

# Influencing Change:

A research report by  
Islington Local Involvement Network  
on the experiences of  
patients leaving hospital



February 2010

# **A research report by Islington Local Involvement Network on:**

## **The experiences of patients leaving hospital**

### **1. Executive Summary**

This was a small scale qualitative study carried out by Islington Local Involvement Network. One to one semi structured interviews were conducted in order to understand the experiences of people who had been discharged from the Whittington and University College Hospital within the past year, from August 2008 to August 2009.

The research wanted to;

- Assess if the individual felt well informed about their discharge from hospital,
- Assess how arrangements were organised for the home circumstances of the individual,
- Assess level of individual's satisfaction with the support/help they had leaving hospital.

The LINK researchers attended a 10-month long training programme on community research. This 10-month training programme was delivered by a specialist in community research, Dr Giovanna Speciale, and the group was supported and co-ordinated by Voluntary Action Islington in collaboration with members of ARVAC (Association for Research in the Voluntary and Community Sector) who also provided an ethics committee of academics with extensive experience in health and social care research. The training programme supported LINK members to develop, carry out a piece of research, analyse the findings and report on them.

We would like to thank all the individuals who contributed to the research and we offer this report to research participants, LINK members, providers and commissioners for consideration and discussion.

## Key findings

### Assessment of feeling informed

- Information, where given with verbal explanations and checks that this had been understood, helped to reduce anxiety. Where this was not the case people were more likely to make errors or not feel in control of their experience of leaving hospital.
- The consistency of information giving varied. Better examples of information giving centred around clinics or specialist services like the Macmillan nurses. Poor examples were found on the ward.
- Information around what people should do/ who they should contact if they have further problems was cited as something that would have been reassuring.
- There was sometimes a gap between the person being discharged from the ward and leaving the hospital building.
- Information about waiting times for medication was not always presented to patients.
- It was reported that there was unclear information regarding entitlement to transport for outpatients appointments which caused confusion.
- Some of the most vulnerable participants described a poorer experience relating to information from the hospital and subsequently this had an impact on the support they received.
- Respondents who were either experienced with going to hospital or who were able to read and understand information presented had a much better experience of feeling informed.

## **Key findings**

### **Assessment of how arrangements were made for home circumstances**

- Where services are more tailored, there is praise for the service and reassurance for the individual.
- Again the most vulnerable described the least support from the hospital. Assessments were not adequate to consider these potential problems.
- Some participants relied heavily on friends, neighbours and family to support them when they arrived home.
- Equipment caused some concern for some respondents. In particular, the untimely arrival of equipment and quick introductions to using equipment just before discharge from the hospital which meant that a person felt unsure about using it.
- There was greater reassurance when district nursing staff visited a person in their home or when follow up contact details were provided.

## **Key findings**

### **Assess level of individual's satisfaction with the support/help they had leaving hospital**

- Participants who had felt staff were attentive were overall more satisfied with their experience.
- Participants who were more knowledgeable or felt more involved had a better experience. Conversely those who did not described the experience as poor.

## Recommendations

- The pre-admission process should make it explicitly clear what services (such as cleaning, shopping, cooking and bathing) may not form part of a post-discharge support package. This may allow the person time to make alternative arrangements if they can.
- The pre-admission process should also make it clear to patients whether they are likely to qualify for patient transport or will need to make their own arrangements.
- In the period that the patient spends in hospital service providers should provide more signposting to external sources of independent financial advice and relevant local support groups. This list could be co-ordinated between all the local hospitals.
- Information about waiting times for prescriptions and sickness certificates needs to be made clearer to patients. The process for allocating medication and certificates could be improved to make waits shorter.
- Some participants mentioned feeling reassured by speaking to others who had been through the same experience. Health and social care professionals should signpost patients to specific services that can offer this kind of support.  
It may be possible to set up a scheme at the hospital, where former patients share contact details so that current patients can talk through their concerns and experiences with former patients.
- There needs to be greater flexibility in the assessment process so that it can really be person-centred and focus on the needs of the individual. This would be particularly beneficial to patients with additional needs.
- Information-giving needs to reflect the needs of the individual. Written information should be given but with greater checks to ensure that recipients understand the information they have been given.
- A mechanism for acknowledging when a patient passes from one service provider to another, by the provider to whose care the patient has passed could help to ensure that information is passed on between professionals.
- There should be greater clarity about who the patient can contact on the wards if they need anything. A clearly defined point of contact would be helpful.

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## 1. Introduction

Islington LINK (Local Involvement Network) is an independent network of local individuals and representatives from local community organisations. LINKs were set up by the Department of Health under the 'Local Government and Public Involvement in Health Act 2007'. A LINK's role is to collect community views on health and social care services in the local area and to feed these views back to providers and commissioners.

This was a small scale qualitative study carried out by Islington Local Involvement Network. Six members of the LINK volunteered to undertake research training from March 2009 to November 2009. These LINK community researchers developed and carried out a piece of research on the experiences of patients when leaving hospital. One to one semi structured interviews were conducted in order to understand the experiences of people who had been discharged from the Whittington and University College Hospital within the past year, from August 2008 to August 2009.

This report has been produced to communicate the findings of the research. This report will also be summarised to be included in the LINK bi-monthly newsletter which will be made widely available

The LINK will hold a launch event to promote the report in March 2010 which participants and local commissioners and providers have been invited to attend.

## **2. Scoping exercises and developing the research question**

From June 2008 to March 2009 Islington LINK held events in the community to ask people for their comments on health and social care services. (This work is ongoing). This included stalls at the Central Library, the Nag's Head Shopping Centre and local forums workshops at the LINK's Annual Fair on 28<sup>th</sup> March 2009 and from comment cards left in local GP practices across the borough and day centres. This provided the LINK with some preliminary evidence that some Islington residents encountered problems when leaving hospital. At the LINK's Annual Meeting attended by 90 local residents 'Leaving Hospital' was prioritised as one of the three issues local people were most concerned about. It was added to the LINK's Work Plan for 2009-10.

### **A local perspective on information and communication in discharge planning**

Initial findings from the preliminary scoping exercises carried out at Islington LINK events included people describing experiences of poor communication between professional staff and patients. For example some people stated that they had been unsure of how to take their medication and unsure of what they should do on their return home. They also described an issue around communication problems between professionals. For example health and social care services that were expected upon someone's return home not being in place, or not being delivered fully because the community staff member had not been prepared for the exact situation. One participant at a table discussion described how when she was sent home she could not be bathed by community care staff. The bath in this person's home was not clean and the member of care staff sent to bathe the person was not employed to clean baths so could not bathe her (patient, 2009) <sup>1</sup>.

The LINK research group looked at patient satisfaction surveys to gather a broader picture of what was happening locally.

The LINK looked through the procedures and processes for the two local general hospitals to get some idea of what patients can expect on discharge. These protocols vary between the two Trusts concerned.

### **A wider perspective on information and communication in discharge planning**

There is much evidence to show that effective communication is paramount in the discharge planning process. LINK members considered reports which offered a national perspective on older people and hospital discharge. The Social Care Institute for Excellence (SCIE) cites a report by J Glasby where 'health providers argue that their efficiency in discharging older people once their healthcare needs have been met is compromised by the inability of local social services to provide appropriate post-discharge care' and that 'passive provision of information, whether written or verbal, may not be enough' (SCIE,2006:). <sup>2</sup>

Intermediate care and discharge planning are an increasingly important area of interface between health and social care partly because social services must reimburse health services when they are unable to provide social care to people who are ready to be discharged from acute care, as outlined by the 2003 Community Care Act.

The report 'Using qualitative research in systematic reviews: Older people's views of hospital discharge' described how older people sometimes see themselves as passive in the discharge process, rather than feeling actively involved in discharge assessment and planning. <sup>3</sup>

Research from a 'Findings' report 'Promoting Person-Centred Care at the Front Line' by the Joseph Rowntree Foundation states that: 'People from minority ethnic groups experience a range of barriers to receiving person-centred care. These include: lack of accessible information; services which often lack cultural understanding; and language and communication difficulties'. <sup>4</sup>

From examining both the local and a national perspective the LINK community researchers aimed to understand the experiences of a small sample of Islington residents leaving hospital and their experiences when they arrived home (or in other words the individual's pathway from hospital to home).

The research wanted to:

- Assess if the individual felt well informed about their discharge from hospital,
- Assess how arrangements were organised for the home circumstances of the individual,
- Assess level of individual's satisfaction with the support/help they had leaving hospital.

### **3. Research methodology and methods**

Six members of the LINK volunteered to undertake research training from March 2009 to November 2009. These LINK community researchers developed and carried out a piece of research on the experiences of patients when leaving hospital.

A separate report and evaluation is available detailing the support given to three research clusters who took part in this community research approach. The LINK community researchers were one research cluster who volunteered to be a part of this programme and attended training and received on-going support to carry out their community research.

This was a qualitative piece of research. The group carried out semi-structured interviews with 13 individuals. The community researchers worked in pairs. All interviews were recorded and transcribed. (For the semi-structured interview schedule see appendix one).

The LINK community researchers had also planned to hold two focus groups of up to ten people. One for each hospital with a moderator and an assistant moderator for each group. Although the community researchers attended the focus group training and worked out the approach they would take it became apparent that there was not enough time to carry out the focus groups and do the face to face interviews. The decision was made not to carry out the focus groups.

#### **Sampling**

The LINK research group recruited participants by creating posters and flyers sent them to be displayed in key places in Islington e.g. GP surgeries, libraries, Children's Centres, day centres and social clubs. Advertisements were placed on the LINK website and on the hospital Trust web-sites. The LINK also sought to recruit participants through existing networks of community groups e.g. the Sickle Cell Support Group, BME Forum, Faith Forum, African Health Forum, Islington Carers Centre and the Islington Disability Network, among others. The research questions were tested on LINK members to check understanding and flow and amended where improvements were necessary.

#### **Recruitment of participants, fieldwork and analysis**

The group recruited participants in July/August 2009 and carried out their fieldwork during August and September 2009. This took longer than expected. Analysis also took longer than anticipated and was carried out in November 2009. The group used a qualitative framework to analyse the data they collected, looking at key themes and coding them and examining the data to answer the initial research questions. The coding system was used to determine which quotes best represent what people were saying and are reported verbatim, to remain true to the evidence as it was collected.

LINK community researchers read through the transcripts of the interviews and looked for themes within the scripts. The transcripts were allocated to different theme groups. Members then took the different themes and looked at the comments given around that theme before starting to write up the report.

The research budget included funds for publicity, venue hire (for the interviews, focus groups and launch event), access needs of participants including travel costs, and the cost of vouchers for participants, transcription and audio recording equipment hire.

## **Ethical considerations**

The LINK community research group considered and acted on a range of ethical considerations including: confidentiality, storage of data, gaining ongoing informed consent, avoiding raising people's expectations and ensuring that the LINK allowed people the opportunity to relate positive experiences of leaving hospital as well as problems and concerns. The LINK also needed to ensure that people with additional needs were not excluded. The LINK aimed to provide feedback to participants in good time so that they would know it was worthwhile taking part in the research and would be invited to attend any events that discussed the research findings. All participants were given information about the research and how they would be involved. Ongoing informed consent was sought. (appendix 2 consent form and research project information) (appendix 3 for a full extract of the ethical decisions made). In writing up the report names and other identifiers have been removed to protect the anonymity of those involved. Where quotes from a participant are included they are presented alongside the participant's number and the initial of the hospital at which they stayed; W for Whittington and U for University College London Hospital.

The LINK community researchers presented their research proposal for ethical consideration to a panel compiled of Academic researchers from ARVAC. Some design changes were made following comments from the panel.

The draft report writing took place in December 2009 and January 2010 and the report was presented to the local statutory partners in March 2010. Some headline findings were sent to the NHS Islington in November so that they could be considered for inclusion in the Joint Strategic Needs Analysis (JSNA).

## 4. Findings

The analysis of participants' interviews identified a range of themes that are highlighted in this part of the report.

The participants described their involvement in the assessment process, the attention given by staff, communication, continuity of care, equipment, finance, information, provision of care in the home and transport. Some conclusions are drawn within each themed area.

### Assessment Process

When participants were asked how involved they were in the decision making process regarding their discharge planning there was a mixed response

Some participants were satisfied with the varying degrees of involvement.

*'I felt I was fully involved in the care taking place in the hospital as well as what I should be doing when I came out. They did check up and see, are you living on your own? Would you like the district nurse to come and visit? Do you want this or that to happen? And most of the answers were no thanks, I can do this that and the other myself or with the help of my neighbour. ... There's very little else they could do but put a plastic tent around me to make sure I don't get anymore viruses' (2,W) This respondent said they declined professional help for when they left hospital as they had been sure that a neighbour would help. (2,W)*

Another participant said they were given an opportunity to ask questions. However they were also a more 'experienced' patient.

*'I'm in a different position because I know most of the answers already...They gave me the chance to ask for anything.'* (4,W)

And another participant described how they felt involved because discussions were carried out 'in front' of the participant:

*'Oh yeah. It wasn't discussed out of my hearing or in another room or whatever. It was all discussed in front of me.'* (10,W)

Another participant was offered a 'social worker'

*'I was offered a social worker and I said 'well, what do you mean?' and they said 'somebody coming to help you' and I said 'oh no thank you' because, well, I didn't really need it. I wasn't incapacitated.'* (13,W).

These participants experienced different levels of involvement with seemingly different approaches to the involvement, but felt involved and informed about the assessment process. The following respondents who identified themselves as having additional needs felt less involved.

One participant mentioned having additional needs, but there seemed to be no additional support to help this person understand medications and arrange further care.(11, W) When asked if the hospital had spoken to the participant about needing a support worker, the participant replied:

*'I told them I had a learning disability but they didn't take any notice... I don't think they really cared...They didn't ask me, they were just looking in my files but they didn't ask me no questions'.....I think they should know if I've got a[n additional need] and the right support when I come out of hospital.'* (11,W)

When the participant was asked to clarify what the right support was the participant responded:

*'Like have somebody coming round to your house when you have a big operation. I'd just like the help when I couldn't do it by myself when I come home from UCH and back at my house I couldn't dress myself and I was having a bit of problem and I was getting upset.'* (11,W)

This participant had recent experience of both the Whittington and of UCLH.

In one case, a participant and his care team (from a local voluntary organisation) contacted the nursing staff and asked for liaison with social services, but the ward nurse said that, first, someone from social services had been called, but finally that no one was available. This participant was discharged without seeing any social services staff.

*'On the Tuesday I was told I was going to be released, discharged that day. I told them I'd been referred to the social services, and she had a word with the nurse and said it had been followed through, they came back at about 17.30 and told me that I was going to be discharged within the next hour or so. I mentioned again that I hadn't been seen by social services and was told that there was nobody available at the time and I was still being discharged.'* (12, W)

One participant did not feel involved in the process until just before they left the hospital and described a rushed response around the provision of equipment and tuition in its use.

*'...ten minutes before I was leaving, I on a Zimmer frame, and I said I don't want a Zimmer frame I'd rather have crutches but there wasn't really time to teach me how to use them so we [participant and hospital staff] went up and down the stairs for about ten minutes didn't get much out of that but, um, so no I still don't know how to use crutches'*

One participant was asked during the interview if they had had support.

*'If my wife not at home, nobody would help me'*. (9,W)

When the participant was questioned as to whether any staff member had asked if they had support at home. Their response was:

*'No no no' (9,W).*

In some cases participants felt that more help should have been offered because despite feeling knowledgeable they felt unwell.

Participant 1 said:

*'Somebody who is as knowledgeable as I am should be able to cope or demand help, but I couldn't because I wasn't very well apart from anything else.'* (1, U).

Participant 6:

*'Although they were aware that I was living on my own they didn't ask if I needed any help or told where I could go to get help. Luckily I know what to do if I did but I wasn't offered any help'* (6,W).

Participant 5:

*'They ask if you have someone who is going to be around with you, but that was at the clinic, the ward doesn't say much'* (5,W).

There were times when the assessment process impeded continuity of care.

*'I mentioned again that I hadn't been seen by social services and was told that there was nobody available at the time and I was still being discharged.'* (12, W)

This participant had nowhere to stay and nowhere safe to take the medicines they had been prescribed.

## Conclusions

Participant's responses showed varying degrees of involvement in the process. The two participants who had the greatest needs were not given the support they needed through the process. One participant repeatedly asked to see someone from social services before being discharged but could not and was discharged despite having nowhere to go. There does not appear to be a consistent system. Assumptions can be made by both participants who are knowledgeable and have family and friends and by staff who perceive that a patient is knowledgeable or that support mechanisms are available because a family member or friend has been identified.

## Attitude of staff

This section looked at the way in which hospital staff interacted with the participants. Many respondents dwelt on the time spent in hospital rather than the discharge process and experience.

In some cases, participants were very positive about the care they had received.

Participant 10 said:

*'...I think I was very lucky because I was on a fantastic ward, and then I had to go on a side ward ... They had fantastic staff there.'* (10, W)

Participant 2:

*'Certainly the attention could not be faulted. It was absolutely fantastic. And it just happened as a matter of course. It was happening to everyone in the ward.'* (2, W)

Participant 4:

*'I had a particularly bit of good luck in that the junior doctor who was in charge of my care, I think it was her first hospital job, but extremely nice and friendly and she went out of her way to answer any of my questions or help me in any way. For instance, my big problem is being deaf, and I had an appointment that was coming up and I was very anxious about how to cancel this appointment but she helped me out, which I think was beyond her duty...'* (4,W)

The perception of interest in and concern for participants as people seems to be an important factor in determining overall patient satisfaction.

*'Well partly the way the physios were making me feel, that I was doing this deliberately, that I was just hanging around and it wasn't true at all. I was pretty sick those first few days ... but I felt I wasn't supported psychologically and that was it really.'* (1,U)

Participants understood that staff were working under pressure and seemed to make allowances for that in their expectations.

Participant 5 said:

*'I find that they are quite busy, a bit short staffed...One of the [Specialist] nurses came up to see me. She wasn't very patient with me... she sees that*

*everyday kind of a thing. But the other one I see regularly, she's really marvellous.'*(5, W)

Participant 4:

*'...the nurses were very efficient with the medication coming around with the trolley, but they never smile. They never treat you like a human being. They just treat you like a lump to be administered this that or the other.'* (4, W)

Participants who had felt staff were attentive were overall more satisfied with their experience. On the occasions where this was not the case, then the lack of attention to seeing the patient as an individual seemed to matter to the participant.

## Communication

This section looks at communication with the participants as patients. Whilst information (covered later) was seen as a one-way process, communication refers to a two-way process of dialogue with the patient.

As highlighted in the previous section, there seemed to be greater satisfaction when participants felt that they had been communicated with, and less when they did not. When asked about having been told information, this participant said:

*No, not at all. Basically, like I say, they put the details on the discharge paper. They didn't tell me anything, I was just discharged.'* (12, W)

Participants did not always feel that they had been communicated with about their condition or after care.

*'...but they didn't say anything about you're only supposed to wear this [shoe] a week. They gave me a letter to give to the practice and ...that's where I got the information that it was going to be just a week to wear the shoe.'* (13, W)

Participants also mentioned a desire for a 'follow-up' contact to be initiated by the hospital:

Participant 1:

*'.....well I did expect there to be more help and for someone to ring me up to see if I was alright.'* (1, U)

Participant 5:

*'It would be nice if sometimes, you know you've got something to ask or something, if you could ring up the ward and say you are feeling really unwell and say you need some advice and they just tell you or contact your GP. I find sometimes the GP don't want to bother with anything. But it would be*

*nice if someone did contact you once you are at home to see if everything was ok. Because I'm like that, I wouldn't ask for help because I'm feeling awkward to do that.'* (5, W)

It seems that the hand-over system from one professional to another is not always clear. Sometimes information is not communicated on from one professional to the next.

*'I thought when the staff changes duties from night to morning staff, I had to sometimes ask for things, like I need a sick certificate, or I need to see this or that, you need to remind them a bit. I know it's the registrar and consultant, who do that, but sometimes you could come out without something you needed and you're not given unless you ask.'* (5, W)

This seemed most important where participants had additional needs. This participant described the lack of communication between their support worker in the community and the Hospital:

*'No, I didn't have the right care when I left hospital because I didn't have no support worker there. When I got home I phoned up my support worker and then I told her and my support worker was a bit cross.'* (11, W)

When the participant was asked if the hospital had discussed the support worker the participant responded:

*'No. I told them I had a learning disability but they didn't take any notice'*  
(11, W)

## Conclusions

The crucial consideration appears to be the feeling of the participant that someone had been able to spend time communicating with them, communication meaning a two way process.

## Continuity of Care

This section looks at how care continues across service providers. Some participants also referred to continuity of care within the hospital which is mentioned here.

Several participants' comments showed they had experienced continuity of care from one service to the next.

Participant 2 said:

*'Well, certainly they did book me in with the district nurse, the podiatry.'*  
(2, W)

*'Yes, and the medication I spoke with the person from the pharmacy on three occasions and it was the same person each time and she was very helpful.'*  
(2, W)

Participant 1:

*'Yes a physiotherapist came round and this was partly because I had rung up before I went in. I thought that well I will be one step ahead of this. And she was very good and she came and gave me some exercises to do and then she sent another young lady around and we walked around the block. And we walked up and down the stairs in my flat, well it's not my flat, outside of the flat. So I saw the physios twice.'* (1, U)

But the same participant felt that more follow-up care was needed.

*'No. I really felt that having a contact like the district nurse would have been helpful because then if she had said 'Well, I'm awfully sorry I can't help you but you should ring up this person' but there was no contact.'* (1, U)

This participant seemed to have had experience of continuity of care when they left hospital:

*'A week later I received all the equipment I needed.... The hospital actually got in touch with everybody that I should have been in touch with, and they in turn got in touch with me 2 or 3 days after I got out of hospital.'* (10,W)

Within the hospital environment, some participants made comments about continuity of care from ward staff.

Participant 4 said:

*'And certainly when I was in hospital I never saw the matron – if I knew who it was. I mean no-one ever came and said I'm the matron, have you got any problems. It was one nurse or another nurse – I never knew who to speak to and I think that is a serious thing. I think the ward sister should go around everyday to check everyone's ok. Or the matron occasionally.'* (4, W)

Participant 1:

*'The thing about the wards which I'm sure you will hear again is that they're so huge you're just in a bay so you don't know who the ward sister is, you don't know who the ward clerk is or anybody really. You get sort of nurses who come and go but you don't feel you belong there.'* (1, U)

Participants seemed satisfied with continuity of care on the whole, although where patients had additional needs the transition through care was not as smooth.

Some participants described seeing a high volume of people on the ward and finding this confusing. Some suggested that a defined person on the ward, like a matron, would help create a feeling of continuity.

## Equipment

We asked if the respondent had received, or expected to receive, any equipment for use during their recovery period.

Several participants were satisfied with the equipment that they received and received it when planned.

As far as the assessment resulting in an outcome that met the needs of the patient, in one case, a physiotherapist visited the participant on the ward to assess mobility issues.

Participant 6:

*'The physiotherapist came to see me and as I'd taken my own folding stick in with me and they said the length was sufficient – I didn't need the hospital stick.'* (6, W)

Participant 10:

*'The only thing I took them up on was the thing for the bath, you know, it works on a battery so it takes me down in the bath and brings me back up because I can't sit down in the bath, well I can, I just can't get up – I don't have enough strength to pull myself back up.'* (10, W)

Others were satisfied with the equipment but had had to wait for it, which had caused problems.

*'They said that well you will have a commode and um, a perching bench neither of which I had ever seen before and it's true a commode turned up but by that time I had discovered I could heave myself up off the lavatory seat by the bathroom door if the bathroom door was open of course which it was because I was on my own. But, um, so I sent the commode back because it depressed me.'... 'The perching bench well that didn't come and it didn't come until I was mobile again and it wasn't very helpful it was just like an ordinary seat.'* (1, U)

This participant had to work out how to wash themselves because they could not have a bath whilst wearing the 'boot' that they had been given to protect their foot. (1, U)

*'Well I had to work out how to wash myself because there was no question of getting into a bath, not for at least three weeks, four weeks.'* (1, U)

This participant had a long wait for equipment but they were pleased with what was provided when they did receive it. (7, U)

*'Well, what we needed, which we eventually got, were things like hand rails to get around the flat. They put a grab handle outside the front door because it's quite steep out there. Most wonderful of all was the intercom so you don't have to go down so many flights of stairs. You can tell them to wait to collect parcels...Once the occupational therapists and the social services had been round and done various assessments on me and the flat, things happened really quickly, but this was three months after when they realised no-one had contacted me, then it took about another fortnight.'* (7, U)

Some could not be offered suitable equipment and seemed to be referred back and forth:

*'I mean I see someone who came in the other day, special people, that they were going to sort out for me, put a handle, but there's nowhere to put a handle, and I've slipped several times. I'm not how I used to be, I may look alright, but I can't manage as well as I used to do, but I didn't get any special equipment given to me or anything like that. If you've got a back problem, sometimes a different department, it's like we deal with this, this and that. You sometimes get referred back to your GP.'* (5, W)

Other participants decided that they did not need what had been offered.

*'Well, they offered me the crutches which they realised that I didn't really need because I was walking fine without them. They tested me on the stairs and everything but it would've been awkward and I didn't need them. The shoe was enough.'* (13, W)

Equipment required that was mainly portable – e.g. crutches, commode was delivered in a timely fashion. However, equipment that required more labour – e.g. bathroom handrails, bathtub lift, door entry buzzer – were often not provided in a timely fashion, if at all.

## Finance

Participants were asked about the support which they needed in the longer term, that is after the first few days at home, and if they had to pay for any of that support. They were not asked about their personal finances. The purpose of these questions was to find out what care had been provided and if there had been any shortfall due to the need to pay privately.

None of the participants reported being assessed as requiring a particular piece of equipment or support for which they would have to pay. Families and friends provided unpaid support to many of the participants. There were also a range of views as to what care was needed in the recovery period and, in particular, to what extent that support covered daily domestic activities such as shopping and cooking.

For one participant the discharge process highlighted a need for home assistance (1, U)

*'...my son has decided he will help me have a home help for two hours a week..... I'm not particularly good at household things, I never have been and it just really is nice to have somebody.'* In either case it was not funded by the Council....oh yes, I paid.' (1, U)

This participant was concerned at not being told before discharge that:

*'...you've got to pay for meals on wheels or whatever it is that you need... ....in about four or five days I had sorted myself out...I have to say that it was just those four or five days that were scary and I thought I really should tell somebody.'* (1, U)

Another participant was in more difficult financial circumstance:

*'Paying my fares and buying my food, all my wages just goes into bills and loans and you're just left with nothing. ... [one of] my daughter[s] often pays off a lot of things for me, but she has her own life as well. ...my daughters made sure I had everything. They did the shopping and this sort of thing.'* (5, W)

Some of the participants in the research project had had to rely on friends and family for both care and financial support.

## Information

Participants were asked about information they were given about medication, and information they were given about their condition and local support services. Participants were also asked whether that information was clear. In the research project, the community researchers viewed 'communication' (covered earlier) as a two-way process whereas 'information' was considered to be a one-way process, the information that was given to the patient by professionals.

This section looks at whether the participant received spoken or written information, whether they received sufficient appropriate information and the implications of this for the participant.

Some of the participants described the types of information they received. A dual approach of written information and face to face explanations of what to do seemed to offer the most reassurance. Consistency of staff was also recognised as helpful. Follow up calls were also seen as a means of relieving anxiety. There seemed to be a lack of consistency in the approach to giving information. Written information when provided was often found to be clear although it is not useful for people who cannot read or who have to find another person to read it for them.

A participant said they were given

*'Tonnes of information... They gave me a leaflet about what would be on offer from district nurses if I needed them.'* (12, 2)

While another participant said:

*'If I did feel at all unwell again like that with a high temperature I was instructed incredibly strongly to be straight back to A&E, to bypass my GP altogether and go straight back in again in case it resurrected itself for this bug that I had.'* (6, W)

And another commented:

*'Most of it again was face to face. There were a whole host of leaflets'. (2, W) and the information was 'clear'.*

This patient was an experienced patient with a long-term condition.

Another participant stated:

*'Yes. Amazing list of medication all neatly listed. A great parcel given to me. seven different types I think with very clear instructions. And an enormous quantity. I still haven't finished them to this day.'* (4, W)

This participant received all the information needed in face-to-face contacts at the hospital and felt that it was all understood.

*'Face to face. Most of the information I needed was from the physios. [P – clear?] Yes very good.'* (4, W)

This participant was asked if the information was clear and responded with the following comment:

*'I think most people would prefer that it was always the same person you see, which it certainly wasn't – there seems to be very little consistency – one day one of them, then the other, but they did seem to know what the other was doing...[it was] clear.'* (4, W)

While this participant said:

*'Yes, they gave me pain killers. And what I found though was I knew about 9.30 that I'd be discharged that day but it was getting on to 2.30 by the time I had the medication given to me which I feel is a rather a long wait – especially if you're arranging for someone to come and take you home. The only advantage was that I got lunch so I didn't have to cook when I got home. But I felt this was a long time to wait for medicine.'* (6, W)

Participant 4 said:

*'Well, the physio's gave me exercises. I was advised about everything I needed to be advised about.'* (4, W)

Participant 9:

*'They just advised me what to do, what medicine to take in time, be careful if you have back pain be careful not to hurt my back.'* (9, W)

Participant 2:

*'I was visited daily by the consultant in charge of my situation and ... who both kept me well informed of everything they wanted to do, and everything they felt was necessary to be done, by them or by me.'* (2, W)

A Participant was given information about an organisation in Archway but stated:

*'I didn't think that was for me so I said thank you but no thank you'* (10, W).

Several participants, however, were not satisfied with the amount of information given at the hospital or were not clear about the information given.

One participant described the information as *'Confusing. Well very far from clear'*. (1, U)

The same participant felt they had little useful information given to them at the hospital about their condition and aftercare.

*'You know people spent a lot of time talking to me they didn't tell me very much and I found that when I did get home it wasn't very applicable to me'* (1, U).

However, the same participant mentioned being given clear information about their medication:

*'It was all labelled clearly and there was a woman who came round who talked to me and asked me if I didn't understand but I did understand. It was all clearly marked on the boxes.'* (1, U).

Another participant also commented on having little information given to them:

*'Well, you see, I got the outpatient appointment, which was clear, but I didn't get any other information at all... When to take the medication, what could happen in the future, if I need another operation or not, they said it could be possible'*.  
(6, W)

One participant did not feel that they were told how to take the tablets. They were told to come back to the hospital if they didn't feel well. (3, W)

*'Yeah he give me tablets and says go tomorrow to your doctor. [P – did they say how to take tablets?] No, he said go eat something, take tablet. He gave me stronger insulin.'* (3, W)

Another participant was given some leaflets, and told to finish their course of medication. When asked whether they were given information:

*'Only a little bit that I was given a couple of leaflets, and just to finish the medication.'* (5, W)

Some of the information was given face-to-face.

*'Some written information, a little bit face to face, just when they come in and drop off the leaflets.'*(5, W)

But the same participant felt that sufficient information was given in follow-up clinics:

*'When I go back to the clinic, the cancer nurse usually gives you booklets...They give you some contact numbers. I contacted the McMillan nurse and she's helped me out quite a bit. One of them... I see her quite regularly, she's the one who gives you the most information, the books with all the clinics. But the wards are different. Not to that extent.'* (5, W).

Participant 11 also felt they did not have much information given to them about their medication:

*'They didn't tell me a lot about my medication. They just told me to take them when I'm in pain. They're a very strong painkiller.'* (11, W)

Participant 13 (13, W) mentioned that the information about their medication was not clear. Written information had not been given to the patient and they were unclear about what they had been given.

*'...when I'd gone into the hospital and the doctor who was going to be in charge of me saw me, he said 'I'm changing your medication'. So I understand that it was still penicillin, well I think it was but I'm not sure about that. There were about 3 different sets of tablets I had to take at certain hours of the day.'* (13, W)

One participant also mentioned not receiving any information about home care. They had had a foot operation and their mobility was restricted.

*'No, I wasn't given any information about would I like to have home care or anything. I wasn't given any information whatsoever.'* (6, W)

A participant mentioned that no local support organisations were mentioned specifically at the hospital; however, they knew of Age Concern and the organisation's Home from Hospital leaflet.

*'I knew about Home from Hospital and I was feeling so much stronger that I would have rung them now but you know at that point [when being discharged] I was feeling pretty helpless. I soon perked up. I was very lucky.'* (1, U)

One participant felt they had not received any of the information that they needed prior to their discharge:

*'They didn't tell me anything, I was just discharged...I was basically told I was being discharged that evening, here's your medication, and thank you very much, blatantly'* (12, W).

The person felt like they had been left:

*'to find a place for myself...if someone had come and given me some advice with knowledge of what I could do when I left, anywhere that could help me instead of leaving me to find a place for myself.'* (12, W)

One participant stated that:

*'I didn't get no advice but I just had a rest and a bit of support when I got home.'* (11, W)

More information was given at a post-hospital clinic:

*'They said read the leaflet and if you've got any problems then phone up.'*  
(11, w)

The participant's regular support worker went through the leaflet with the participant at home as the participant had not been able to understand it.

One participant described the lack of information so that 'shoe' they were supplied with was incorrectly used. It should have been removed after one week and not worn continuously till the participant could see the district nurse or GP, so the information was inadequate.

*'Well, they just said that it would keep my toes off the ground to protect...but they didn't say anything about you're only supposed to wear this a week. I read the letter (for the practice) and that's where I got the information that it was going to be just a week to wear the shoe, and when the doctor wasn't there I chose to keep wearing it because I wanted him to see exactly how it was.'* (13, W)

Several participants mentioned being given information orally but not remembering getting information in a written format.

Participant 10:

[P - Were you given any written information?]  
*'...No, I think I was just told...'* (10, W)

Participant 6:

*'I was given an outpatient appointment for 2 weeks later to see how the operation went. [P] They just said do some exercises and try to walk as normal as possible. [P] I wasn't given any more information'* (6, W)

There were very varied responses regarding information. Whilst information about medication seemed to generally be quite clear, information about follow up services and support organisations did not seem to be so readily available. Several patients felt that they had not received enough relevant, clear information. Some patients had not received written information and had not been clear about their situation. Perhaps written information or a follow up contact would have alleviated some of these concerns. Again, there seemed to have been more difficulty where patients had a greater need.

There is a point between being discharged from the ward but having to remain in the building that caused anxiety. Several participants had also raised as an issue the fact that they had been discharged but could not leave the hospital because they were waiting for medication and/or sick certificates. Some participants had to wait more than half a day for the pharmacy to deliver their medications to take home.

*'Well, I was due out in the morning but I had to wait until half past four, five o'clock, before the medication came onto the ward before I could leave because I couldn't leave until I got all my medication. So I waited all day.'* (10, W)

It was also mentioned that waits for prescriptions slowed down the discharge process for the individual.

Participant 5:

*'...from morning it took them before I went home was gone half past one, and usually a porter comes in and takes you downstairs or something like that, but there was none of that. Just 'oh, you still haven't gone'. I had to ask my daughter to come and pick me up but because they didn't sort out what time, and I needed a sick certificate as well, if those things are sorted out and the medication...so I didn't like the abruptness sort of thing.'* (5, W)

Participant 6:

*'Yes, they gave me pain killers. And what I found though was I knew about 9.30 that I'd be discharged that day but it was getting on to 2.30 by the time I had the medication given to me which I feel is a rather a long wait – especially if you're arranging for someone to come and take you home. The only advantage was that I got lunch so I didn't have to cook when I got home. But I felt this was a long time to wait for medicine.'* (6, W)

## **Provision of care**

This section looks at the provision of care that was made for the participants when they got home from hospital. It includes both what kind of care was needed, who provided it and what gaps in provision were discovered.

Participants had a wide range of needs once they got home including social service care such as home help and medical care such as visits by a district nurse.

Participant 11 said:

*'They support me, they come to go shopping and support me for bathing. [P – how long?] For two weeks.'* (11, W)

Participant 13:

*'At the time the doctor came round to tell me I was going home, he said that the district nurse would see me on Wednesday and he would see me on Friday.'* (13, W)

The majority of participants that said they needed care after leaving hospital seemed to rely heavily on friends, family and neighbours to provide it for them.

Participant 2 said:

*'My neighbours had been very good and there was milk in the fridge... you know I'd only been in for 12 days so coffee and teabags were all still there.'* (2, W)

Participant 5:

*'Yes, my daughter did that and arranged everything...I had to be a bit careful not to lift things, not to do certain things...Mostly was with lifting anything, cooking. Other domestic help with anything you need at home, washing, bathrooms or whatever, the girls did most of it... My sister sometimes came up on the weekends. My youngest daughter has very awkward shifts. So sometimes when they cooked they prepared more things and left it in the fridge. And I did as much as I could.'* (5, W)

One participant said that they had planned in advance to ensure that they had the things they needed whilst another had relied upon 'going online' for food supplies.

Participant 6:

*'I wasn't sure what my mobility was going to be like so I made sure I had sufficient things in the way of food etc.'* (6, W)

Participant 4:

*'I wasn't particularly worried about it. I mean I have very good neighbours so I am very lucky – all sorts of people to help me in whatever way.'* (4, W) *'[P – did you have everything you needed?] Yes I did, but my daughter had fixed things up for me. She comes from [outside London] and made sure everything was done. But I think social services would have got everything done.'* (4, W)

Participant 10:

*'I was given every opportunity for everything and I declined it because I had the back up of friends. I was very lucky, very lucky and still am.'* (10, W)

Whilst others expressed concern about how much they had to rely on the support of their friends and family.

*'I'm not dissatisfied but I'm not fully satisfied either. Sort of between. Say if I didn't have the girls around with me. Luckily I had my sisters. They all work as well...so it's quite a distance for them to come.'* (5, W)

Three of the participants stated that they were offered care and support when they were leaving hospital for when they were at home. Two of these people said that they were happy and satisfied with the level of support that they were offered when they were leaving hospital though one person commented that they would have preferred to have had the same person each day to support them.

*'A home help was provided who helped me to get dressed in the morning and then gave me breakfast. I didn't want anyone in the evening because I have a grand daughter. They gave me all the help I asked for...I had someone to help me for two weeks to get up, wash. The helpers were very nice and very competent but as always one regrets the lack of continuity. I would have liked it to be the same person but every time it was very different.'* (4, W)

Other participants explained that they did not feel that they needed help so they did not take it. They said that they were reassured that it had been offered to them though and one participant commented on feeling reassured that a district nurse came to visit them regularly.

Participant 10 said:

*'Long term I didn't get any help at all because I didn't need it. That was me telling them 'no thank you'. I've got enough strength to do it myself now. It was a bit hairy at first, 2 or 3 months, but I got over it and I'm walking away fine now. [P – district nurse important?] Yes, because she had to change the dressings on the wound and see that everything was ok and there wasn't an infection there which was important to me because I didn't fancy going into hospital again with another infection, so that was ok. I felt a bit more safer with the district nurse coming in.'* (10, W)

Participant 13:

*'Well, as I say, it [support] was there had I needed it, but I didn't need it. It's very reassuring and I tell people not to knock the NHS, and one person said I was very lucky!'* (13, W)

Participant 5:

*'Once I got home, nothing from the hospital. You usually don't get any help. [P – no support?] The ward doesn't. The only people who would come and visit you at home are the MacMillan nurses... Because it's to do with cancer you've got a different kind of support there... Since I've been having the [treatment] every 3 weeks, I haven't been able to find anyone to come with me so I just go myself and when I come back if I really feel awful I have to arrange myself for a carer to take me home because again, short staffed.'* (5, W)

Another participant had learning difficulties and reported that necessary care had not been provided when leaving the hospital. This participant had also not been asked if they needed any support.

*'No, I didn't have the right care when I left hospital because I didn't have no support worker there... [P – when wasn't your support worker there?] At the hospital. I done it all by myself. [P – did the hospital ask you about a support worker?] No. I told them I had a learning disability but they didn't take any*

*notice ...they were just looking in my files but they didn't ask me no questions.'* (11, W)

One participant needed support from social services but did not receive the help that they needed. One of their issues was having a safe place to take their medication but this need was not met by the hospital staff or by social services.

*'.....because you have to leave at 8.30 in the morning, it was a bit difficult because I had nowhere to go so I had to find somewhere I could sit down and that because I was still feeling unsteady in myself. [P – what did you do?] I went to the library because I thought it was the warmest place.'* (12, W)

The participant said they would have liked information from the hospital on:

*'Temporary accommodation, or how to go about helping myself like somewhere safe to take my medication because that was something I was worried about because I was having to take quite a bit of medication. Basically that really.'* (12, W)

However the participant did report that when they went back to a clinic at the hospital the staff there were very helpful and arranged a way for them to take their medication safely.

*'When I went back up the chest (clinic), they were very helpful. They arranged for me to go up there everyday to take the medicine. They arranged a bus pass for me so I was able to travel from...where I was staying at to get up there and take the medicine. They also arranged for me to speak to a social worker at the time, and she helped me as best she could with that.'* (12, W)

Overall there seemed to be a mixture of positive and negative experiences in the provision of care to participants when leaving hospital. Those who seemed satisfied with their experience tended to be the ones who had been asked what their needs were, those that did not need any support or those who had other sources of support such as family and neighbours.

The two people who had additional needs seem to have had the least satisfactory amount of care provided. They were not asked about what they would need when they got home at all. This seems to show a strong link between the assessment process and the provision of care to the patient when they leave hospital. It appears that patients who were inadequately assessed then went on to be provided with inadequate care once they left hospital.

Several participants stated that they felt it was important and reassuring to have someone to come and check on them, for example a district nurse.

## Transport

Participants were asked about how they got home from hospital and whether they were satisfied or not with their travel arrangements.

Those that were satisfied with transport arrangements also seemed to feel ready to leave the hospital.

*'Yes, I was well enough to get a bus....It was quite fine to let me do that... I was feeling much, much better.'* (2, W)

Other patients had arranged with friends and family to be picked up from the hospital.

*'Well another friend of mine came up to the hospital, picked me up and took me home.'* (10, W)

Those that were not satisfied with the arrangements felt unprepared for their return home.

Participant 6 said:

*'... it was an operation on my foot...I had no-one to pick me up... I thought I'd have some transport, a taxi to get home. I had to find my own way home. There was a freephone but no offer of help.... I was left to my own devices.'* (6, W)

Participant 12:

*'No [wasn't offered transport] I was basically told I was being discharged that evening, here's your medication'* (12, W)

A patient had been provided with transport from the hospital to their home but then found that they were not eligible for hospital transport for follow up appointments. This also caused confusion.

*'They sent me home in an ambulance very pro-actively, which made it seem strange that three days later I wasn't worth looking after.'* (1, U) [Three days later the patient had had to return for an outpatient appointment].

Comments from participants showed that after the patient was discharged there seemed to be very little involvement of hospital staff to ensure that the participant could get to the hospital exit. Porters were not always available.

*'...bearing in mind it was an operation on my foot... not even a wheelchair, someone just took my bag down to reception.'* (6, W)

In one case, the participant's daughter arranged for a cab; she also helped to get the participant down to the front as a porter was not available (5, W).

Participants' responses to the questions on transport home from the hospital showed there was some confusion about who was and was not eligible for hospital-provided

or funded transport. There may be a difference between patient expectation and what is actually available. Sometimes this led to participants' expectations not being met.

## Additional Needs

There were other issues raised through the course of the interviews about people's experiences whilst they were in the hospital that did not fall within the remit of this research as they were not about leaving hospital. These included issues around provision of care and communication whilst on the ward and issues with accessing the hospital pharmacy services.

Several participants reported communication issues whilst they were in hospital. One participant had not been able to get a toothbrush despite asking the nurse for one but on a later visit to the hospital the participant found that they could have bought one from the hospital shop. However they had not been told this by the nurses at the time that one was needed.

*'I had no toothbrush and I've had a lot of problems with my teeth and a student nurse said that she'd looked for one but couldn't find any ... So afterwards when I went into the Whittington [hospital] I answered one of the questionnaires and I said...I thought it should be noted that I couldn't get a toothbrush, but the man on the desk said I could buy one in the shop there. But I didn't know there was a shop.'* (13, W)

Another had needed more visits by ward staff, and had sometimes been unable to go to the toilet when they had needed to. (3, W)

Another participant who had an additional need reported that they felt they had not been listened to by hospital staff. They did not have their support worker with them and it seems that this may have led to poor communication between the hospital staff and the participant. The participant reported that they were repeatedly discharged from hospital as staff had assumed that no medical emergency existed. This led to the participant having to call their GP who arranged an ambulance to take them back to hospital for emergency surgery;

*'[P – you said the experience was terrible, can you explain?] I just didn't get...people didn't take me seriously when I was ill. [P] The staff in the [hospital]. They said there was nothing wrong and I had to go home. And after that I called my GP and my GP called the ambulance and I went ... and had my appendix out...I was in a lot of pain ... and they were just sending me away all the time. That's why I changed hospital. I kept going there to get myself better but they wouldn't have it, like they wouldn't see me, take me seriously, just send me home.'* (11, W)

Although these issues are not about the leaving hospital process, it was felt that they were important so should still be included in the final report.

## 5. Conclusions and recommendations

### Conclusions

- Participant's responses showed varying degrees of involvement in the process. The two participants who had the greatest needs were not given the support they needed through the process. Assumptions can sometimes be made about what support mechanisms are available to the patient by staff or by the patient themselves who are not aware of what support they are eligible for.
- Participants who had felt staff were attentive were overall more satisfied with their experience.
- Patients felt reassured where communication with them had been clear and, as they saw it, sufficient for their needs.
- Portable equipment was delivered in a timely fashion. However, equipment that required fitting was sometimes not provided in a timely fashion, if at all.
- Information about medication seemed to generally be quite clear.
- A dual approach of written information and face to face seemed to offer participants the most reassurance. Consistency of staff giving information was also recognised as helpful.
- Information about follow up services and support organisations did not seem to be so readily available. There seemed to have been more difficulty where patients had a greater need.
- Sometimes discharge was delayed by waits for pharmacy or the need to wait for a sickness certificate. This caused anxiety and frustration in some cases.
- Overall there seemed to be a mixture of positive and negative experiences in the provision of care to participants when leaving hospital. Those who seemed satisfied with their experience tended to be the ones who had been asked what their needs were, those that did not need any support or those who had other sources of support such as family and neighbours.
- The two people who had additional needs seem to have had the least satisfactory amount of care provided. They were not asked about what they would need when they got home at all.
- There seems to be a strong link between the assessment process and the provision of care to the patient when they leave hospital. It appears that patients who were inadequately assessed then went on to be provided with inadequate care once they left hospital.

- Several participants stated that they felt it was important and reassuring to have someone to come and check on them, for example a district nurse.
- Participants' responses to the questions on transport home from the hospital showed there was some confusion about who was and was not eligible for hospital-provided or funded transport. There may be a difference between patient expectation and what is actually available.

## Recommendations

- The pre-admission process should make it explicitly clear what services (such as cleaning, shopping, cooking and bathing) may not form part of a post-discharge support package. This may allow the person time to make alternative arrangements if they can.
- The pre-admission process should also make it clear to patients whether they are likely to qualify for patient transport or will need to make their own arrangements.
- In the period that the patient spends in hospital, service providers should provide more signposting to external sources of independent financial advice and relevant local support groups. This list could be co-ordinated between all the local hospitals.
- Information about waiting times for prescriptions and sickness certificates needs to be made clearer to patients. The process for allocating medication and certificates could be improved to make waits shorter.
- Some participants mentioned feeling reassured by speaking to others who had been through the same experience. Health and social care professionals should signpost patients to specific services that can offer this kind of support.  
It may be possible to set up a scheme at the hospital, where former patients share contact details so that current patients can talk through their concerns and experiences with former patients.
- There needs to be greater flexibility in the assessment process so that it can really be person-centred and focus on the needs of the individual. This would be particularly beneficial to patients with additional needs.
- Information-giving needs to reflect the needs of the individual. Written information should be given but with greater checks to ensure that recipients understand the information they have been given.

- A mechanism for acknowledging when a patient passes from one service provider to another, by the provider to whose care the patient has passed could help to ensure that information is passed on between professionals.
- There should be greater clarity about who the patient can contact on the wards if they need anything. A clearly defined point of contact would be helpful.

## 6. References

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- <sup>3</sup> SCIE Report 9. (2006) *Using qualitative research in systematic reviews: Older people's views of hospital discharge*. Available at <http://www.wales.nhs.uk/sitesplus/documents/829/Patients%20%26%20Carers%20-%20Discharge%20Review%20Report.PDF> (accessed May 2009)
- <sup>4</sup> Innes, A, Macpherson, S McCabe, L. (2006) '*Promoting Person-Centred Care at the Front Line*'. Joseph Rowntree Foundation: Available at <http://www.jrf.org.uk/sites/files/jrf/9781859354520.pdf> (accessed May 2009)

## 8. Appendices

### Appendix 1

#### Hospital Discharge Semi Structured Interview Schedule

Opening question

#### **When were you last in the hospital?**

*If participant struggles to remember exactly, let them know that an approximate date is OK/ you can come back to this question*

#### **Stage one**

Before you left the ward

#### **1. Were you given any information about your condition or further treatment by hospital staff or social services before leaving hospital?**

*If 'yes' can you talk me through what you were told?  
If 'no' go straight to the prompting questions  
Did staff tell you about or give you leaflets when you left?*

#### **2. Did you have any extra medication that you had to take at home when you left hospital?**

*If YES can you talk me through what you were told about your medication before leaving hospital?  
If NO continue to the next question*

#### **3. Were you given any equipment to use once you got home?**

*If YES can you talk me through what you were told about the equipment?  
If NO continue to the next question*

#### **4. Were you given any advice about how to take care of yourself whilst you were recovering?**

*If YES can you talk me through what you were told about things you needed to do to care of yourself at home  
If NO continue to the next question*

#### **5. Were you given any information about organizations that could help you to get back to normal life once you had left hospital?**

*If YES can you talk me through what you were told  
If NO continue to the next question*

- 6. What information was given to you regarding any follow up treatments or what to do if you had any problems?**

*If YES can you talk me through what you were told  
If NO continue to the next question*

- 7. Did someone tell you this information face to face or were you given it as written information?**

- 8. Was information you were given before you left hospital clear or confusing?**

*Probe for what information was particularly confusing  
Probe for what made the information confusing*

- 9. Did you or your anybody else have any say in the decisions that were made about the arrangements that were made for your care after leaving hospital?**

*If YES Can you describe how you were involved  
If NO Can you describe to me the decisions that you would have liked to have had a say in*

- 10. When you left the ward, how did you feel about the prospect of going home?**

### **Stage two**

- 11. How did you get home?**

- 12. How satisfied or dissatisfied were you with travel arrangements?**

### **Stage three**

Arrival Home

- 13. When you arrived home did you have everything you needed?**

- 14. What sort of help did you need in the first few days after arriving home?**

- 15. What sort of help did you need at home in the long term, that is, from the first week after you left hospital?**

- 16. What sort of help did you get?**

- 17. Did you have to contribute financially to these services?**

*If YES: How far did this affect whether you were able to get the help you needed  
If No: Continue to the next question*

**18. What do you think of the overall experience of support provided when you left hospital?**

**19. What, if anything, could have been done to improve your experience of leaving hospital and recovering at home?**

**20. Do you have anything else to add?**

**Supported by**  
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