key Message

Elizabeth isn't made aware of the HFH service whilst at hospital and is only referred to the service because her daughter, who works as a carer, knows about it. Elizabeth is independent and has family support and a good social network, however, without the HFH service she would be totally reliant on her busy daughters to help her and Elizabeth would have felt like a burden. The HFH service enables Elizabeth to move back home from her daughter's bungalow and provides the practical support Elizabeth needs whilst she regains her independence.

Research Timeline



Quotes

Age UK, I didn't know anything about care in the home after hospital discharge, nobody told me about that at the hospital, nobody even gave me an inkling, it was my daughter who's a carer informed me this could be possible for me to have. So had my daughter not have told me I would not have known

Yeah the first week back to my house, one of the ladies came out on the Thursday to do my shopping, then the following week two ladies came out so one did the shopping and stripped my bed, made my bed for me, put the washing in for me and then two or three days later I had shopping

I would have felt awful cos I would have had to ask my daughters who both work full time, both have their family, I know they both drive, one lives about eight miles out from here, but the point is you don't want to, not be a burden, but put on them so I would have been lost if I hadn't had Age UK to come round

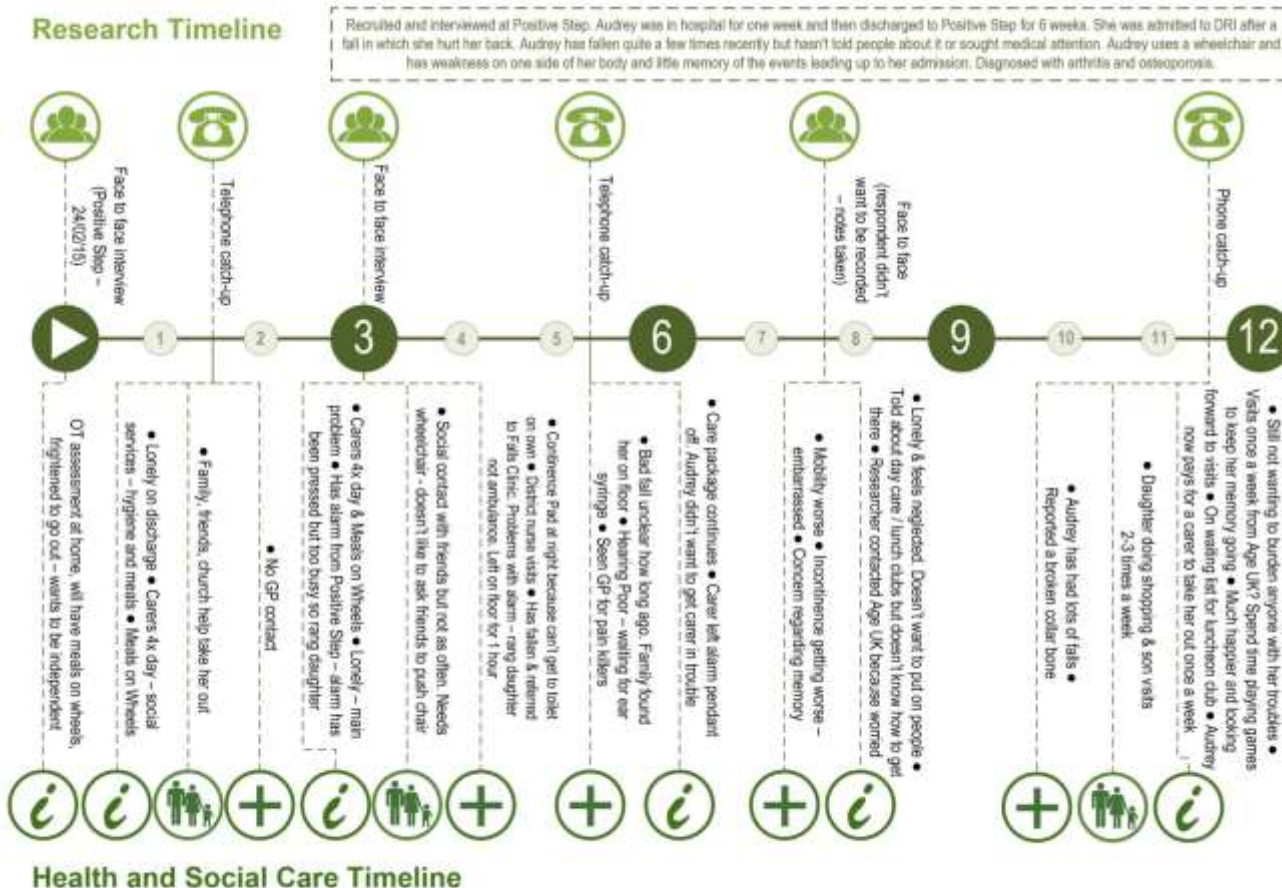
No because I've always managed on my own, I'm an independent person, you've got to be, you can't keep relying on people, so until this happened I'd never thought about anyone helping me for anything, I manage everything on my own, you have to. So if it hadn't been for Age UK I would have been relying on the family again

Now I do for me but 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

CLIENT TIMELINE: AUDREY

Key Message

Audrey is very lonely, doesn't like to make a fuss and often puts on a 'brave face'. She wants to go home and remain as independent as possible. Although Audrey has support through family and her church network she doesn't really like to ask for help or bother people with her problems. Although her practical needs are taken care of, her loneliness deteriorates during the study and her emotional needs are not identified until the researcher intervenes.



Quotes

It's been horrendous really, I would have been better if I'd been more open with it [telling people about her falls] but I've kept it to myself and thought that people would think I was moaning all the time, but we've got by

I miss the company...it's very quiet.... Being on my own yeah. Some days I don't see anyone, I've never spoken to a soul and it makes you feel really isolated and yet I've got a family, they've got everything in here that I need but it's not like visitors, they'll say 'what else can I do mum?'

I think they are very good [carers].... they are enabling me to cope, which I wouldn't be able to on my own

Yeah but it's worked out very well. I was very embarrassed, I thought I would be, I didn't want it to happen, I didn't want anyone bathing me, but I needn't have worried cos they've talked to me and everything's worked out fine

I have found that a bit, my friends don't come round like they used to do, cos I have to use the wheelchair for everything and it's not very convenient

I would go to these places if I felt I was confident enough and someone would look after me

I look forward to seeing her [Age UK befriender] and I'm very pleased to see her

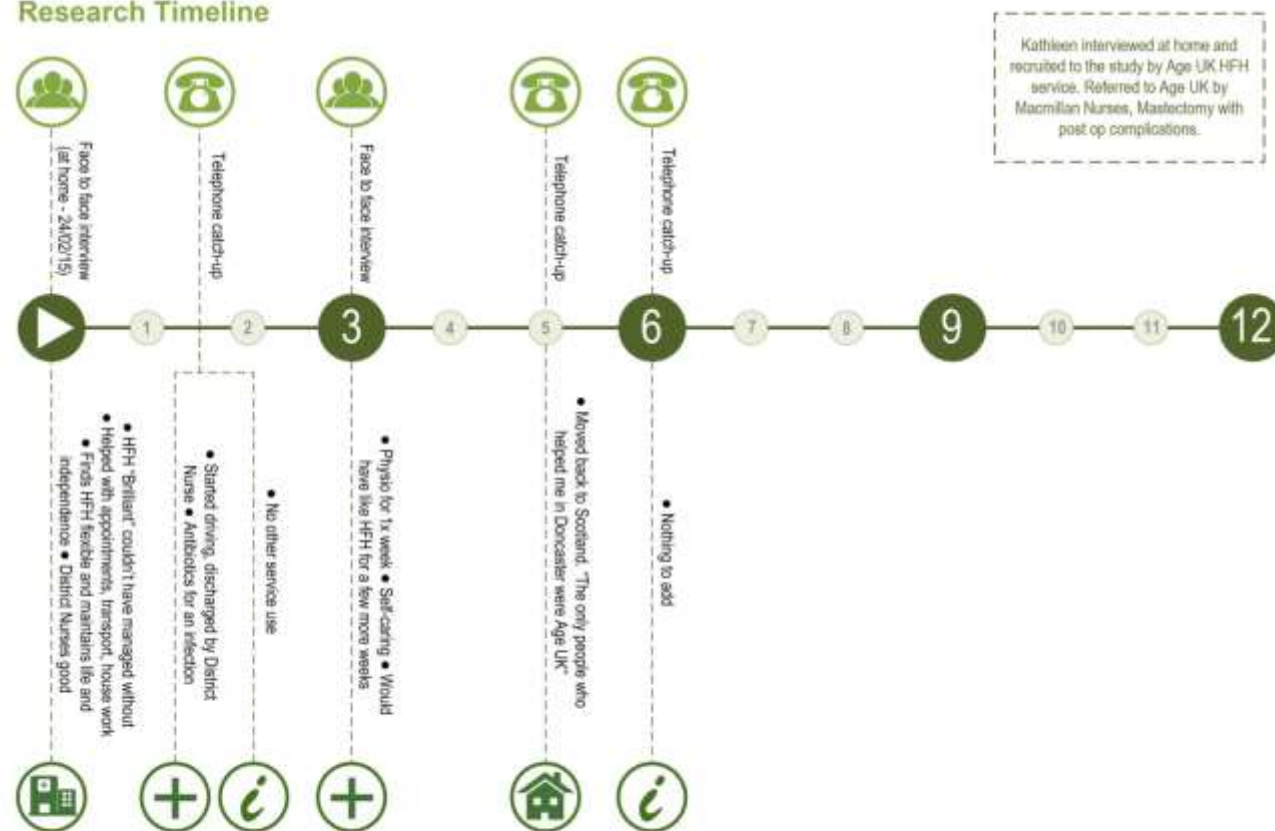
I love Wednesday afternoons, I love fresh air, I love to get out

CLIENT TIMELINE: KATHLEEN

Key Message

Kathleen didn't have a good experience in hospital and wasn't happy with the way she was treated. Kathleen lives alone and has little awareness of services which can help her situation. Kathleen appreciates the accessibility and flexibility of the HFH service and couldn't have managed without this short term intervention. The responsiveness of the HFH service in meeting Kathleen's needs compared favourably with other services. Communication between other parts of the system didn't seem 'joined up' to Kathleen and she feels she has had to sort things for herself.

Research Timeline



Quotes

I was just about having a nervous breakdown, they [the hospital] were saying 'we haven't got this and we can't do that, we can't get you any cars, you'll have to get taxis' I said 'I can't get taxis for all my appointments, there's no buses here, I can't get in there' 'oh well we don't do that, we used to but we don't do this anymore'

I said to the district nurse the other day this is like something out of Monty Python, like do your own surgery, organise your own medicines, organise your own discharge, it seems like I'm having to do everything myself and that's exactly what I've had to do

I feel this should have been the hospital's place to do all this, you can't just say 'you've got cancer, you can come in, we'll whip your breast off and then you're on your own, out you go, sort it yourself', so I couldn't have managed, in fact I would have had to say I can't have it done, I wouldn't have been able to have any treatment without Age UK, that's the top and bottom

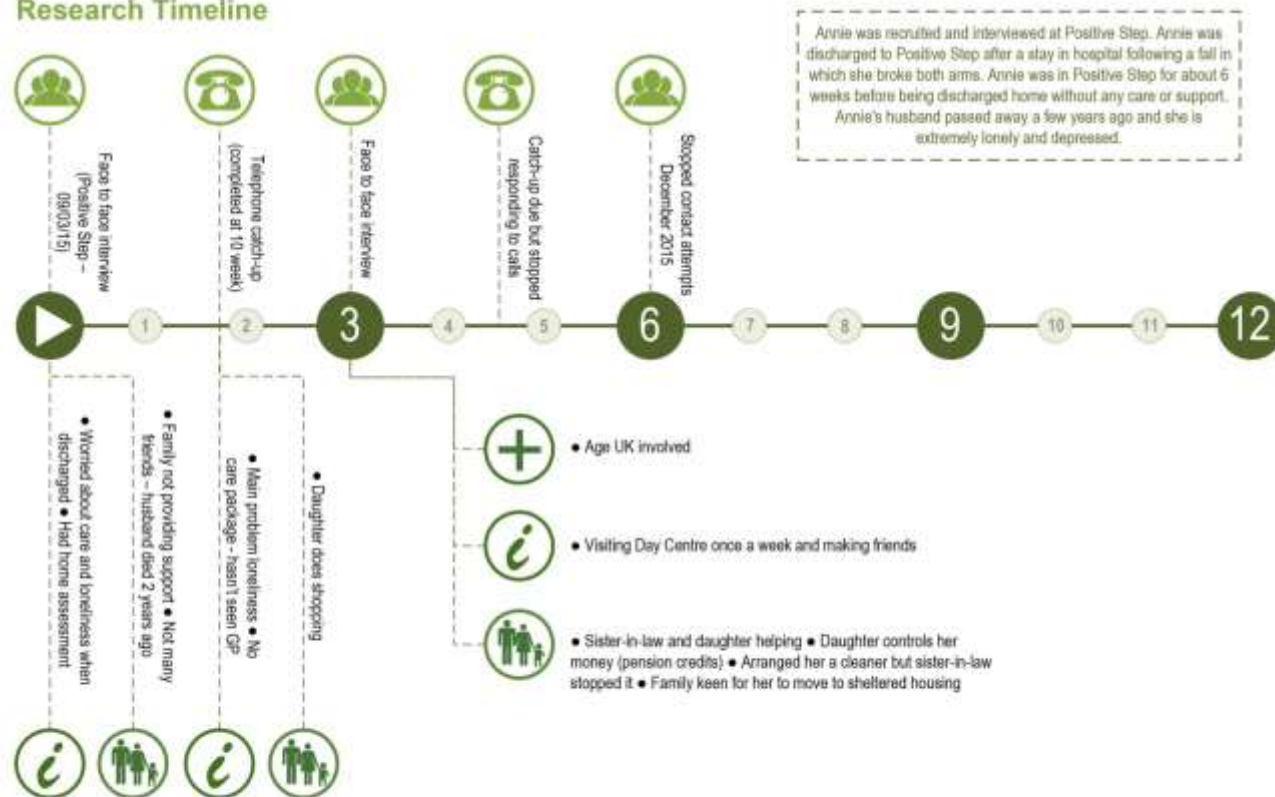
I'm just over the moon with Age UK, I can't believe how good they've been, and the district nurses as well... To me it's a brilliant system. They said if you want anything phone up and we'll get it whatever you need, your needs will be met and they've made it clear my needs will be met

CLIENT TIMELINE: ANNIE

Key Message

Annie is in a state of not knowing and is extremely lonely when she is at home. The information she has received hasn't been sufficient for her to understand what is going on and she doesn't know about the services that can help her and what she might be entitled to. This uncertainty makes it difficult for Annie to ask for help and limits the understanding services have of her needs. As a result Annie's most pressing need for emotional support and practical help to engage in social activities is not identified at Positive Step. Age UK contact Annie sometime after she gets back home and she goes to a day centre once a week which helps her feel a bit better.

Research Timeline



Health and Social Care Timeline

Quotes

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....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

It's just living, just everyday living [in Positive Step] but you've got company, where I'm on my own at home, I'm always on my own. In here you've got company with you all the time and that's good if you're like I was, lonely

Mm yeah, my husband passed away two years ago, ever since then it's just been loneliness

I don't know how I'll be when I go home, I'm dreading it

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'

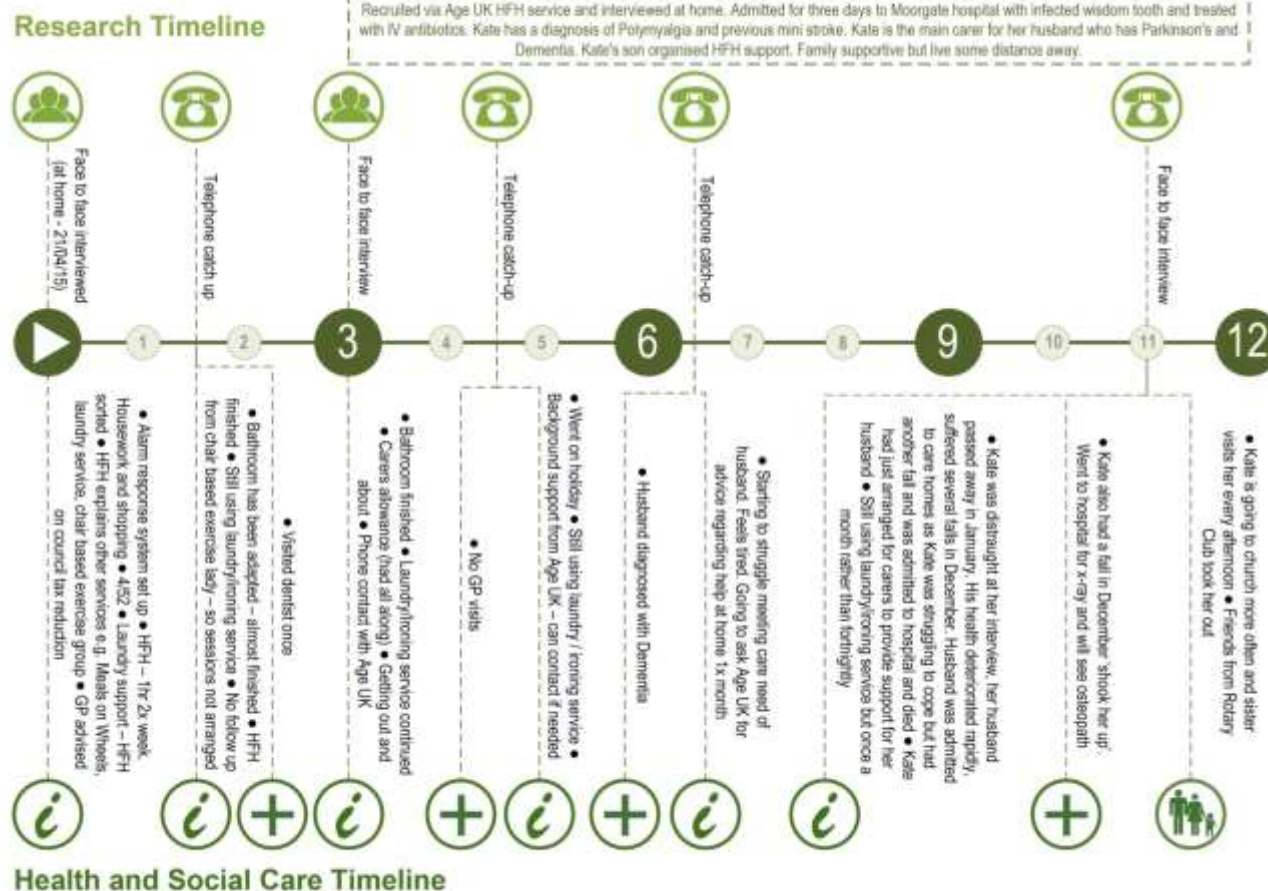
People are saying that [about day centres] but I've got to go there, that's what...Well I don't know where it is and going

Well it means I get out once a week, I'm out for the day so I'm seeing people which has made me feel better for the rest of the week

CLIENT TIMELINE: KATE

Key Message

Kate appears to be coping in her role as carer for her husband. The HFH service informs Kate about other services which can help and the service makes things happen for Kate. Kate appreciates the additional practical support because it 'takes the burden off' but feels that she should do things herself and doesn't like making a fuss. She is reassured that there is help in the background if she needs it. There are indications that Kate is beginning to struggle and the situation exacerbates as her husband's condition deteriorates. Kate's needs as a carer are somewhat overlooked. Although there is support in the background things have to get very bad before Kate asks for help.



Quotes

So yes it has helped me [HFH service] 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

[I'm] Fine, just get tired with age and doing things, that's all really, looking after my husband

Well not really [need further support] I'm managing to do things and until I can't do things, that'll be when I'll have to get more help

I just get tired, that's the thing. We've got Age UK, and other things we can ring too if we need help

I'm coping but I'm going to see if I can probably have someone give me a hand at times. I do feel tired, when you have to cope with just about everything, the finances, answering the telephone, post, you know everything

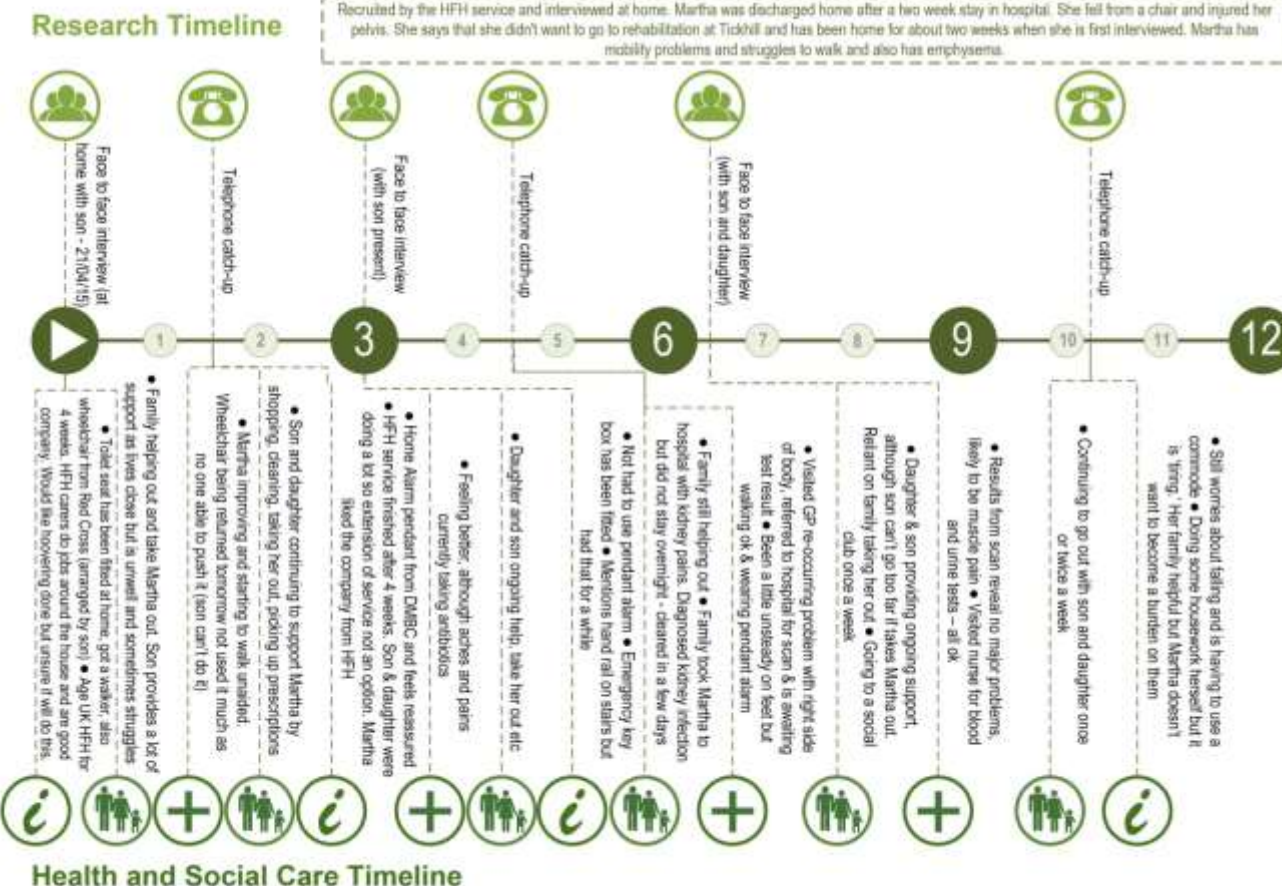
It shook me up [her fall] next day I carried on as I was

Things [meeting husband's care needs] getting too much here on my own

CLIENT TIMELINE: MARTHA

Key Message

Martha is in a state of not knowing and not asking. Martha is proud, independent but is unsure about the type of support she may be entitled to and what type of help she can expect. Her uncertainty about entitlement means she is often reluctant to ask for help. Although she is getting help from the HFH service Martha is unsure what she can ask them to do or what she is entitled to and feels she can't ask for anything because the service is free. She appreciates the company offered by the service most of all. Martha's family provide a great deal of support around the house and take her out, but she tries to do as much as she can as she doesn't want to be a burden. Martha would benefit from more practical support with household tasks.



Quotes

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?

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

You can't really ask them to do a lot if you're not paying them.... I got the impression that they just come to see that you're all right, they sign the paper to say that everything's all right.... I don't ask them. Just little jobs, but what's a little job?

That's it, the lady that rang up she said 'are you walking about?' I said 'yes' she said 'gracious you have done well, you are independent aren't you?' so it must be down on my papers that I'm very independent

Every morning he used to come [her son] to get my breakfast so I saved him that and I did it myself, it took some doing, I used to go from stool to table to fridge to door and round again, I were always within reach of something

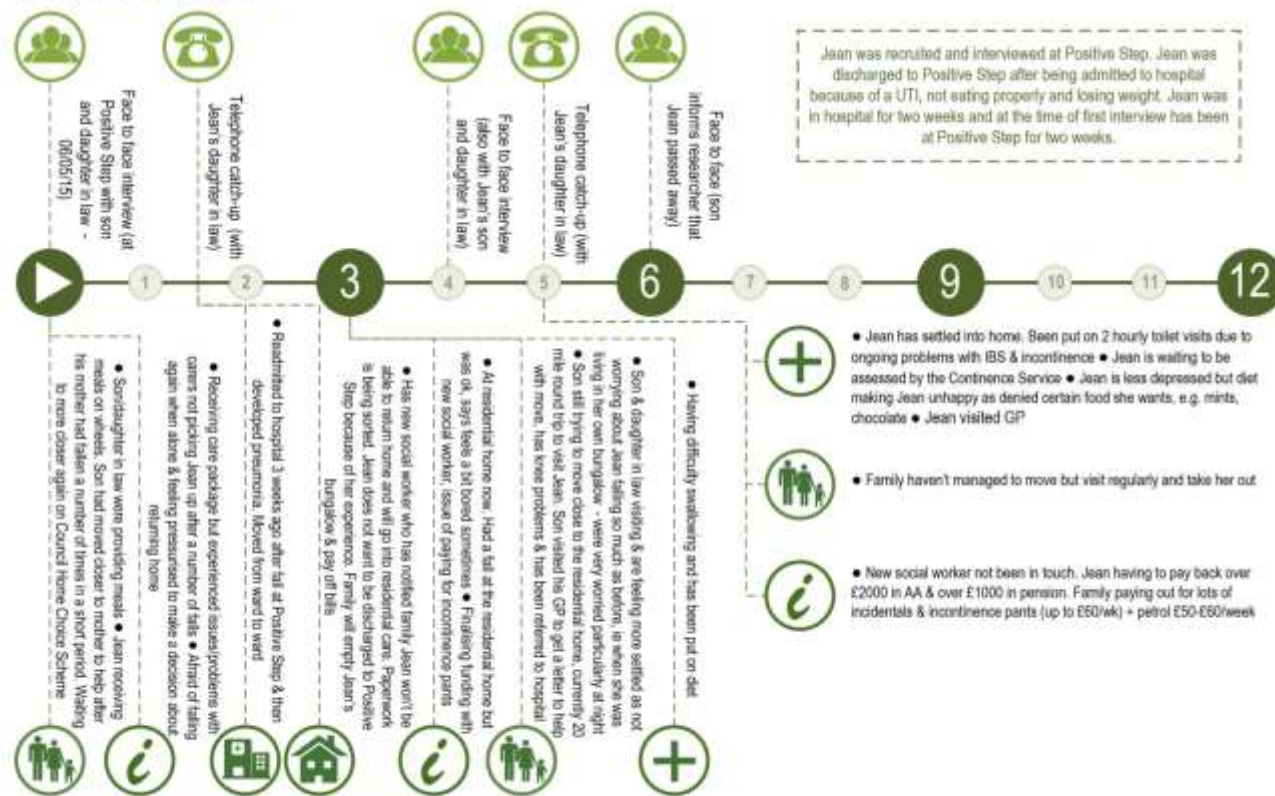
No, if I'm due to it I'd have it but if they don't think I need it then I shan't have it then I don't have to say thank you

CLIENT TIMELINE: JEAN

Key Message

Jean is extremely vulnerable she has fallen a lot recently and is increasingly frightened about being alone at home. Without her family Jean's predicament would be much worse but the responsibility of supporting Jean is putting strain on her son and daughter in law. Jean has had some bad experiences of home care. The lack of flexibility in the delivery of home care services and the inability to respond to her needs didn't make sense to Jean and her family and has caused distress. Once Jean moves into a care home her family are less worried and Jean feels more secure and reassured that if she falls there is someone to pick her up. Although she settles in to the home and is happier Jean feels bored and frustrated sometimes and would like more things to do and to be taken out.

Research Timeline



Quotes

Son: All they did [carers] was make her a drink, she was only allowed to change the sheet once a week or every fortnight

Son: There's been times she's been bed ridden and she wouldn't eat and I've had to go back two or three times a day...10 miles each way, that's a 20 mile round trip and then we could be stuck in traffic

Son: 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

Daughter in law: We're more settled at night now cos when she was in the bungalow we were always panicking at night can she get in bed all right, has she fell out of bed, now we don't have that problem

I get bored with myself sometimes but I come to the view that it's better to be here [at the care home] than risk any more falls. The [home] carers weren't even allowed to pick me up, where somebody fell out of that chair the other day, two of them picked her up

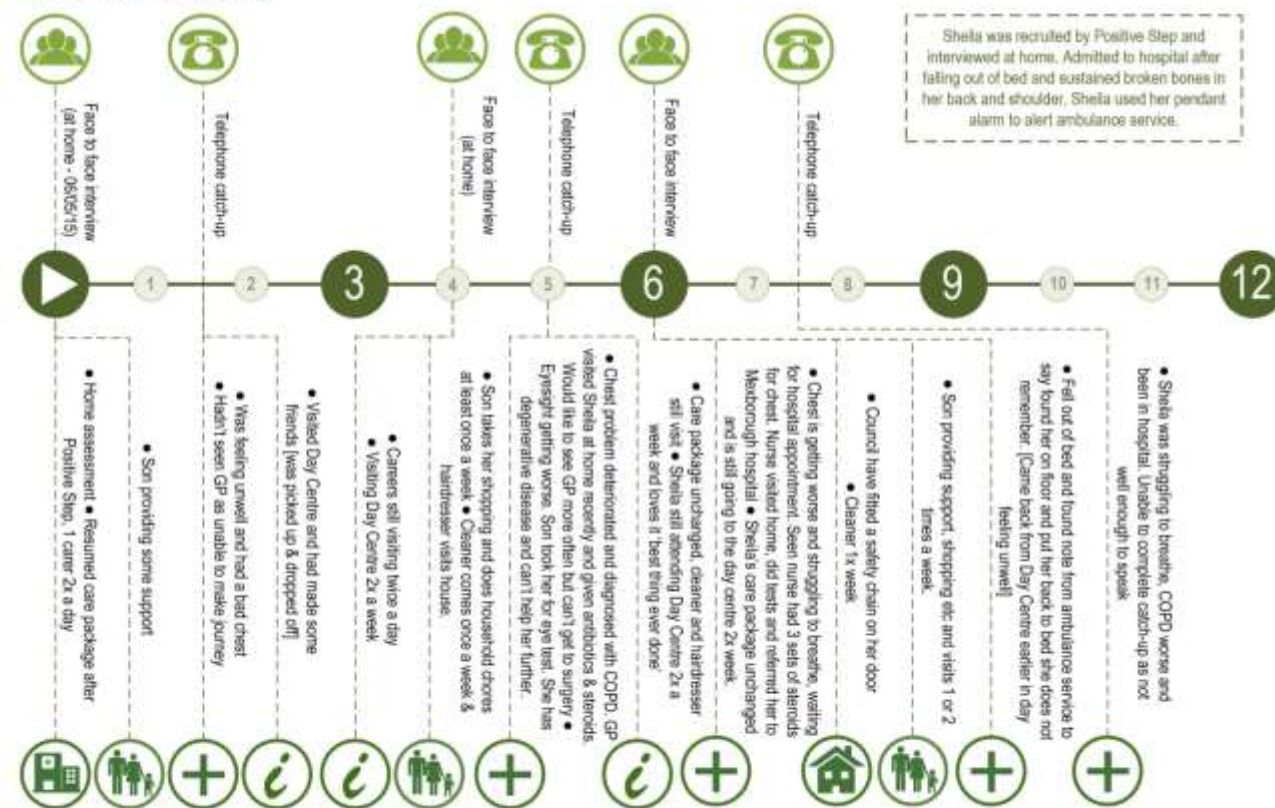
That's right, as long as people understand me, but I don't go out on my own any more like I used to and I think I'm a bit frustrated as well but I'd like to get out and about a bit more

CLIENT TIMELINE: SHEILA

Key Message

Sheila is independent and tries to do as much for herself as possible. Things like opening cans, drawers and reaching cupboards are becoming increasingly difficult but sometimes the people who help her don't always appreciate the inconvenience that 'such little things' can cause her. Short carer visits limit what carers can do but Sheila appreciates it when her carers manage to go the extra mile to be flexible in order to accommodate her needs and requests. Although Sheila has a good support network with carers coming in every day, a son who visits regularly and helps her with jobs like shopping and washing, and a cleaner, she is sometimes lonely and feels low and depressed in winter. Once she starts going to a Day Centre twice a week, her mood lifts and she isn't so worried about the winter coming.

Research Timeline



Quotes

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

I asked her [the 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

Winter, dark weather, nowhere to go, looking at black space there, go to dustbin, I feel safe, I don't feel threatened by anybody cos I've got all friends round which is good but it means I can't get out and there's nowhere to go anyway, there's only Asda and I can't go just riding round streets

I am coping, it's just when the dark nights come

And getting into me cupboards, I've got to keep them where I can reach, but carer come other day...she put them in me cutlery drawer and then I couldn't open drawer silly things like that and there's a thing to put them in

I love it, oh I love it [attending Day Centre]....It's the best thing I've done

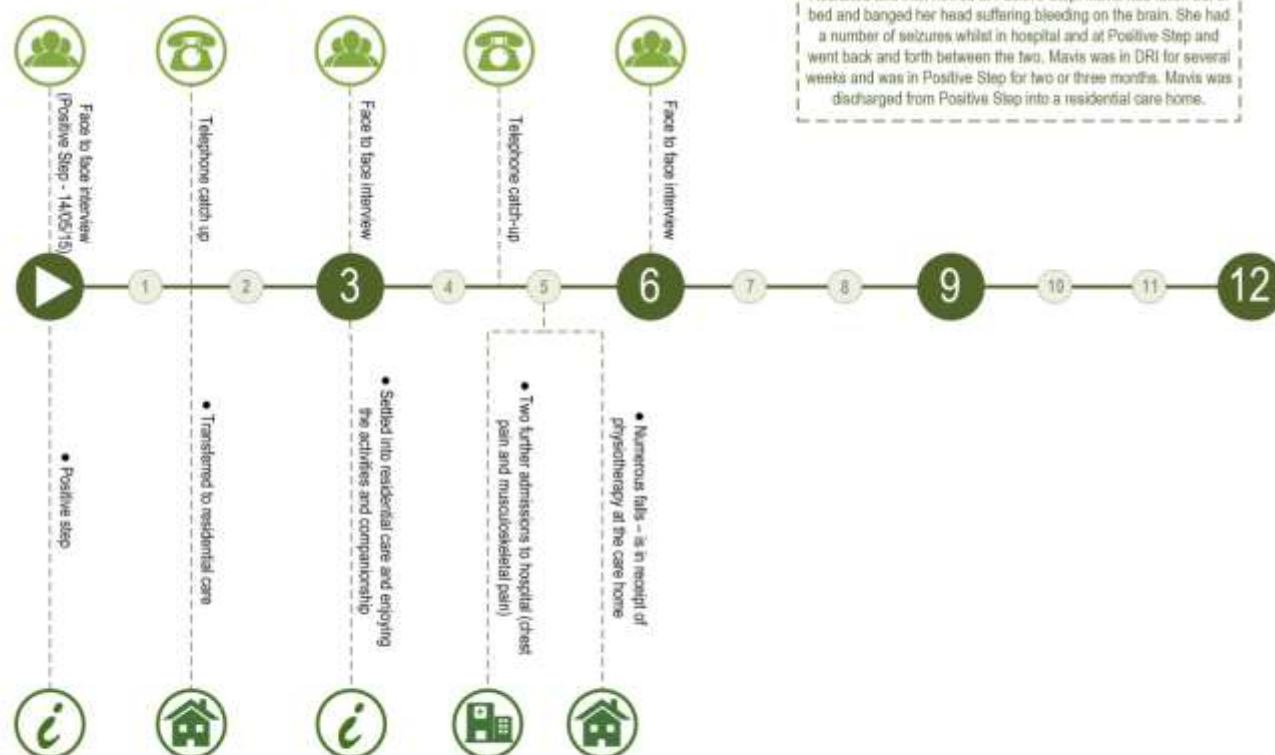
I think this winter's going to be different, just because I'm going out and meeting these new people, some of them less fortunate than me... and they take us out for dinner...and there'll be a Christmas party

CLIENT TIMELINE: MAVIS

Key Message

Pre admission to hospital Mavis is reluctant to tell her family that she keeps falling as she knows it will upset them. Mavis is scared about returning to her own home but wants to ensure she keeps as much independence as possible and isn't treated like a child by the care home that she goes to.

Research Timeline



Health and Social Care Timeline

Quotes

If they put me in a place, as long as they're alright with me I'll be alright 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

[My daughter] used to get upset 'mam, have you fallen today?' Sometimes I'd fall and I wouldn't tell them cos they'd get upset and my granddaughter would start crying

I were worried in case they don't send me in a home and I'd have to go home and just carry on

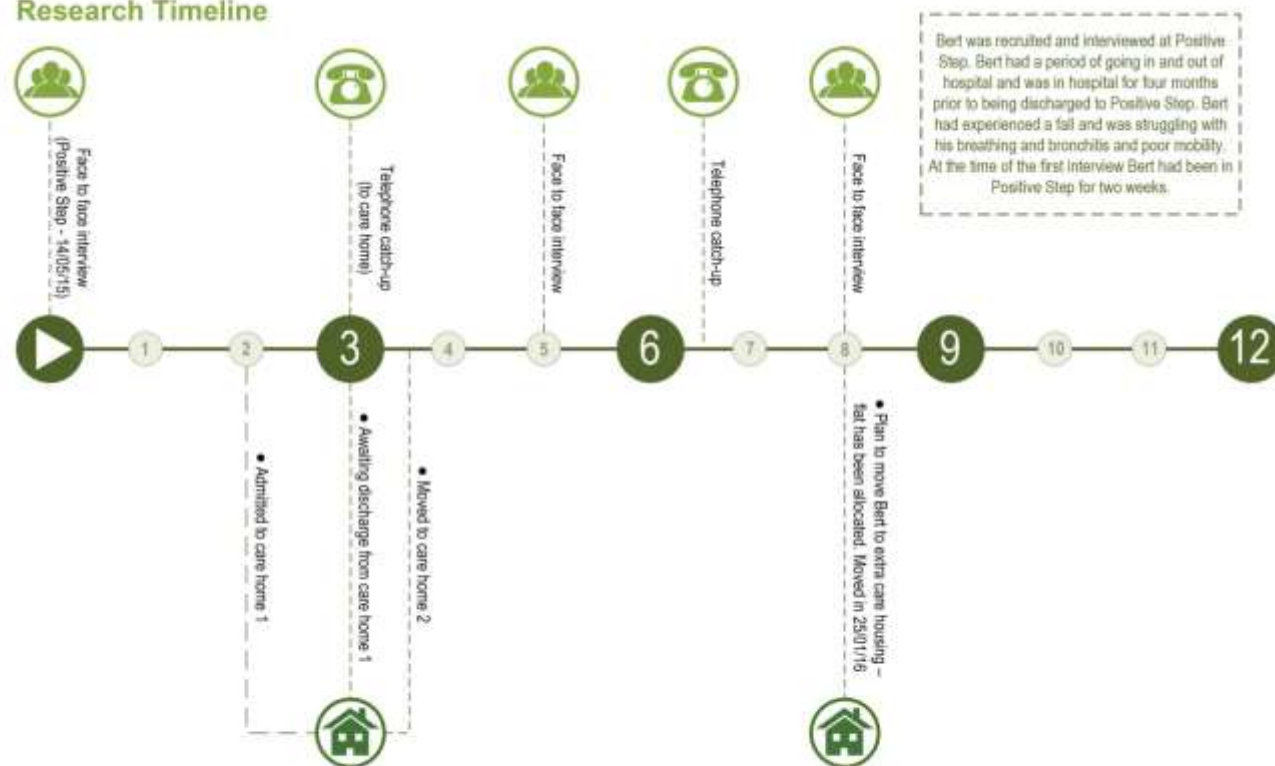
[In the Care Home] They're good to me and they worry and I know they like me

CLIENT TIMELINE: BERT

Key Message

Bert wants to be more mobile so that he can live independently again. Bert lives on a top floor flat but needs to be moved to a ground floor flat so that he can get out more easily. Bert wants to be treated as 'a person' and values staff and carers having the time and patience to talk and listen to him. In particular Bert would like people to take more time with him to introduce themselves and explain what they do and how they can help. Bert would like more information as the situation at Positive Step is all new to him and he doesn't know what is going to happen next. Bert is moved from one care home to another during the study and doesn't feel as if he is in the 'right place'. Bert feels as though the professionals think he is in the right place (better where he is) but doesn't agree and doesn't feel involved in the decision making process.

Research Timeline



Health and Social Care Timeline

Quotes

No I've no idea. I'll see as it comes

To strengthen up, I've got to strengthen up'

I don't know the titles, it's all new you see, care worker, social worker, I don't know all the titles. [I want to know]...who they are and what they can do for me

I just wish they had more patience with you, they just say 'I'm doing something, I'm doing something

They don't spend enough time with me

They could be more kind

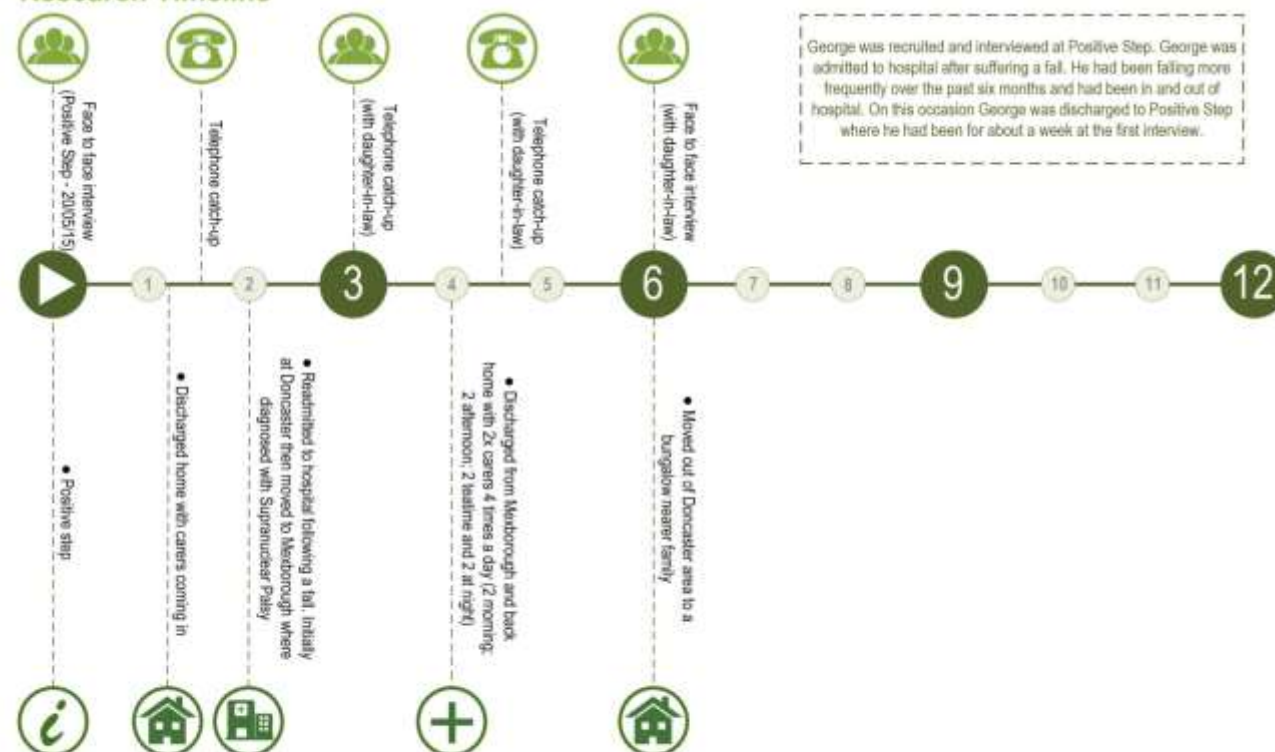
There is no problem but I'm just not happy here, I'm not really in the right place, not being looked after properly

CLIENT TIMELINE: GEORGE

Key Message

Before admission to hospital George lives independently at home with the help of aids and adaptations and support from carers, but is frustrated in Positive Step as he feels like his life is drifting away. George doesn't know what is going to happen to him and would like carers to sit and talk sometimes and really listen to him. He doesn't like being treated like a fool and doesn't like having to ask for help. George sometimes gets frustrated with carers and the way care is delivered at hospital and Positive Step. Some of George's frustration and irritability is down to his Supranuclear Palsy which George's daughter in law thinks isn't always taken into account by carers at home or by Positive Step. George's daughter in law feels that George doesn't receive the help he needs whilst at Positive Step.

Research Timeline



Quotes

Now I feel like life's drifted away. I get frustrated sometimes and start arguing with the nurses

[Carers] telling me what to do and I already know what they're going to say. They say, when I'm walking down the 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

I can't get up out of the chair now and it frustrates me cos the carers, the people, you have to call them, to shout them to your bed 'what do you want?' I say I don't want owt I'm just practicing standing up... so the carers, I don't like asking them cos they seem a bit bitchy

Daughter in law: [What is valued about care] A bit of respect and a bit of time. They don't spend time and they don't listen to what that person wants. I know father can be really hard to understand and I'll say to him 'calm down and take your time and tell me, don't matter if it takes you 20 minutes just say' and it's just having that bit of patience

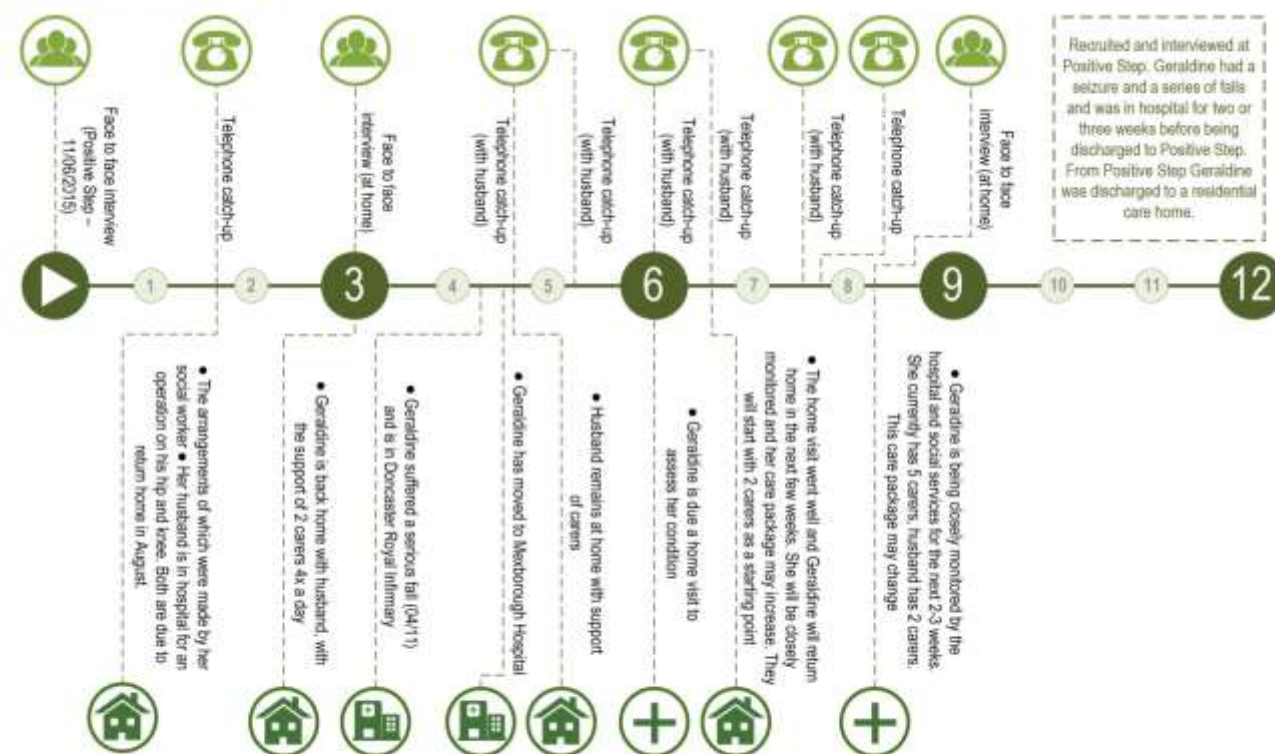
Daughter in law: I didn't rate [Positive Step] they didn't do nowt to help with the condition that he's got, he should have a physiotherapist, one of these that help you talk, speech therapist and something to do with his eyes

CLIENT TIMELINE: GERALDINE

Key Message

Geraldine experiences a lot of change in a short period of time and moves from place to place (Positive Step into to a residential care home, then back to her own home, back to DRI and Mexborough Hospital and then home again) during the study. The long periods of separation take their toll on both Geraldine and her husband who also has health issues. Both Geraldine and her husband have home carers who are 'very helpful' and additional support from a gardener and a friend who does their cleaning and other jobs such as decorating. Geraldine finds not being able to get out difficult and talks about feeling bored whilst she is in Positive Step. Worsening health further reduces Geraldine's ability to go out and increases her loneliness and isolation. Geraldine's husband is apprehensive about her return home and both have worries about what the future will hold.

Research Timeline



Quotes

I do get a bit down sometimes when I'm just sitting here and dreaming and thinking about all the things I used to be able to do, I get a bit upset with it sometimes but I tell myself carry on, you've got to do it... but I feel apprehensive

Husband: About six months last year all together [we were away from each other]. It's a long time when you've been married 60 odd years

Husband: I've been looking after myself apart from carers coming in but its been quiet and different [without Geraldine]

I can't walk very well and wouldn't dream of going without my frame so it impedes me going out. I went across to the shops the other day, I was going down to the hall but me bowels were playing up so I couldn't go but [my husband] went

Cos I wasn't up to it, [my husband] could go but he said he doesn't want to go if he's got to leave me here but I don't mind that, I'm used to my own company

Husband: It's all going through the mind what to do best. Nobody knows how many years you've got, Geraldine's 84 this month and I'm already 84 last month

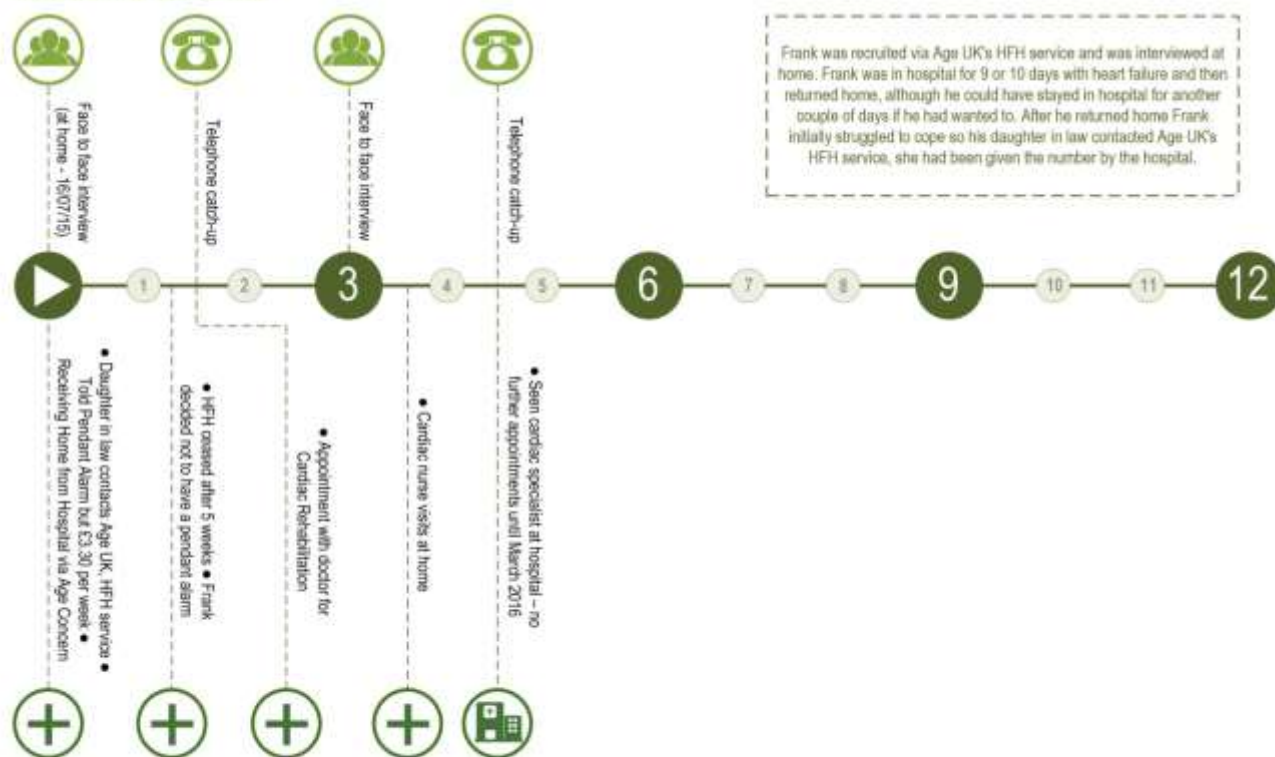
Husband: I'm frightened if she went upstairs she'd get up, you can't get up out of bed very well now and before she got up she had a fall in the bedroom so I'm frightened of the stairs and her falling. It was a sight I didn't want to see, propped up on the stairs with blood on her head'

CLIENT TIMELINE: FRANK

Key Message

When Frank returns home he feels he might have come out of hospital a bit too soon and his daughter in law contacts Age UK. Frank struggles at first because for the first few days at home he needs more help than the HFH service can offer. Frank is independent and wants to stay at home, after 5 weeks HFH service he manages by himself with help from his niece who helps with shopping and his cleaner who comes once a week. Although Frank is able to get out on his scooter there are indications that he would like more regular social contact particularly as his family aren't always able to come and see him.

Research Timeline



Health and Social Care Timeline

Quotes

I should have stopped in another two or three days to get properly right, cos when I come home I couldn't do nothing.....My daughter in law, it was her that phoned Age UK

[Age UK] came in and told me what they could do and what they couldn't do and it wasn't a lot. It was practically; we'll come and make you a cup of tea or go shopping for you and wash up. Things like that. But the first couple of days I needed someone to get me in and out of the bathroom, which wasn't there

I wish I'd stayed in hospital first two or three days cos the nurses in the hospital used to help you get a shower, they had showers you could sit in

[HFH] come in two or three times a week and they'll do a bit of shopping if you want it or a bit of washing or a bit of clearing up

Well a regular visit, people tend to phone up, like me son's, phone up 'are you all right, do you need anything?' 'yeah I'm all right, I don't need anything' so that's it, I don't see them. If you don't say you're dying and I feel terrible they won't bother coming, they've got their own things to do

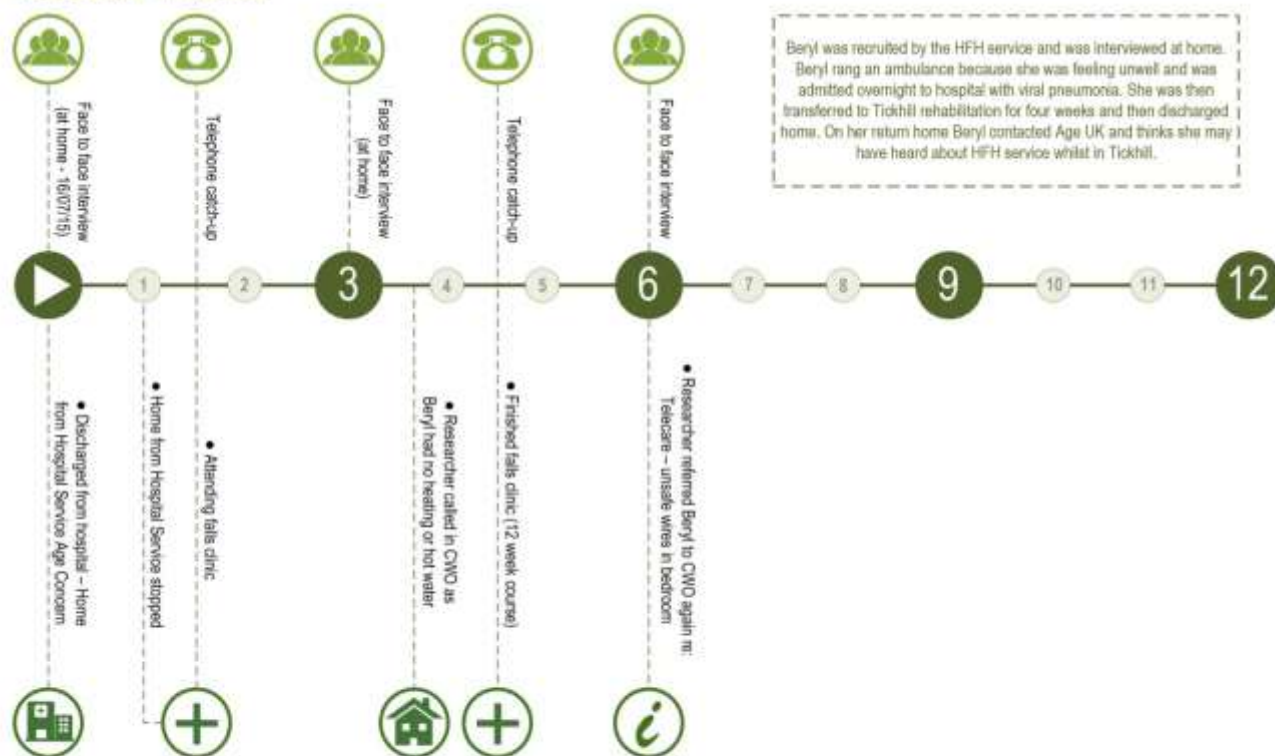
Just to sit and talk to you for a bit, cup of tea, like a social visit

CLIENT TIMELINE: BERYL

Key Message

Beryl has a very positive experience of care at Tickhill rehabilitation. Beryl lives on her own and doesn't have family or other significant support apart from a neighbour who does her shopping but who is moving away soon. This situation has implications if Beryl needs help. Whilst Beryl is independent her lack of a support network increases her vulnerability. Loneliness and social isolation are key concerns and she would benefit from opportunities to socialise and get out more. During the study the researcher intervenes and contacts the council on Beryl's behalf when she finds Beryl with no hot water and wires from her telecare system causing a trip hazard. It is unclear who would have helped Beryl if the researcher hadn't stepped in and referred her to the Community Wellbeing Service.

Research Timeline



Health and Social Care Timeline

Quotes

The staff were wonderful ... I was exceedingly well looked after, it's a comfortable hospital, nice and modern, kept beautifully clean and I enjoyed the food

By the time I got home I was running out of money. I tried to contact the bank but didn't have the right phone number. One of [HFH service] staff came round in her car and took me to the bank and I got my money

Being independent and being able to walk up and down steps and around the house and go to the shop. All the little things you miss when you find you've got a disability

The [Community Wellbeing Officer], she got me that fire and a little fire that I can put on in the bathroom and it was she who gave two of those little blankets, so I have one on my bed and I've kept one downstairs as they're lovely and warm...I've met her, she's spoken to me. I've got the telephone number so I can ring her

My only regret with Age UK is that when you read the charges to go and spend a day with them they're very expensive

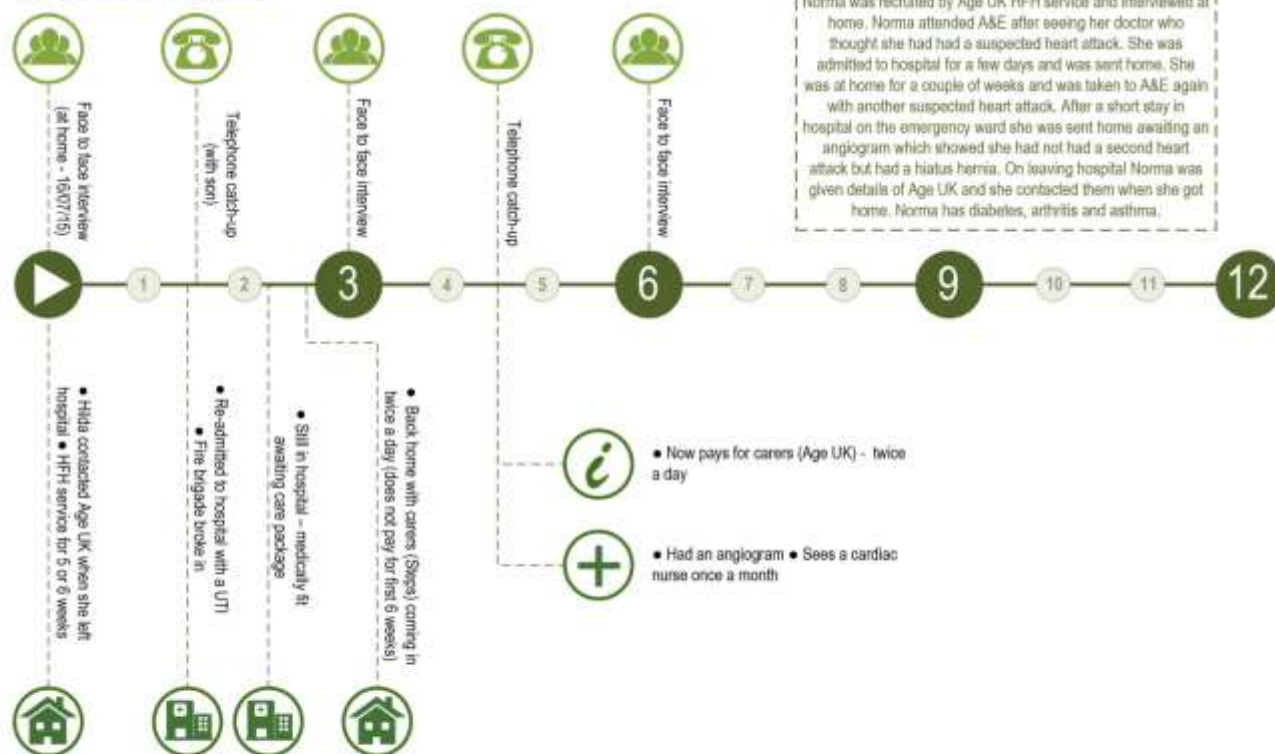
Socially being out of the house was wonderful. That's what I do find, getting out, cos I can't get out. You do miss people. I've gone week after week and never really spoken to anyone

CLIENT TIMELINE: NORMA

Key Message

Norma is very active and independent. She enjoys keep fit and a good social life. On leaving hospital she contacts the HFH service and gets help with her shopping which means she isn't so reliant on her neighbour. Norma's neighbour used to take her shopping but since Norma has been ill she doesn't want to take her so much. Accessing the HFH service is easy and when Norma starts paying for Age UK carers she appreciates the flexibility of the service because they do whatever she needs and come at a time she wants. Norma is happy with her carers and likes the continuity of the care and having the same carer at night time.

Research Timeline



Quotes

Very helpful, my neighbour, I normally go shopping with her but cos she knows I can't walk very far she doesn't want to take me

Yes over the phone, they were very good [HFH Service]. There wasn't anything specific at the time that I needed but they explained that somebody could do some shopping for me

[Because of Age UK] I no longer feel that I'm putting on my neighbour, she's so helpful but I don't like doing it all the time and this is giving her a bit of respite

You can pay [Age UK] per quarter of an hour so they come for quarter of an hour in the morning, quarter of an hour at night, so it's half an hour per day

That's the other thing, Age UK will come at my time whereas Steps don't

Yes she stopped doing it [talking about the neighbour doing the shopping] and my cleaner will do a little bit ... I've also started using the internet

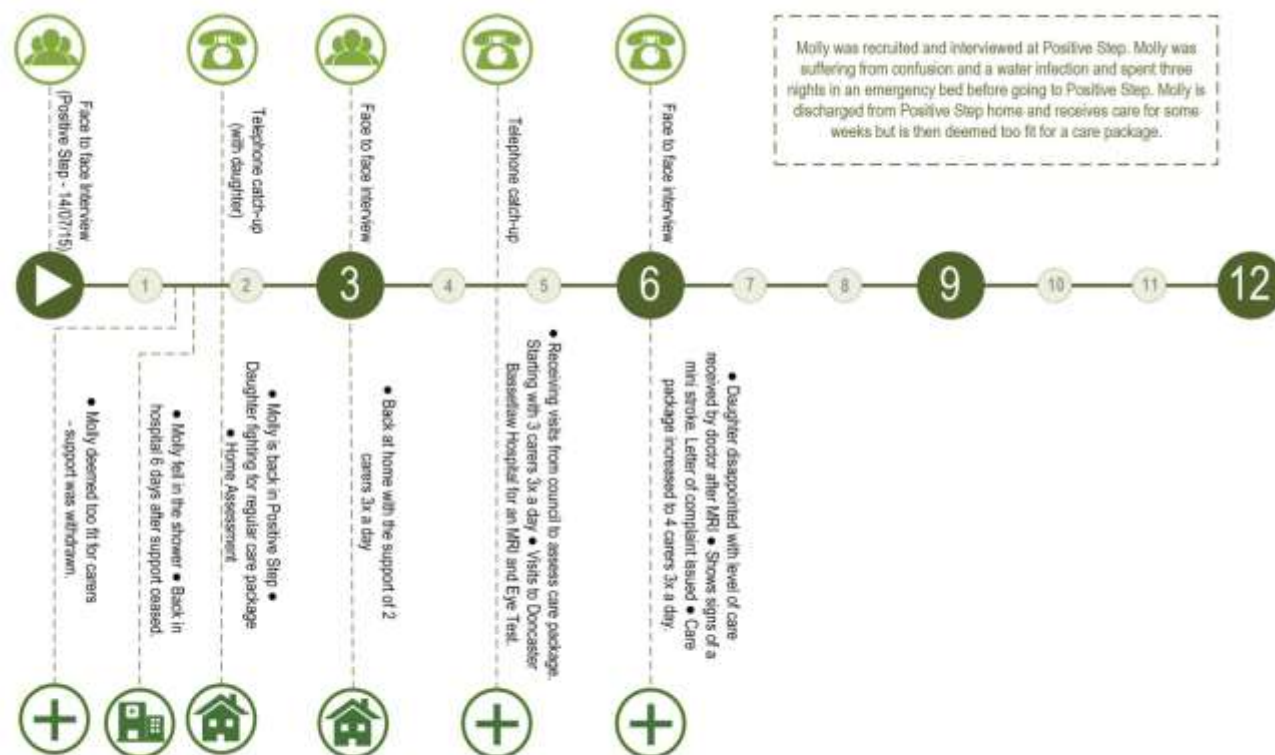
[What the carers do] I have a cleaner so they don't really do any cleaning, they would if I needed it. The one that comes at night is very good. I think she's getting used to my ways and she's putting my shopping away for me

CLIENT TIMELINE: MOLLY

Key Message

Molly wants to be as independent as possible and to stay at home. The last time Molly went into hospital she received care at home for a number of weeks. Six days after care is withdrawn Molly falls in the shower and ends up in hospital and at Positive Step again. There are signs Molly is struggling, she still misses her husband who died six years ago and her daughter feels Molly is becoming depressed and unable to cope. It doesn't make sense to Molly's daughter why Molly is deemed fit enough to live independently - the nurses at hospital thought Molly needed a regular care package. Molly's family help out but can only visit at the weekend and Molly needs additional support. Once regular care is sorted alongside her family support and regular help from her cleaner Molly manages better.

Research Timeline



Quotes

Well it's got me feeling a lot better [talking about Positive Step] than I did when I came in, I do feel a lot better, my family say I look a lot better, I act a lot better

I wanted to be home, that was what I wanted, all right I don't cook my dinner very well but I cook it so I can eat it. I try and keep the place tidy, I don't do so bad. I try to be independent, it keeps me here

It's just somebody there to see that you're alright

Yes and I lost my husband as well and that doesn't help, six years ago now but I still miss him. But to be honest as my daughter says I wasn't looking after myself properly, I wasn't eating properly, I wasn't taking my pills properly cos I couldn't see them

All I wanted to do was get home, ...but when you've got help you can cope with it, I get them [carers] every morning, every lunchtime, every night time, they see me into bed, they won't let me fall, if I go like that they're there

Doncaster Hospital Discharge Pathway Study: Final report

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