A Qualitative Study into Patient Experiences of Discharge from Hospital to the Community

Undertaken by Dr Natalie Lynch
Involvement Innovation Ltd

Jointly commissioned by Birmingham and Solihull LINks

October, 2011
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Acknowledgements

This consultation was commissioned by Solihull LINk and Birmingham LINk to investigate older patients (and their carers) experiences of hospital discharge in Solihull and Birmingham East and North. As well as the author, the research team included Meanaz Akhtar and Lucy McDonald who carried out some of the interviews and Dr Peter Quaife who advised on methodology and contributed to the production of the report.

We are grateful to everyone who helped us to recruit patients and carers for interviews; particularly Sue Newman and Amie Westwood from Age UK Solihull (Linking People), Mary Alcock and Karen Grant from the Stroke Association, Anne Marie Howes Centre, Ardenleigh Court and Waterloo Housing Association. We also thank Jamie Emery and Tom McLoughlin and the rest of the team at the Heart of England Foundation Trust (HEFT), especially for making arrangements for us to recruit participants from discharge lounges.

We also thank Anne Marie Howes Centre, Ward End Asian Elders and Ashram (Bosworth Drive Community Centre) for allowing us to use their venues for focus groups. We especially thank volunteers from the Consultative Health Council (CHC) at HEFT and in particular Gerry Robinson, Chair of the CHC.

Most of all we thank the patients, carers and families who gave us their time to tell us their stories about hospital discharge.

The organisations involved

Local Involvement Networks (LINks)
LINks were created by the Local Government and Public Involvement Act of 2007 and provide a mechanism whereby lay people can influence the provision of local health and social care services. They have statutory powers which mean that health and social care providers must take their views into account. Solihull LINk and Birmingham LINk jointly commissioned Involvement Innovation Ltd to carry out this qualitative study. Project management on behalf of Solihull LINk was undertaken by Catherine Gulati, and for Birmingham LINk, by Andrew John.

Involvement Innovation Ltd
Involvement Innovation is a research consultancy specialising in consultation, evaluation and community needs analysis. The organisation specialises in community engagement and has particular expertise in consulting vulnerable groups. Involvement Innovation is managed by Dr Natalie Lynch who holds a PhD in Psychology, a Masters in Research Methods and is a member of the Social Research Association. She also lectures on social research methods at Aston University and delivers training on qualitative research techniques to NHS clinical staff and commissioners.
Executive Summary

Birmingham and Solihull Local Involvement Networks (LINks) commissioned Involvement Innovation Ltd to explore the experiences of elderly patients with complex health needs of hospital discharge. This was a qualitative study which examined patients and carers experiences of hospital discharge and makes suggestions for improving discharge. The overall aim of this of consultation was to explore the transition from a health to a social care setting from the patient perspective.

Fourteen people took part in three exploratory focus groups and 47 people took part in in-depth interviews across Solihull and Birmingham East and North. In total 71 people took part in this consultation.

Communication was the major theme to emerge from this work and was emphasised at every stage of the discharge process. The main findings in relation to communication are as follows:

1. Patients who had the most positive experience of discharge referred to good communication around planning for discharge and ongoing care.
2. Patients and carers highlighted the importance of receiving information on support services, local agencies and self and ongoing care.
3. Patients and carers also referred to the importance of communication between health and social care agencies and its role in the seamless transition from hospital to a community setting.

A number of recommendations were made to improve hospital discharge, they have been listed below.

<table>
<thead>
<tr>
<th>Finding</th>
<th>Recommendation</th>
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<tr>
<td>1. Some patients felt that they were not adequately consulted about decisions regarding their care. Additionally carers felt that they were often omitted from decision making but felt that their input was also important.</td>
<td>Discharge planning must include greater patient &amp; carer involvement. Where appropriate a family centred approach to discharge planning and decision making should take place.</td>
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<td>2. Carers and patients felt that communication around needs assessments and discharge planning was poor. This was regarded as a cause for avoidable readmissions to hospital.</td>
<td>Better communication is needed around assessing needs, discharge notice and the timing of discharge.</td>
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<td>3. Some carers and patients felt that needs assessments were carried out in an unrealistic way so were not accurate. This was seen to increase the likelihood of readmissions.</td>
<td>More accurate methods for assessing patients need to be carried out, for instance some suggested that assessments could be carried out in patients homes prior to discharge.</td>
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<td>4. Where patients had long waits in discharge lounges they often found chairs uncomfortable</td>
<td>Discharge lounges should have a variety of seating/reclining options.</td>
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<td>5. Patients often experienced discomfort from being immobile whilst waiting in discharge lounges</td>
<td>Patients should receive support in staying mobile whilst waiting in discharge lounges.</td>
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<td>6. Patients comment that delays in their discharge were often due to the delay in receiving their medicines</td>
<td>Medicines should be prepared the day prior to discharge or patients should be given prescriptions to take home.</td>
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<td>7. Some patients have difficulty with everyday tasks such as shopping and cooking. Some return home with no food but have difficulty getting provisions.</td>
<td>Checks should be made on whether patients will have support upon their return home; where appropriate patients should be given basic food supplies or referred to social services.</td>
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<td>8. Some patients return home with no information about self-care or actions to take should complications/relapses occur.</td>
<td>Information about ongoing treatment should be given alongside instructions should complications occur.</td>
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<td>9. Both patients and carers commented that they returned home with no information about local support agencies.</td>
<td>Both carers and patients should be given an information pack containing details of organisations who offer support.</td>
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<td>10. Some patients felt that communication around their discharge was handled in an insensitive manner, especially patients who had difficulty communicating.</td>
<td>Hospital staff should improve the way they communicate with elderly patients; especially for patients who have difficulty communicating.</td>
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<td>11. Patients who needed support from social services (Adults &amp; Communities) generally reported better outcomes when there was good communication between health and social care teams.</td>
<td>Better communication between health and social care is needed so that patients experience a seamless transition.</td>
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<td>12. Some patients and families had to make arrangements to see a social worker after returning home, some found this a difficult and stressful process.</td>
<td>Patients who need the support of social services should see a social worker whilst in hospital. Or Patients and carers should be given contact information for social services before returning home.</td>
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<tr>
<td>13. There were some patients who were offered support from social services, however some declined any support for a number of reasons. Some were deterred by paperwork, others because they assumed their carer could cope and others feared the consequences of admitting they couldn’t cope.</td>
<td>Perceived barriers to accepting social support need to be reduced; Social Services should consider current communication techniques. Further investigation into perceived barriers is recommended so that suitable communication methods can be found.</td>
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This consultation generated a considerable amount of information enabling us to understand the aspects of hospital discharge that older adults and their carers are concerned about. It is important that communication and the provision of information across the whole discharge process are improved. Poor experiences can leave carers and patients with negative feelings and views about the NHS which may deter them seeking early care in the future. Furthermore, involving patients and carers in decision making will lead to more accurate needs assessments and more appropriate care in a community setting. It is important to get this right because not only will this alleviate stress for both carer and patients, research shows that this can also avoid hospital readmissions. Hospital readmissions currently cost the NHS £2.2bn, so in the current economic climate it is vitally important that we improve discharge by ensuring that effective communication policies are in place.

Our ageing population places further strain on the NHS; it is therefore important that commissioners and service providers react and respond to the needs and views of service users in planning for this change. The experiences reported by carers and patients in this consultation do not differ from earlier research findings dating back decades in some cases, despite changes in policy. It follows therefore that existing policies are either inappropriate or inadequately implemented and that fresh solutions are required to address the issues this report raises.

**Background and Project Aims**

The aim of this consultation was to explore the patient and carer experience of hospital discharge and explore the transition to a community setting for elderly patients with complex health needs at hospital sites in the Heart of England Foundation Trust (HEFT)

In relation to discharge HEFT define complex health needs as follows:

‘A transfer of care is deemed to be complex when several members of the Multi-disciplinary team are required to carry out comprehensive assessments in order to facilitate a safe, appropriate and timely transfer. This will involve co-ordination between Primary and Secondary Care and Community Care Services may require home or site visits with the provision of specialist equipment which may be organised by the Occupational
Therapist, Tissue Viability Nurse of Complex Discharge Nurse Specialists (CDNS previously DLN).’ (HEFT discharge policy, version 5, 2008).

**Setting the context**

Previous research has tended to concentrate specifically on delayed discharge and the issue of bed-blocking which is often the result of a shortage of community care. Delays are also due to patients waiting for community health care assessments or appropriate placements. Much of the existing policy is also aimed at reducing incidences of delayed discharge. This research has generally taken a ‘systems’ approach with the aim of eliminating bottlenecks in the system. This consultation instead explored the service user perspective (patients and carers) of the entire patient journey by examining the transition from hospital to a community setting (home, sheltered housing or a care setting).

In 2003 the Department of Health published a Hospital Discharge Workbook (2003b) which emphasised a whole systems approach to discharge and covered a wide range of topics including user involvement, co-ordinating the patient journey and the role of community support such as housing providers.

Several key Acts have been passed and policies implemented in an attempt to create an effective and seamless hospital discharge experience. In 2002 the Health and Social Care agent team was created to support the implementation of the National Service Framework for older people. The aim of this framework was to develop a single health and social system and partnership working with local agencies to reduce delayed hospital discharge.

The following have been identified as causal factors in delayed discharge:

- ‘Poor communication between hospital and community
- Lack of planning and assessment for discharge
- Inadequate notice of discharge
- Inadequate consultation with patients and their carers
- Over reliance on informal support and a lack of (or slow) statutory service provision
- Inattention to the special needs of vulnerable groups such as frail older people’
Intermediate care

Hospital Discharge has long been an important issue in Health and Social care. In 1997 the House of Commons Health Committee introduced a range of measures to reduce instances of delayed discharges from hospital and invested heavily in intermediate care services.

The role of intermediate care is to rehabilitate and prepare elderly people to return home so acts as a bridge between social, primary and secondary care services (Carpenter, Gladman, Parker & Potter, 2002). Within the National Service Framework for Older People the aim of intermediate care was stated to be ‘to provide integrated services to promote faster recovery from illness, prevent unnecessary hospital admissions, support timely discharge and maximise independent living’ (VFM Audit Intermediate care). In 2006 a white paper (Our health, our care, our say) documented that intermediate care and related community services resulted in a reduction of delayed discharge from acute hospitals by 64% in England.

Intermediate care and discharge planning are therefore an increasingly important area of the interface between health and social care.

Health and Social Care

The integration of Health and Social Care is vital for effective discharge planning. Under the ‘Choice of Accommodation Directive’ (1992), if a patient has been assessed as no longer needing inpatient care, they do not have the right ‘to occupy indefinitely an NHS bed’. The Community Care Act (2003) in relation to delayed discharge states that 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.

According to HEFT policy on hospital discharge patients should receive a referral to a specialist nurse, social worker or therapist within one day of being assessed so that the transition to a community setting can begin. It is also the responsibility of the Multi-Disciplinary team to liaise with patients and carers about discharge planning.
Patient and Carer Involvement
The need to involve individual older patients and their carers is important in discharge planning and the Department of Health (2001 & 2002) have called for a more patient centred approach. In particular the DoH has issued guidance on the discharge and care of elderly stroke patients and advocates carer and patient consultation. The aims are 'to ensure that older people are treated as individuals and they receive appropriate and timely packages of care that meet their needs as individuals, regardless of Health and Social care boundaries’. Research findings have shown that involving patients and carers in the planning of their care can improve services and their outcomes in terms of readmissions and patient satisfaction (Andrew, Manthorpe & Watson 2004; Bull & Roberts, 2001). Furthermore, the DoH states that patient involvement ‘promotes more responsive services and better outcomes of care’.

Carer Involvement
The involvement of individual carers has been found to increase their satisfaction with services and acceptance of their caring role (Bull, Hanson and Gross, 2001). In relation to carers government policy states that 'at the time of discharge, carers must be fully informed and involved in the planning of future care of the patient; so that assumptions aren’t made about their ability or willingness to care’ (Department of Health, 1999). The involvement of carers in discharge planning is crucial because caring can affect a person’s physical and psychological wellbeing (Henwood, 1998).

Community Support
Concerns identified by both patients and carers around the planning of future care include:

- Whether they will be able to cope
- Whether there will be adequate statutory provision for them
- Where their care will take place

Patients and carers also have many practical concerns such as how they will cope with everyday tasks such as cooking, shopping and cleaning (Cunliffe et al. 2004; Holzehausen, 2001; Glaseby, Littlechild & Price, 2004; Jewel, 1999; Roberts, 2002).
They may also have financial concerns as hospital care is free whilst social/community care may be means tested which can cause anxiety regarding both money and filling in paperwork (Hudgell, Gifford, & Lee, 2004; Negus, 2004).

**Discharge in Solihull and Birmingham**

According to the Care Quality Commission 40% of patients experience some form of delay in their discharge. HEFT regularly conducts its own surveys to gather information about patient’s discharges to ascertain causes for delayed discharges. Based upon the feedback of 185 patients discharged between 19th July and 26 July in 2010, it was found that 62% of respondents reported experiencing some form of delay; a figure considerably higher than the national average. The survey also highlighted issues around communication such as 50% of patients stating that they were not informed about when they would be discharged and 25% said that they were not kept informed as to why there was a delay in their discharge. When patients were informed about their discharge 59% of patients were informed that they would be discharged before midday, however 49% did not get home until after 3pm, 9% of patients did not get home until after 6pm. The survey data shows that the main reasons for delays were caused by delays in receiving medicines.

Some local consultations have taken place on hospital discharge; the Stroke Association has found that both patients and carers highlight the importance of being provided with information about their ongoing health needs. Patients and carers also wanted greater involvement in decision making.

Birmingham Advisory Council for Older People (BACOP, 2009) surveyed older people on their experiences of hospital which included asking about their discharge experience. The findings from this survey showed that most delays were caused by the wait for medications and there was a lack of information about patient’s conditions, medications and follow up care.

The local Health and Scrutiny Board produced a report which made recommendations for reducing incidences of delayed discharge; one of which included early consultation with patients and carers about discharge.
Communication & Information

Under point 6 of the HEFT discharge policy document (version 5) a list of aims and objectives have been listed for simple and complex discharge. These include:

- Ensuring appropriate use of resources and informing patients of discharge plans to prevent delays due to inadequate planning (Discharge Checklist).
- Ensuring all patients are provided with appropriate discharge information on admission.

Furthermore, the policy states that, ‘The planning and implementation of an appropriate discharge plan for every patient is dependent upon good communication between all members of the multi-disciplinary team, the patient, their family and carers, accessing interpreting and advocacy services as appropriate. The patient, family and carers will be made aware of the Trust’s discharge process at the onset of the assessment process and kept informed of progress against discharge plans and involved in decisions relating to discharge arrangements’ (page 9).

This policy statement is supported by previous research which shows that having access to information about their condition, treatment and available services is crucial to the ability of patients and their carers to contribute to decisions (Bull & Roberts, 2001; Huby, Stewart, Tierny, Rogers, 2004). It is therefore crucial to keep patients and carers fully informed if they are to be meaningfully involved in the planning of their discharge and ongoing care.

Witherington, Pirzada and Avery (2008) examined reasons for hospital readmissions. They attributed poor communication between hospital and community support organisations as a main reason. They also found that in many cases insufficient information was being passed onto to care agencies.

Summary

In summary, both research and policy suggest that factors important for seamless and timely discharge include:

- Good communication between health and social care agencies
- Good communication between agencies and patient and carers
- Patient and carer involvement in decision making
- Accurate needs assessments

**Aims and Objectives**

The aims of this consultation are to explore the patient and carer perspective of hospital discharge for elderly patients with complex health needs.

The main objectives were:

- to examine patients and carers experiences of hospital discharge (transition from health care to social care).
- to collate patients and carers suggestions for improving hospital discharge.

These are the main questions we asked in relation to hospital discharge:

1. How are patients and carers involved and informed about discharge planning?
2. What are patients and carers experiences of the transition between health and social care systems?
3. What are patients and carers experiences of community care and support?

**Methods of investigation**

The consultation was data driven. This means that its starting point was not existing research or other literature, but the recent experiences of patients and carers in the target group. This research orientation helps to reduce the tendency to replicate earlier studies by recycling the ideas contained in them. In this context, it ensures the user voice takes centre stage. Despite this, a literature review was undertaken, but was used after the data was collected as a point of comparison, not as a driver for the data collection. This approach is most commonly known as Grounded Theory (Strauss and Corbin 1998).
Focus Groups
The first phase of the project was three focus groups, conducted with patients and carers in the target groups. These took place in March, 2011. The purpose was to generate topics for inclusion in the interviews which were the primary data collection method.

We conducted 2 focus groups in Birmingham East and North, they took place at the Ward End Asian Elders Association with 4 participants and at Anne Marie Howes Centre (Intermediate care) with 4 participants. A further focus group took place in North Solihull at Ashram (Bosworth Drive) with 6 participants.

Focus groups with older people can be problematic for a variety of reasons. This age group are more likely to suffer from a range of impairments (speech, auditory and physical disabilities). We therefore ran focus groups with smaller numbers of participants to ensure that those who attended were able to contribute fully. We experienced a great deal of difficulty arranging focus groups because many people weren’t able to attend due to their health if they had recently been discharged or lacked the confidence to travel to a location they were unfamiliar with. We therefore arranged transportation for participants and awarded them £10 to thank them for their time.

Focus groups are particularly good for generating ideas because group interaction is typically more creative and wide-ranging than would be the case in an interview situation (Krueger and Casey 2000). Facilitators kept intervention to a minimum; their role was limited to stimulating debate and ensuring discussion stayed on topic. From this, a topic guide was created to structure the interviews. This preliminary phase meant that the ideas the interviews were based on came from patients and carers, not from academics or medical professionals.

Interviews
The second phase was 47 one-to-one interviews which took place throughout March and April, 2011. Interviews were based on the topic guides prepared in phase one, brief demographic information was collected at the same time.

Respondents were encouraged to speak in their own words, giving as much detail as they wished as well as offering their own interpretations of events. In some cases interviewees had difficulty communicating often due to impaired speech; in such cases carers were often present in these
interviews. Interviewers encouraged elaboration where this seemed necessary and used the topic guide to ensure all interviews covered the same issues.

46 interviews were undertaken by Involvement Innovation Ltd. An additional interview was undertaken by a volunteer interviewer (Gerry Robinson) from the CHC who had considerable experience conducting interviews of this nature. Other volunteer interviewers from the CHC were ready to conduct interviews, but it was not possible to recruit participants at suitable times who could be interviewed by them.

**Selection of Respondents**

Qualitative studies typically do not require a large number of interviews; saturation can be reached with numbers as low as 15 (Guest, Bunce, & Johnson 2006). However the target group had a diverse range of experiences so a larger number of interviews (47) were conducted in order that a range of different experiences could be explored. As the remit of the project was to explore elderly patients with complex health needs we prioritised patients who were aged 60 or over or carers/families who cared for someone above this age. Out of the 47 interviews 28 were conducted with patients, 12 were conducted with carers and 7 were conducted with both patient and carer present; a total of 57 participants took part in this stage of the consultation.

Reasons for hospital admission included falls, strokes, heart attacks, breathing difficulties and routine admissions although the majority of participants also had one or more other long term condition. In the majority of cases interviewees were admitted as emergency cases. We also ensured we captured experiences to a variety of discharge locations, these included discharge to sheltered housing, care homes, intermediate care and the patient's own homes (demographic information is in Appendix 1).

We recruited the participants through Age UK Solihull (linking people), Ward End Asian Elders Association, Anne Marie Howes Centres, Waterloo Housing Association, district nurses, social workers and the Stroke Association. Some participants were recruited via discharge lounges at HEFT hospitals but we ensured that they had been home for at least 4 weeks before interviewing them.

We limited the sample to patients and carers whose most recent discharge experience occurred within 3 months prior to this consultation taking place.
This is because they would be more likely to recall the rich detail of their experience. We also ensured that participants had been discharged from hospital for at least 4 weeks so that they were able to refer to experiences of community support. In some cases participants had several recent experiences of being discharged from hospital; comparing these experiences allowed us to explore examples of good practice and suggestions for improving hospital discharge. As one of the aims of this consultation was to specifically explore experiences of patients discharged from HEFT sites (Heartlands, Good Hope and Solihull) participants were recruited in Birmingham East and North and Solihull PCT localities.

It is important to note that this selection method, while entirely appropriate for a qualitative study will not produce statistically valid numerical data. For that reason no such data is presented in this report.

**Data Analysis**

All interviews were recorded and transcribed fully. They were anonymised where necessary to protect the identities of participants and the medical personnel they referred to. False starts, hesitation and non-standard syntax were all included, which combine to give a vivid picture of what was said. The aim of analysis was to generate themes and categories and to explore relationships between them. We used a thematic approach to data analysis which involved becoming familiar with the data by reading through transcripts and listening to the recordings. Data was indexed using QSR Nvivo software (version 9) to code, develop categories and to explore relationships between categories.

QSR Nvivo has been designed specifically for qualitative analysis of rich text-based data, where deep levels of analysis on large volumes of data can be carried out. It helps users to organise and analyse non-numerical or unstructured data. The software enables data to be classified, sorted and arranged. The researcher is able to test theories, identify trends and cross-examine information in a variety of ways. Observations in the software can be made and a body of evidence to support their case or project can be built (Dearne, 2008).

Once the categories had been developed, subdivided and applied to the interview material, the themes contained within the data could be teased out. All the material on a particular theme could be retrieved, suitable
examples extracted for inclusion in the report, and explanatory text added. Relationships between different themes were also explored.

The final stage of the data analysis took the theme based material, compared it to existing literature and research and cross-referenced it where appropriate to existing policy.

**Findings**

The findings will be divided between the 3 main stages of the hospital discharge experience:

1. Discharge planning, communication and information
2. The day of discharge and transition to a community setting
3. Community (social services) support

Each section concludes with suggestions for improvements made by the interviewees. The findings are illustrated throughout by excerpts from the interview material on which the report is based. Each excerpt is presented as boxed text, with clarification by the author in square brackets. Interviewees have been given false names that are gendered and are culturally and age appropriate.

The most prominent theme/issue raised in this consultation was communication. Concerns around communication were raised across all stages of hospital discharge; therefore this issue will be discussed in each of the 3 stages outlined above.

**1. Discharge Planning Communication and Information**

Communication and information about discharge to carers and patients was a broad theme running through the various stages, therefore this theme has been broken down into further subcategories.

**Assessing patients needs**

For many patients the first stage of their journey home began with their needs being assessed whilst in hospital. The excerpt below outlines the experience of Marion and her daughter Anne of a needs assessment. Marion was admitted to Solihull after suffering a chronic lung infection.
(Marion) I don't know, I forget. I think they said somebody would be coming to see me like to arrange what needs to be done.

(Anne) They did do an assessment on you, you had to make a cup of tea, didn’t you?

(Marion) Yes they did take me downstairs to make a cup of tea and when I saw it was a teapot, to be quite honest, I don't usually use a teapot to make a cup of tea, I think I've got one... so anyway I had to use the teapot (laughing) so I don't know, I did it all right. They said that's fine, and then she put me back in the chair and wheeled me back upstairs.

Marion (patient) aged 88 and Anne (carer)

Interviewees had a range of opinions about how their needs were assessed. More favourable comments were given when patients felt that there was good communication with the health professionals, for instance Tess talks about her husband’s needs assessment.

Yes, fairly good actually. The OT saw him in hospital, and the social worker. They’ve been here to see me, apart from the social worker. The OT was brilliant. She explained everything and things were got quickly.

Tess (carer)

Some carers spoke about the accuracy of the needs assessment, some felt that the ability tests carried out in the hospital did not accurately test how well elderly patients will cope in their home environment. Sharon blames the methods used to assess her mother as the cause for her readmission.

Erm it’s not a true assessment because obviously I would feel or I would imagine that someone would be walking beside her at the time, obviously to show her where the things are, she would feel confident there..... because she’s now in her surroundings she doesn’t feel confident. Erm she was discharged at 12.30 on the Monday and we had to have the paramedics back by half past eight on the Tuesday morning, because she was trying to do it and fell over again.
And also again, there wasn’t things in place for her, because she can’t manage to get from the toilet to the bathroom, but nobody had come out to assess for a commode to put into the bedroom and nobody really spoke to us about her needs.

Sharon (carer)

Notice about discharge
Interviewees had a range of experiences of being informed about when they were going home. For instance some said they were given little or no notice and spoke about the surprise at being informed. In the example below Shamila talks about the first time she was informed that her father Harif would be returning home.

I just, I went to see him and then, I don’t know, I asked something from the nurse and she’s just like, ‘Oh no, he’s going to go today anyways.’ And then that’s it. I think it was pretty like a shock wasn’t it? They told us like really quick. Because we didn’t expect it, like he’s coming home.

Shamila (carer)

In the excerpt below Harry talks about his surprise at returning from the bathroom and finding that his possessions had been packed and that he was being discharged.

Not a word. I went up to the washroom and someone told me I was going home. Just like that. I’d been in 26 days. When I came back to the ward they’d cleaned my locker out and cleared all the stuff off the top. In fact they missed a towel. I couldn’t believe it. When I came back the nurse had got my frame on her shoulder, ready to go down.

Harry (patient) aged 82

Other patients also express surprise at the notice they were given about their discharge.

And the nurse came along and said, I said: Oh you’ve come to move me? She said no you’re going home.

And that was the first you’d heard?

The first I’d heard of it and then it was an hour or so later I was down in the discharge lounge when I met you.
Beth (patient) aged 64

Those who were given little notice about their discharge often attribute this to there being a shortage of beds.

The morning he came out the doctor had been to see him, and he’d said nothing about coming out. So he went down to the washroom and halfway through someone poked their head round the door and said you’re going home.

So you didn’t know?
I had a phone call then. They told me to bring in his clothes so I rushed in with his clothes and when I got there they said he’s going home in an ambulance so he won’t need them. So I rushed home again!

Did the social worker and OT know he was being discharged that day?
I don’t think so. But all the time he was there on ward 17 they were short of beds. I know that. Perhaps those that were close to going home were sent home.

Tess (carer)

Others spoke about the poor communication around their discharge and how this caused distress for both the patient and their carers/families.

Anne (Marion’s Carer/daughter): On the Monday she was due to come home, I filled her fridge with food and that. Then when I went in on the Sunday they said you can’t come out on the Monday, didn’t they? You didn’t know whether you were coming or going, you got all worked up, didn’t you. And then I come out of work on the Monday and my sister-in-law had got her home. And that was bad, wasn’t it, you were upset.

Did you feel informed?
Marion: Not really, now you’re thinking: how am I going home?
Anne: If we wanted to know anything we had to keep going and finding someone.

Marion (patient) aged 88 and Anne (Marion’s daughter)

David also refers to spending his last few days in hospital wondering when he would be discharged.

Well I was confused because erm originally I was told I could be discharged by the doctor, and then it was I believe eight days before I actually got out, erm which seemed like a bit of a waste all round. Erm and I was never actually told when I was going until I was actually going. But it’d always been made clear it could be any minute. And of course that meant a week of let me out of this place like, because the food’s terrible.

David (patient) aged 62

Many of those who felt that they were given little notice about the timing of their discharge spoke about feeling unprepared and having insufficient time to make the necessary arrangements. Lynda talks about the difficulty she faced in making arrangements for the return of her husband Douglas (aged 63) who was returning home from Heartlands Hospital.

Well I don’t think it was very good really, because they never give us enough information in time for me to get things organised if you like. You know, if they’d have told us a couple of days before, I probably could’ve arranged something different, do you know what I mean?

Lynda (carer)

Some patients spoke about difficulty they’d have in making arrangements for their carers families to pick them up as they were often uncertain about the exact time they would be discharged, in the two excerpts below Meryl and Violet outline their experiences.

as I say, it was all a bit of a rush in the end. Okay, I’d had all day, but I’d got, I’d had to have someone waiting for me to tell them well I can come out now, rather than come and wait all day at the hospital with me. Erm so, you know, it was a case of within half an
hour, you know, I’d got to ring them and they’d got to come and fetch me. So it was all a bit, you know, hit and miss really I suppose in that respect.

Meryl (patient) aged 65

No it was, oh well perhaps er Thursday. And then Thursday comes, no, well perhaps tomorrow. But they wouldn’t give me a definite answer. And of course my god daughter, I mean she works so it was a bit inconvenient to her. And she even phoned up before she left home and they didn’t say a definite yes, okay. And I finally came home about six o’clock on the Friday evening.

Violet (patient) aged 78

Carers also spoke about the frustration about not knowing exactly when their relative would be coming home.

They just said she was coming home, so it would be a matter of hours that she was told that she’d be coming home. But then a bit later she was told she’s not coming home. Then a bit later they’d phoned me again, ‘She is coming home,’ I said, ‘I’ve just had a phone call to say she’s not.’ ‘Ambulance is ordered, she’s coming,’ and that was it.

Adrian (carer)

Some carers needed notice so that they could arrange transportation.

Shamila: Kind of, but like just saying, giving only two or three hours before he was going to get discharged...... It just came out, like all of a sudden.

Gurjit: Because my step-brother’s a businessman, he hasn’t got like time, sometimes he doesn’t have the time, he’s in some other country.

Shamila: Yeah, sometimes he’s out.
Gurjit: If he wasn’t there, we would have to like arrange a taxi and then like go, because we could’ve had difficulty like getting dad a taxi or something.

Shamila and Gurjit (carers)

For many patients and carers their main issue around discharge was the poor communication.

I don’t think there is any [communication] actually. I think it’s down to individual people. I don’t think there’s any set procedures for it.

Erm at no point did it endanger my health at all, or anything like that. Erm but it was unnecessarily long, erm and lack of communication was the big one, and never knowing properly. So you reach a point where one day it’ll happen, you know, and you just wait. And every time you see erm one of the ambulance crews coming down the corridor you think, ‘Oh yes,’ and it wasn’t, but er such is life.

David (patient) aged 62

Timing of the discharge

Many patients and carers spoke about the timing of their discharge, some felt that they should have been discharged much sooner whilst others would have preferred to have been kept in hospital longer. In the majority of cases patients said that they would have preferred to have been discharged sooner.

So you feel you were too long in hospital?

I was just taking the tablets and I could’ve took them here.

You would have liked to come home or come out of hospital much sooner?

I would do yeah. I’ve been a lot of times and all for the same reason, yes. I was walking out of the village and then I went (fainted).
Ken (patient) aged 91

In many cases carers and patients had different views about the timing of the discharge; patients were often keen to get home as soon as possible whereas some carers felt the patient should be kept in hospital for longer.

He just wanted to come home, yeah. He would’ve preferred to have been discharged sooner, but I preferred it the way it was. I think it helped us better.

Tracey (carer for husband Alan)

Some carers talk about their relative being unfit to return home, in the example below Richard speaks about his wife’s return from Solihull Hospital after suffering a stroke.

Then the next day and half are a day and a half that I want to forget about, because she should never have been sent home full of diarrhoea and god knows what. I was constantly washing and changing beds and she should, to my way of thinking she should never have been sent home in the condition that she was in.

Adrian (carer for wife Jane aged 71)

In the excerpt below, Peter and Margaret talk about the discharge of their mother from Heartlands hospital, they talk about feeling ‘bullied’ into taking her home when they felt she was too ill.

Margaret: Erm and then, yeah he tried to bully us into taking her home, that’s the only words we can describe it because he approached us both separately.

Peter: Approached us both separately.

Margaret: When we’d moved away from where mom was and weren’t together, to try
and get us to take her home in the middle of the night. And we said no, she was writhing in pain and so distressed wasn’t she?

Peter: Yeah. Erm so we were then told that we needed to take her home, despite the fact that she shouldn’t go home, and it wasn’t a safe discharge and we’d filled in all the paperwork.

Peter & Margaret (carers)

Peter and Margaret’s mother was subsequently readmitted into hospital another 2 times over a 2 week period. They highlight poor communication and lack of carer involvement as reasons for these re-admissions; these themes are highlighted throughout this section.

Patient involvement in decision making
Some patients felt that decisions were made on their behalf without their involvement. For instance Daisy was admitted to Solihull hospital after a fall in the home. She talks about being independent throughout life but was upset at not being involved in discussions about her care whilst in hospital

**What do you think it was about your stay that worked well?**
It was quite alright I liked it except the doctors coming.

**Because they don’t talk to you?**
No. And they should talk to you because I’ve been in hospital years ago, the doctors always talked to you, tell you what’s the matter, and they should do. We’re not daft, you know!
So did they share with you what they thought was the problem?

He went back and talk to these other three men but whatever they were saying I was too far away to hear.

So you couldn’t hear the discussion about you?

No.

Was anybody else involved in discussions?

No. And when you’ve been used to being in charge, you don’t like to just be a hanger-on. When they examine you they should talk to you. It’s your body. They should talk to you, one-to-one.

Daisy (patient) aged 92

In relation to expressing their views, some patients felt that they had no say in decisions about them.

I don’t think I had a choice in anything; it was just wait and see.

David (patient) aged 62

Some said that although they were not involved in decisions about their care they were happy for their families to make decisions on their behalf. For instance Burt was originally admitted into Solihull hospital after suffering a stroke, he was interviewed in an intermediate care centre.

So when you were in hospital, were you given a choice about coming here [Ardenleigh]?

No we were told like we were coming here. No I wasn’t involved in it.

Okay, and would you have liked to have been involved?

No I was happy for my son, because he arranges everything for me, he’s good like that.
Burt (patient) aged 72

**Carer Involvement**

As highlighted in the previous section some patients were happy for carers to make decisions on their behalf. Many carers felt that their involvement was important because the person they cared for wasn't able to make fully informed decisions. In the excerpt below Tracey talks about her involvement in decisions about her husband Alan who had been admitted to Heartlands Hospital after having a stroke.

*I think the nurses were brilliant but not the doctors, not the doctors. We had to keep going to the nurses and asking them things, and I don’t think the doctors were very good at all. They liaised with me because his understanding isn’t very good at the moment.*

**Okay, and how did that make you feel?**

*Better, better, because I could answer his questions better. Because like when he first went in and they was asking him questions, he was just saying yes to everything, you know. So it made me feel better because at least I could tell him properly what was happening.*

Tracey (carer)

Other carers talk about not being involved in discussions and subsequently having to enquire about conversations that have taken place with their relative. Linda talks about her experience regarding her husband Douglas who had been admitted to Heartlands Hospital after experiencing breathing difficulties.

*Or when I come, whatever. Because they’d say something to him like, and then he’d kind of tell us, is it right or what, has he got it right or what? And then I used to have to go and ask.*

Linda (carer)
Margaret and Peter talk about their frustration at not being involved in decisions about their mother’s care and felt that their mother was too ill to provide meaningful answers to questions she was being asked.

Margaret: We didn’t feel we had a say in it, did we? Anyway, we just said, ‘Well we don’t think we can take her home,’ and he huffed and went away.

Peter: So the plan was, you were saying the plan was to eventually take her to a rehabilitative care setting? Okay.

Margaret: Yeah, that was the plan. Erm yes, but only set up because of the fuss we’d have to make the day before.

But my fear was they were going to get there, they’d ask a question, she was answering, erm she was answering all sorts of weird answers wasn’t she? Saying she was fine when she wasn’t, that she was eating when she wasn’t.

Peter: She told them she’d never had any heart problems and she’s had a triple heart bypass.

Margaret: Yeah, she said... they asked if she’s ever had anything wrong with her eyes, she said, ‘No, no,’ when she’s had two cornea transplants and two cataract operations. So that’s the state her mind was in at that point because of the infection. Erm so we then stayed on that ward until the following evening.

Peter: We kept saying, ‘You need to tell us what’s going on, not tell mum because she’s confused and she’s not telling us.’

Margaret: Yeah, nothing was ever set up for us to be involved in anything, erm which was vital, we needed to know because, you know, it falls on us to then try and keep mum out of hospital now. Erm but yeah, to actually have involved us, which they didn’t. That would be such a strong recommendation wouldn’t it?

Margaret & Peter (carers)
Other carers feel that assumptions are made by both staff and the patient themselves about the carers ability to cope with their role; making their involvement vitally important.

Another thing is you see, my mum might had said, ‘Oh no, I’m fine, I’ve got my daughter.’ Because they don’t realise what they’re putting on you. So really I think they need to make sure they see the person that’s actually caring for that person [the patient].

Because I think they’re [hospital staff] more on the patient, which they’ve got to be, but people like mum go, ‘Oh yeah, everything’s fine’,

It’s not, and it’s the outside people [family] that suffer I think. They’re not so informed I don’t think, of what is going on. They [hospital staff] don’t always say what is actually wrong, or if they’ve found anything.

Sheila (carer)

Barry speaks about family involvement in relation to his father’s discharge from Solihull after being admitted for a fall. His mother is the main carer for his father but is in the early stages of dementia, Barry talks about the crucial role the family plays around hospital discharge.

I suspect if I hadn’t have been around, and it had just been mum dealing with it, I suspect there might have been a little bit more thrust upon her. And there wasn’t really a meeting explaining what’s going to happen. I did have to push a little bit to find out, you know, when do you think he’s going to come out, what support is there going to be in place, what assessment have you done in terms of incontinence, that kind of thing.

You’ve got the hospital and what goes on in the hospital is to some extent distant from the patient or the family. Now maybe they were talking to dad, but dad wasn’t able to communicate to us what was being said.

See I don’t know how much discussion was had with dad or with mum about things which
I wasn’t party to. Erm both of them get thoroughly confused, both of them are probably not going to say, ‘I’m not happy with this, I think I need more help here,’ you know, they’re of that generation that anybody in the medical profession is, you know, is God er and they wouldn’t dream of complaining about anything.

I think where there are children involved and around and interested, then I think they should very much be part of the conversations. I understand people are busy, but I think it’s... for those families where they do try and do a lot for the patient post discharge, they need to know more about the situation to be able to do their best. It is our problem and we want to do what we can do. We’re the ones left to pick up the pieces if it all goes wrong.

Barry (carer)

Barry later describes his family’s experience of hospital discharge when his father suffered a stroke a few years previously. In this excerpt he highlights a good example of a family centred approach.

So what made that [his father discharge after having a stroke] a very good experience of discharge?

I think more involvement of the family. So I guess particularly it was a big change from, you know, pre-stroke to stroke, there was a massive change in the person, er their life will never be the same again. Whereas I think maybe what dad had, and maybe a lot of the people who go into the ward where dad was, they’re ill, they come back and they’re sort of similar to what they were before they went in.

Well for when dad had his stroke, as I mentioned earlier, there’s a lot, there seemed to be a lot more parties coming together, whether it’s Social Services, physiotherapy, hospitals, medical people to assess the individual patient and their needs and discuss that with the patient and the family, so that everybody is on the same page in terms of not just what’s going to happen but also what’s happened to the person, and how that person might, might improve or not in the following weeks and months ahead. Er and I suppose
therefore what works well is that, and therefore by definition what’s happened this time round was not as comprehensive as that. And maybe it shouldn’t be, and maybe we can’t afford for it to be, and I understand that. But maybe there’s some bits of let’s try and make it a bit more inclusive and include the family.

Barry (carer)

Section Summary
The following themes were from conversations around discharge planning:

1. Communication with patients and carers is perceived to be generally poor in discharge planning.
2. Needs assessments are improved when carers and patients are involved
3. Carers/families would prefer a family centred approach

The day of Discharge and Transition to home

Experiences of discharge Lounges

Interviewees had a variety of opinions about waiting in hospital discharge lounges.

Malcolm aged 92 was admitted to Solihull Hospital after suffering a stroke. He talks about his frustration of waiting for seven hours in the discharge lounge.

*I had to wait for 7 hours in the discharge lounge.*

*In a way, the turnaround from the time you’re told you’ll be discharged and you go to the discharge lounge, to the time you actually go, well, I think it’s far too long, especially at*
my age, going into 92 years of age. I kind of needed somewhere to rest my head a little bit.

Not comfortable at all. I think to myself it’s not got to be a routine situation, it’s got to be person to person.

I always have a sleep in the afternoon, and the point is they’d taken that away and I was getting a little bit agitated. I didn’t let them know because they’d got their routine.

I would have liked to have been able to be recumbent, laid back a bit. I was in the discharge lounge for seven hours, in a chair. I wasn’t moaning much but I was getting a bit niggly inside.

Malcolm (patient) aged 92

Beth talks about the discomfort of sitting down for the long periods of time due to her health condition.

Last time I came out of Heartlands hospital, by the time that it came to take me into the car park my leg had set. Cos I’d sat for so long and not moved at all. We were lucky this time as it was only two hours sitting in the discharge lounge, it would have been difficult if it was any longer really. Y’see I’d been in just over a week since I had the operation so I needed to keep moving, mobile, so it was the muscles starting to work again.

Beth (patient) aged 64

For some participants the long wait and the uncertainty of when they would be leaving was distressing.

You go in a special room there.

The discharge lounge?
Yes. It was about five hours waiting for the ambulance.

**Do you remember the discharge lounge? How was that?**
Yes I do! (laughing) I would rather stay on the ward where I was to be honest. I do remember and you couldn’t help it each time the ambulance man came in, becoming excited. But it wasn’t us. And one girl was with me she said: it’s only going to such and such a place and he could drop me off (laughing). When they did come they were lovely and got a special chair thing to bring me up.

**What time did you get home?**
It was in the afternoon sometime because. They brought sandwiches round. The (discharge lounge) staff were very nice to me but I would prefer not to go to the discharge lounge…yes it is sitting at a long time. There were a lot of us. It was a long time for us, lots of coming and going.

Cynthia (patient) aged 83

Others did not like the discharge lounges and mentioned the contrast between being on the ward and being in a discharge lounge.

I think the wait in the discharge lounge is the worst part. You’re really looked after on the ward and then wheeled down to that discharge lounge, just sitting there in the chair. I felt that was a shock to the system though.

**When you got to the discharge lounge did you have any idea how long you’d be there?**
No. My biggest problem was in the discharge lounge, not knowing where the toilet was.

Molly (carer)

However some interviewees did talk about their time in the discharge lounge very favourably.
In the room where we was taken I was looked after, no complaints. Ten out of ten.

And how long were you in the discharge lounge?

About three hours, at a guess. They even gave me a sandwich. Because I’m a diabetic and they said would you like a sandwich and they reeled off what they’d got. I had a cheese sandwich.

Harry (patient) aged 84

But I thought the staff in the dispatch [discharge] lounge were very good. I thought they were exceptional.

Paul (patient) aged 71

The same interviewee however did express frustration about the length of time he had to wait in the discharge lounge.

My only comment is there’s too long a period between when they get you to pack up on the ward to when you leave the dispatch lounge. I was ready to go in the ward at 10.30. They were in trouble for ambulances but Joanna was coming to pick me up, nobody else was involved.

They didn’t check that with you?
She phoned and spoke to the nurses three times.
But they didn’t phone her when you left the ward?
No.

Paul (Patient) aged 71

Many interviewees talked about the manner in which they were discharged and the quality of the communication that took place about their discharge.

In the following excerpt Mohammed talks about how the discharge procedures and processes in place made him feel.
I mean surely they should have said, ‘Alright, from our side you’re free to go, take your time.’ Rather than once you are up and about in a wash room or anything like that, the nurse would come round, just rip the sheets and they get in there quickly, so therefore you can’t go back.

No they didn’t erm care about me, how I left or when I left. You know, I just changed my clothes and left.

Mohammed (patient) aged 68

Many interviewees talk about feeling rushed to vacate their bed on the day of their discharge and refer to the behaviour of hospital staff.

But with regards to being discussed where I was going to, I don’t think they really cared where I went to as long as I give them an empty bed.

Slap happy. Just, as I said to you before, they just wanted you out of the bed and out of the ward. And you know, they’d be grateful if nobody went into your bed. It would be less hassle for them. It would be less erm, less work for them. So consequently they could play around and laugh around with the doctors and that at the nurses’ station.

They haven’t got, they haven’t got compassion, they’ve got no compassion in them. They don’t like their jobs. They don’t like being nurses but they do it because people hold them in esteem, you understand?

I know for a fact that they couldn’t give two pennies for them people that’s in there,
because you’re just a number and once you’ve gone out, you know, that’s it.

They’re like er, you know, when things go ... conveyor belt, that’s it, they’re just like a conveyor belt now. And you don’t count, you don’t count, you’re out, you’re out, you’re out. Three strikes and you’re out, that’s it. Go on then.

Katie (patient) aged 68

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I think it’s ad hoc. It’s not, it’s not professional. To me, it’s not; it’s er the quicker they get you in, the quicker they get somebody else in the bed. They get you out, get somebody in.

When you get to my age, they don’t care, treat you like pieces of meat.

Graham (patient) aged 62

Arthur aged 78 was admitted to Heartlands hospital after suffering a stroke. After his stroke Arthur’s speech was a greatly affected, his keyworker was present in the interview and helped him to communicate. Arthur speaks about the communication that took place with hospital staff on the day of his discharge.

Arthur: They could have been more genuine with me....[imitates staff] ‘now sit down there John there’s a good man’....I’m not an animal, I’m not an animal my dear I’ve got a name.

Don’t do that’, .....‘sit down there, ....’I haven’t got time, go back to bed’

How could discharge procedures be improved / what are key recommendations?

Arthur: Well if they treat you properly and talk to me properly.

Yeah manners they haven’t got none!

I mentioned it [the way he was treated] to one or two people but it was like talking to a concrete wall. Every time I talked about it was like a concrete wall.

Keyworker: From what I am picking up here I guess people never took the time to sit with him and talk to him at a sort of a pace which he could have understand and they could have understood. So it could be a miscommunication breakdown really.

Did anyone sit down with you and explain things?

Keyworker: Not that he’s incapable of understanding, but if you’re not going to deliver it in a right way he’s not going to understand full stop and that way he’s going to get confused.

Arthur (patient) aged 68
Delays
Some patients had to wait for a considerable length of time to be discharged and this was often a cause of stress and anxiety. Pal (aged 58) who had suffered a stroke and his wife Bhavini talk about their experience of waiting for his discharge.

Pal: Well anything could change at that time, I hadn’t left the hospital I’m still there I was thinking they can change their mind, this can’t be true and the nurse would say I’m sorry you have got to go back to your bed.

Bhavini: He was dreading the fact that they might turn around and say something, something has happened and you can’t go and he was dreading that fact. He just wanted to get out of there. And every minute for him was too much.

Pharmacy and the wait for medications was a common frustration for both carer and patients and was perceived as an avoidable cause for delays.

Katie aged 68 was admitted to Heartlands after a fall in her home which resulted in her breaking her arm. In the example below she talks about a couple of experiences of having her discharge delayed due to the wait for her medication.

Well erm yes and no. Erm it was in the respect that I couldn’t wait to get out of hospital. But in respect that the pharmacy was supposed to give me tablets to take home with me, right?

When I was coming out they said that can my son come back after five o’clock and get the tablets? My son rang up after five o’clock; they said the tablets hadn’t come up from the dispensary, could he come back the next day. So he rang up, consequently, being as I had no tablets, he had to go through my own GP and get an emergency supply because I have an under active thyroid and I can’t do without the Levothyroxine, understand? And he got
them. And he asked around the hospital at five o’clock in the evening, and they told him
the tablets hadn’t come up from the dispensary, and my son consequently said to them,
‘Well we’ve already had an emergency supply from the doctor, so we won’t be bothering
you anymore.’

There’s always a delay for your medication. But usually, I’m going back again when I was
in there before, erm what happens is erm they like your people to come up, er you know,
come up after five o’clock or that because that’s the time when your medication comes
from the pharmacy. And them times, they wouldn’t discharge you unless you had your
medication. Because I mean last time, I can’t remember, I think I was in for an angiogram
or something, erm we had to wait until nearly seven o’clock for our medication, but they
wouldn’t discharge you until you actually had your medication. But now, erm when we
asked her about the medication she said it hadn’t come up from the pharmacy, can your
son come up after five o’clock and he can have it, alright?

Katie (patient) aged 68

However in relation to Heartlands Donald was happy with the service he
received from the pharmacy.

The medication thing here is very efficient, they’re so used to it, you see. It’s just part of
the place, that’s all very efficient. I couldn’t have begun to do it. I just take what’s given
me.

Donald (patient) aged 87

Marion also had a positive experience but also talks about previous
experiences.

How long did you wait for your prescription?
They were already made up but usually you have to wait quite a while. When I had the
pneumonia we did have to wait quite a long while, then it was too long really.

Marion (patient) aged 88

Beth was admitted to Heartlands for a hip replacement, in the excerpt below
she makes some suggestions for improving the current system of
dispensing medicines.
I think they could work out a better system of either giving you a normal prescription to take to a chemist yourself or take this to a doctor. You could it get done a lot quicker but it’s the sitting around waiting, when they tell you that you’re going home all you want to do is go home!

I know the pharmacy are dealing with a lot of people and other things going on, I can understand that, they either need more staff or to make things different. The only thing I was waiting for was my injections to stop blood clots, that’s all I was waiting for. I’d got all the rest of my tablets. I’ve got to say there’s got to be an easier way of doing it. It’s such a sticking point. Everybody is in exactly the same boat as I said, I really don’t know, the only thing I can think of is writing the prescription out so you can go home, take it to chemist. Even if they haven’t got it, you know they’d get it the next day. Everyone we’ve spoken to who’s been in hospital has had the same problem and also the same way. Just give us a prescription.

Beth (patient) aged 64

David also makes a suggestion for improving the current system.

They know when you’re going, I don’t see why they don’t have a system where they put your medicines together the day before your discharge.

David (patient) aged 62

Returning home

Interviewees returned to a variety of settings, these included sheltered housing, care homes, intermediate care or their own homes.

Many interviewees were discharged over the Christmas and New Year period, Violet comments on the cold weather and the impact it had for returning home.

Well no, there was nobody here. And erm fortunately my god daughter had come and put the heating on before she came to pick me up. But I mean it was January and you know what the weather was like in January. And er I mean I had food in
the freezer and things like that. But you know, it was rather...well I think it could’ve been better.

Violet (patient) aged 78

In comparison David gives an example of returning home with useful provisions to aid his return home.

They did everything by the book; they were very good, very good. They made sure I knew how my oxygen worked as well so that I was well conversed with and that.

It was very quick. Oh yes, yes, nice people. One good thing of the package of sending me home from hospital was they included a small bag of groceries, the basics, tea, milk, sugar, that sort of thing, which I didn’t actually need myself, but for a lot of people it could’ve been useful.

But er I mean my sister and that had sorted that stuff out before ready for us.

David (patient) aged 62

In the excerpt below Tracey gives an example of a ‘seamless’ transition in relation to her husband’s return home from Heartlands after suffering a stroke. This example highlights how good communication, accurate needs assessment and a patient centred approach can contribute to positive transition to a community setting.

Er they told me they’d be bringing my husband home between 10 and half 10, that the physiotherapy and the speech and language people would come with him. So they came in about quarter past 10, erm they sat with us and had a chat in the living room. Then they asked my husband if he could...they’d been teaching him how to make a cup of coffee and tea, and they asked him if he’d make them a cup of tea and coffee, which he did. And they asked him if he would show them upstairs and he took them upstairs. And they asked him to show him the bedroom, the toilet, the bathroom, showed him all round. And while they was up there they checked to see if I needed any more handrails and things like that.

They brought his medication with him. As I say, he was home for quarter past 10, and they said between 10 and half past 10. So no, there was no hanging about, it was lovely.
Yeah, they brought him home, which was good.

And then did they escort Alan from the patient transport into the home?
Into the home. They stayed and talked and things. I mean they didn’t rush us at all. And they stayed until they felt he was quite ready to be left kind of thing.

Do you think your needs prior to discharge were assessed accurately.
Yeah I do definitely. I think if they’d brought him home and he’d had to go back, it would have set him right back. I think what they did was the right thing, you know, they brought him home and they stayed to see that he was able, and he was.

Them actually bringing him home and staying with him a while. I think that really worked really well. Because I think like if I had to go and fetch him and wait for transport, he might have been more stressed out. Whereas when he came he was quite calm and, you know, it was really good.

Tracey (carer)

Information about post discharge support
Many carers and patients spoke about returning home without knowing how or where to go for support and help. For instance Dorothy was admitted to hospital after a fall in her flat (sheltered accommodation) speaks about returning home and not knowing how to arrange carer support.

Well the hospital did tell me that I needed carers. I said, ‘Well how do I get them?’ Well the social will see to that. I have a lady come Wednesdays. She’s coming Thursday but it wasn’t last time. I don’t know what she’s come for, just talks to me, very nice lady. And I asked her about these carers, how do I get them? Well I don’t know. I don’t know how to, how to contact them at all.

Dorothy (patient) aged 89

In the excerpt below Katie talks about her concerns for her health should she suffer any side effects or complications after returning home.

There was no numbers to say if this happens you start bleeding, or this happens you faint, or this happens you do that. There was no papers or any, any sort of numbers to ring, you
know, when you come out. If there’s an emergency during the day maybe, and they can
give you a letter to say blah, blah, blah, this lady has had this or this operation. So if you
pass out, you know, or anything happens and you have to go back in hospital, it’s taking
you half an hour to tell them what your operation was all about, you know.

You weren’t given, you weren’t given any sort of things like that, you know. I mean I
haven’t even had a letter, I haven’t even had a letter from them telling me what I’d had
done or anything. Er I’m under them erm psychiatrists, and I mean when I go to see him,
one letter comes to me and one goes to me doctor. And erm I thought that was the same.

Katie (patient) aged 68

Other patients and carers talk about being unaware about funding and
support available to them. In some cases where patients meet certain
criteria they may be eligible for reablement support for a period of six weeks
which can be delivered in a number of settings such as intermediate care,
transition services or a person’s own home. In the excerpt below Violet
speaks about the enquiries she made about reablement support.

When I came out, having, when I went for my examination prior, the girl told me, I asked if
there was any help afterwards and she said, ‘No, not now, we don’t do that.’
So anyway, I came home say on the Friday eventually, and on the Monday I rang erm Age
Concern, I found a number. And from there I learnt that they did supply six weeks erm help
free of charge. Er so they put me in touch with the organisation, and towards the end of
that week somebody did come in. And then they sorted it out and somebody came in
morning and evening for erm... they didn’t come for the full six weeks, fortunately I didn’t
really need them, so they gradually cut down the evening visits and then finished the
morning visits.

And the same with, when I went for my physio afterwards, because you go for physio, erm
they don’t provide any transport for you. Well the first week I went one of my friends was
able to take me, and I learnt that you could have transport but you had to fix it up yourself.
Well that’s alright. They gave me the number and er you ring up and fix it up. When I was
in hospital nobody came to see me, and no I wasn’t given any information.
Violet (patient) aged 78

Patient and carers made suggestions for improving procedures for the provision of information prior to discharge. For instance Mohammed suggests that patients should be provided with information upon their departure.

And the only, they gave me a letter saying, ‘Give it to your GP,’ that’s all. Er, I mean it [discharge process] wasn’t sympathetic I would say, you know, I’d not enough sufficient information and anything like that.

I would’ve said they should be more sympathetic to the person who’s going to be ... the patient, to the patient, they should tell them that you are being discharged now because you’re going to get this, you’re going to get that, you know. There should be vast information about it. But there was none for me, yeah I think they need a bit of improvement there.

Mohammed (patient) aged 68

Some carers also commented on being given insufficient information about support and help available to them. In the excerpt below Sheila makes recommendations for ensuring that carers are also provided with information.

But then I was left on my limb, and knowing what I know now I would’ve contacted Social Services. But I did feel then I was on my own out in the dark a bit. I did feel we were left. I mean they didn’t ask if she’d got care at home much either this time, but is it their responsibility? I don’t know.

I think somebody needs to, to say ‘has she got help at home, you know’, and, give a list of the agencies or whatever, but make sure they – I know it’s hard – give it to the person who’s taking her home, or somebody, not the patient, because the patient, like mum, she’ll say, ‘Oh I’m fine, I’ve got relatives.’ And relatives can’t cope. And they don’t realise.

Shelia (carer)

Section Summary

1. Patient comfort is an issue for patients who have long waits in discharge lounges.
2. Communication was often insufficient about the cause of delays.
3. Medications was seen the most common cause for delays.
4. Some patients return home to unsuitable environments (e.g. cold conditions or no food)
5. Smoother transitions occur when there is good communication and a patient centred approach; consequently patients are more satisfied with their experience.
6. Patients need information about funding and support agencies.
7. Some patients perceived that staff gave more priority to beds than patients which resulted in some patients feeling disrespected.
8. Some patients felt that hospital staff did not treat them with respect.

Community Support

Intermediate care
Some patients were sent to an intermediate care centre before returning home and all interviewees who experienced intermediate care gave favourable appraisals.

In the example below Nancy talks about her time at Ardenleigh.

*It was only about two days afterwards... I know I was quite surprised - they gave me a private room and they came to me and said you're going to go to Solihull, which I was pleased about then I said: what's the catch.. you have to pay? They said 'no'. And they’d worked all this out because they knew I was a widow. I was worrying at the back of my mind, I thought: my daughter’s widowed she can’t give up her teaching to get up here. My son is in Shropshire, works in Worcester. He can’t get here. And I was worried and that all just lifted!*

*So was it a relief to you?*

*I just thought oh what do I do? She [daughter] is so far away, four hours drive and I thought a day so, that was just wonderful and the food...! These people here, they need a medal*
Do you think it’s been at the right step for you?
Yes, it couldn’t be better. They’ve been wonderful. I started to eat here, I couldn’t do in the hospital, which they were concerned about. I couldn’t eat. So it’s been a good way to move towards home?

Nancy (patient) aged 84

Anne Maries Howes Centre also received positive reviews, Dorothy talks about her experience in the excerpt below.

When I was in Solihull, when I come out of hospital they put me into a… well it was a lovely place, Anne Marie Howes, really nice.

Really nice that was. I was in there for three or four weeks, the maximum was six weeks and I come out, it was lovely in there.

Dorothy (patient) aged 89

Mary also talks about being at Anne Marie Howes Centre and refers to the beneficial effect of being surrounded by other residents who are reaching milestones, such as walking.

Yes, yes I walked sort of thing, you know. But I was a long time without walking at all. But then I remember I was sitting in the lounge in this place, I’d sit there and watch other people. I said, ‘They can do it, they can do it, why can’t I do it?’ And I must do it, I must do it. In the end, well it was a laugh really. One morning, this was the week I was determined to do something about it. And like I was getting off the toilet, and this young lady with the white coat was there, and in the end in desperation I said, ‘I’ll do it for the physio,’ and I looked at her, and I can remember they looked strange. But anyway, this young one got
me by the arm, and I did get up and take a few steps, if it was only to the chair. But of course in the afternoon, later on in the afternoon I found out this girl was not a physio, she was a student nurse.

And er, and it gave me courage I think to take another couple of steps.
Now it wasn’t walking independently, it was just kind of transferring from the bed I was able to walk. I still haven’t mastered it properly.

**So do you think Ann Marie was a suitable place for you to be discharged to?**

Oh yes, yes. I think they’re great. I think they’re great. And I know people, you know, I know people who are here and got out of this, you know, and were walking again. And I can think of one lady in particular that must’ve been my age or a bit more, and she was er in this place and she went home walking. And she’s very good, she’s the type that wouldn’t er, wouldn’t use the stick or anything, you know, she just started to walk.

Mary (patient) aged 83

Mary then talks about her fear of returning back to home to sheltered accommodation.

**The only thing, as I say, I was kind of shocked when I heard I was going on a home visit and it unnerved me for a bit, you know, because I thought, ‘They’re doing it too soon. They’re doing it too soon,’ but then, you know, Cathleen came up and she said, ‘They’re not doing it immediately mum, they won’t. No way will they put you out immediately if you’re not ready to go. Just calm down and do your best,’ she said.**

Families of patients also speak about intermediate care centres in high regard, Margaret and Peter talk about their mothers experience in intermediate care.

**Margaret: But anyway, she went to Arran Court, they were brilliant. They started**
getting her eating properly, erm got her using her stick properly. And although she didn’t come out of her room very much, she built herself up while she was there.

Peter: She didn’t like being there, but she didn’t not enjoy it if that makes sense?

Margaret: She didn’t like being there but she made, she got on with it.

Peter: She couldn’t wait to get home.

Margaret: Yeah, she got really chatty with the people, didn’t she, and they all loved her to bits.

Margaret and Peter (carers)

Transition from Health to Social Care
Patients and carers had a variety of experiences regarding their transition from health care to social care.

Edward aged 72 was admitted to hospital for a triple heart bypass and had splint operations on both legs. Due to his operations Edward had great difficulty walking and wanted help with everyday tasks. In the excerpt below he talks about his return home and highlights inadequate information on follow up care or funding that he was eligible to receive.

_I was talking to a friend one day and he said, ‘Did they ask you, didn’t they mention about getting help?’ I said, ‘No, where from?’ They said, ‘After care,’ no, ‘Carers.’ I said, ‘No.’ So they said er, they said, ‘When I get home I’ll give you the number.’ He said, ‘I haven’t got in on me, it was for the wife.’ He rang me and I rang them.

And they said, ‘What is it you want?’ I told them, you know, what you had and all of that, and when did you come out? I said, ‘A few weeks ago now.’ And they said, ‘Well what is it you want?’ I said, ‘I just want somebody to fetch me a bit of food in everyday, because I like…’ you know, and they said, ‘No problem.’ ‘Oh,’ I said, ‘That’s good.’ Then they said,
'£12.50 an hour.' And I said, 'What?' They said, '£12.50 an hour.' I said, 'I can’t afford that.'

Edward later found out that he was eligible for attendance allowance and was able to pay someone to do his shopping for him.

Edward later speaks about poor communication and his surprise at carers arriving at his home.

And then one morning, it was about 10 o’clock my bell went. And I opened the door and it was two nurses. Now they were like sumo wrestlers, nothing against them they were nice girls. But the size of them, I thought, ‘No good asking you for a diet sheet.’ Anyway, they said, ‘We’ve come to change your socks and the thing.’ And I said, ‘Oh, well I’ve got another week to go.’ And they said, ‘No, we’ve come now to do it.’ I said, ‘Oh okay’

Did you know they were coming?

I never knew. Nobody told me, no nothing, they just rang me bell and when I opened it I could see they were nurses like.

Anyway, they said, ‘Well are you alright?’ I said, ‘Yes thank you.’ I said, ‘But I can’t walk.’ They said, ‘Oh no, you won’t for a while.’ And I said, ‘Well who sent you?’ And they said, ‘Well it doesn’t matter, we’re here.’ And I thought, ‘Bloody hell, why don’t they say they’re from somewhere.’ But they didn’t, got that? They didn’t say a word.

Edward (patient) aged 72

Katie also talks about returning home with no information.

It was just a procedure, erm you’re going home, goodbye and that was it. There was no anything in between, there was not anything when you come home.
Katie (patient) aged 68

Some interviewees felt that there was no communication between the health care system and social services.

**Do you think that you would have received help upon leaving hospital if you hadn’t have pushed for it?**

*Probably eventually, but I think it took them too long to either decide or to order or whatever; there was no cohesion between them. Erm I don’t know whether they work as a team or whether they work as just individuals, but there doesn’t seem to be any cross-communication, erm A doesn’t know what B’s doing or whatever, so asking questions is pointless.*

David (patient) aged 62

Peter and Margaret ‘s mother was admitted into hospital 3 times over a 2 week period. They blame poor and communication and lack of family involvement for her re-admissions. In the excerpt below they explicitly refer to the communication between health and social care and speak of their mothers third discharge in more favourable terms; attributing this to the early involvement of social services.

*Peter: And then she chased it up[care package] and they had had a referral come in but it hadn’t been dealt with, and she shouldn’t have left the ward until the social workers had actually been involved and checked.*

*Margaret: Right, so a recommendation would be then to improve communication between kind of the....hospital and the social team.*

*Peter: When that, when that actually works, like the third time we actually had the social worker from day one.*

*Margaret: Yeah, so cross communication [health and social care]*

*Peter: The last time was was a lot better.*
Margaret: They, they fell over themselves to make sure...

Peter: They did everything to the book, making sure everything was double checked.

Margaret: [named social worker] was involved again, I can’t remember her other name, she was one of the social workers at Solihull.

Peter: Well they were going on about they were getting a care package.

Peter: Yeah, the actual notice to say she was going was only probably about 24 hours wasn’t it?

Because [named social worker] came and visited mum all the way through on and off didn’t she?

Margaret: Yeah just, you know, trying to keep her informed, or us informed. But there were little tiny snippets of information, or, ‘Nothing’s happened yet, I’m still working,’ usually just stay, ‘I’m still working on it, just hang in there, we will be, you know, we will get it sorted.’

Peter: Just that it starts, again starts properly with the social workers from day one.

Margaret: Yeah, that it’s not just talked about, that’s it’s actually actioned on.
Because it was talked about from day one, the discharge.

Margaret and Peter (carers)

Patients who had support in place after returning home talked about seeing a social worker whilst they were in hospital.
Has there been any discussion about any care support when you get home?

Yes they came and told me yesterday.

A social worker?

Oh yes a social worker came to the house and she's quite happy with it. And the physiotherapist said: all this is great. They’re going to have somebody in the morning at nine o'clock as I’m an early riser. They come about tea time to make me a sandwich and I could do that, I’m sure, I have a stool but I can’t go high at the moment. So that's a great help.

Nancy (patient) aged 84

Patients who had better transitions from health to social care tended to be those who were being supported by the Stoke Association. In the excerpt below Bhavini talks about the support she receives for her husband Pal aged 58 who had suffered a stroke.

This was it I knew there was allowances available but I wasn’t sure who to contact so I contacted the Stroke Association, the lady on our ward [named person] and she came out and said you’re on my list to contact. So I made an appointment for her to come down and then she also brought into the process the person who looks after the benefits to contact me and then I made an appointment with him to come down and fill in the Disability Living allowance benefit and the carers help.

Bhavini (carer)

Some interviewees talked about the difficulty of getting support from social services after returning home.

And did anybody talk to you about any sort of goals when you came home?

(Marion) No no, it's just up to me self, really.

(Anne)The doctor didn’t even give you a call, did he? No one came. The carers didn’t come
to the Wednesday, so mum had to ring the doctor to ask if there was anybody there to help.

(Anne) Yes, I phoned and ask the doctor to come but he didn’t come he sent somebody else. She was very nice and very understanding, so I explained that I hadn’t had the carers come yet and she did get in touch, like, and you know, they came the next day.

So you didn’t have a number to ring for the carers, or anything?
(Anne) No and now you can’t always get through to your doctor, it’s getting worse.

Had anybody sent you a letter or given you a letter saying these are the things you can expect when you get home?
(Anne) No

Marion (patient) aged 88 and Anne (carer)

Other interviewees talked about the suitability of the environment that they returned to. Connie talks about how the home was adapted for the return of her husband and the interaction between health and social care teams.

Yes, fairly good actually. The OT saw him in hospital, and the social worker. They’ve been here to see me, apart from the social worker. The OT was brilliant. She explained everything and things were got quickly.

No, they really sort of said; we’re giving you this. That’s what I’ve got upstairs. But when she visited him in hospital he said he’d liked to help with the washing up. Even with a dickie heart he used to, he was as active has he could be. And he told them that, so they provided a perching stool, but as yet he hasn’t used it! (Laughing)

Connie (carer)

Reluctance to accept social support
Many interviewees talked about declining offers of extra support and help; they did so for a variety of reasons.

In the excerpt below Barry talks about his parents’ reluctance to accept help, fearing that they might be moved or separated.
So I guess there’s a question mark in my mind whether there was enough consideration as to the mental capacity of mum and dad for them to have these conversations and to take what they say as gospel. Because they could say to mum, ‘Do you think you’re able to cope?’ And she’ll say, ‘Yes,’ you know, ‘I think I am able to cope,’ because she’s proud etc.

Is she genuinely able to cope? Probably not as much as she thinks she is.

I think it’s been fine in terms of what they’ve tried to do. I’m sure you’ve met lots of old people, they’re very proud, so when the carer support lady came, mum was quite defensive, she was very proud, ‘I’m coping fine,’ you know, ‘Yes it’s not easy but I manage, and I don’t need any help.’ So she was sort of quite… it’s like accepting charity isn’t it? It might be seen as a sign of failing, to take services, we should be able to do it, and they are proud people.

Whereas I would say she’s less capable than she thinks she is. Er I think there’s an element of a bit of fear, that all these different people are coming to see them, bearing in mind they are mentally not quite with it. Are they coming to try and take us away, move us out the house? Is there a bit of a hidden agenda, or are they going to say I’m mad? Whatever it is, I think there’s a bit of a fear factor.

And I think there’s probably also a little bit of er, it’s going to sound horrible, I’m going to say racism. I think there’s an element of they’re not all 50 year old matronly people, white, middle class, whatever it might be. Then again, if that makes sense.

Barry (carer)

Some interviewees mentioned a reluctance to accept any support from social services because they were uncomfortable receiving help from the state.

They have sent me an attendance allowance form. I’ll have to ask my son to come over and help me fill it in. It doesn’t come easy to accept handouts from the state.
Tess (carer)

Other patients thought that claiming support and funding would slow down the process of returning home.

I was asked if I wanted help but I refused. I don’t like fussing. I was asked the day before I left hospital what the situation was like at home and was told about the possibility of having more help at home. I said ‘no’ because I didn’t want the process slowed down, I wanted to get home to my own little world.

Malcolm (patient) aged 92

Others said that although they saw a social worker they felt that they didn’t need any help or support.

My carer brought me home. They organized this social worker to come in. I’m not being critical but for me, for them to come in for five minutes is a waste of time. I can get a cup of tea myself, I can get a snack, I’m not reliant on them for that.

Paul (patient) aged 71

In Ken’s case he talks about the discomfort of talking about his finances.

What she was trying to do was get me some help to pay for it but what she wants... every detail of my finances... she comes down here on the ward. She said: remember me and I said yes and while I’ve been here (home) she phoned me up, she said: I hear you’re back home. She wanted all my financial details!

Ken (patient) aged 91

In the case of Shelia who cares for mother, she felt that sometimes patients decline support because they assume their carers/families are willing and able to care for them.

... another thing is you see, my mum might have said, ‘Oh no, I’m fine, I’ve got my daughter.’ Because they don’t realise what they’re putting on you.
Carer Support
We interviewed several carers to listen to their experiences; some carers also needed support from social services to enable them to care for their relative.

In some cases carers also had health problems which made it difficult to care for their relative. In the example below Enid describes how her needs were identified.

**Did you have an assessment of your needs as a carer?**

*Oh, no. Anyway the OT came and she followed me upstairs to see what Harry needed upstairs and she picked up on me being breathless, which I thought was very good. So she said we needed a stairlift, but she rang me after she got that going to say she’d actually put me down as needing the stairlift.*

Enid (carer)

**As a carer, how able did you feel to look after your husband?**

*Nobody really asked me if I could cope. He’s a big man, and we don’t always have carers all the time. I have arthritis so sometimes it’s difficult lifting him.*

Rose (carer)

Section Summary
1. Intermediate care is highly valued
2. Patients felt that better communication was needed about ongoing care and support available to them upon returning home.
3. Patients wanted information about self-care
4. Patients report more satisfaction when there is a seamless transition from health to social care
5. Patients and carers would like to be given information about community support.
6. Some patients decline support from social services because they are deterred by paperwork, disclosing their finances or fear the consequences of admitting they’re unable to cope.

7. Some carers feel that their own support needs have to be identified.

Discussion

Discharge planning, communication and information

Needs assessments were seen as a vital component for planning discharge but questions were raised around the suitability of assessing patients in a clinical setting. Some carers also raised concerns about being left out of this process and felt they should be given the opportunity to contribute to the needs assessment. Communication between staff, carers and patients was seen as being vital for assessing patient needs and planning ongoing care. Many attributed inaccurate or insufficient needs assessments as a cause for unnecessary hospital readmissions. It is therefore vital that both patients and carers are given the opportunity to be involved in this process.

Discharge notice was also an aspect of discharge that could cause distress. Both carers and patients felt they were not given sufficient notice to make arrangements such as arranging transportation or making adjustments to the patient’s home. Patients also said that the wait to be discharged was frustrating, some spoke about being informed that their discharge was imminent but waiting for several days to be discharged. Many patients were eager to return home so the prolonged wait to be discharged was often difficult. This has important implications for HEFT policy; it currently states that discharge planning should begin early, involving communication with both patients and carers. Testimonies from many participants suggest that
this isn’t routinely happening so this is an important area of the discharge process that needs to be addressed.

In terms of the discharge timing patients felt that either they returned home at the right time or would have preferred to be discharged sooner. However some carers felt that some discharges happened too soon either because they felt unable to cope or because they felt the patient was unfit to return. The latter was seen to be a cause for unnecessary readmissions. Research findings show that greater carer and patient involvement can reduce hospital readmissions (Andrew, Manthorpe and Watson, 2004). National figures show that 8% of patients are readmitted to hospital within 28 days of being discharged, costing the NHS an estimated £2.2bn a year. Arguably better communication with patients and carers could prevent inappropriate discharges therefore reducing the likelihood of readmissions; providing huge savings for the NHS.

Many patients and carers felt that they were not involved in decisions about their care and that communication was generally poor. Patients felt frustration about not being involved in decisions about their care and felt that this was due to a culture where older people are treated differently and not fully consulted. In 2001 the Department of Health issued guidelines stating the importance of patient involvement in discharge planning and advocate carer and patient consultation. The benefit of involving patients and carers in decision making is that it promotes more responsive services and better outcomes of care such as hospital readmission and patient satisfaction (Andrew, Manthorpe & Watson, 2004; Bull & Roberts, 2001).

Carers also felt left out of communications and decision making and felt that their involvement was essential. Either because they felt their relative wasn’t able to make fully informed decisions or because the carer themselves felt assumptions were made about their ability or willingness to care for their relative, this is consistent with previous findings (Bull, Hanson & Gross, 2001). Research shows that the involvement of carers is crucial because it can affect a person’s physical and psychological wellbeing (Henwood, 1998).

HEFT policy on discharge emphasises the importance communication across agencies as well as communication with patients and carers. Patients and carers commented on good and bad experiences of communication, therefore more consistency is needed to ensure that all patients and carers are kept fully informed. Furthermore, the Health and Scrutiny Board investigated reasons for delayed discharge; this report also
highlighted the importance of communication and made recommendations for ensuring that patients and carers understand the discharge process. It is important because research shows that access to information is crucial so that patients are carers can fully contribute to decisions about their care (Huby, Stewart, Tierny & Rogers, 2004). Furthermore, this consultation highlighted that patients and carers need and want information about their discharge, those who felt they were given insufficient information speak about the anxiety this causes. Omitting input from patients and carers could increase the likelihood of readmissions and could have serious implications for those being inappropriately discharged.

**Suggested Improvements**
This report will give some key suggestions for improving hospital discharge, but these should not be regarded as a definitive list. One of the aims of this report is to provide an overview of the patient and carer experience of hospital discharge to help Health and Social Care teams to understand discharge from the service user perspective. Therefore it is advised that teams make their own recommendations for improving the patient experience by referring to the user testimonies found in this report. A full list of all recommendations can be found at the end of this report. Suggested improvements for discharge planning, communication and information are:

1. Greater patient & carer involvement; and where appropriate a family centred approach to discharge planning and decision making.
2. Improved communication around assessing needs, discharge notice and the timing of discharge.
3. More accurate needs assessments.

**2. Day of discharge and the transition to a community setting**

Patients did not generally make criticisms about discharge lounges; they tended to be dissatisfied about the duration of time they spent in them. Some commented on the discomfort of sitting in chairs for several hours. Others refer to the anxiety of not knowing exactly when they were going to be discharged and were frustrated at not being kept informed about their
discharge and the causes of delays; this is consistent with HEFTs own survey data and findings from the BACOP survey (2009).

Consistent with findings from the Health Scrutiny Board, the HEFT survey and BACOPs survey many attributed the prolonged waiting period to the delay in receiving their medications, HEFTs survey data shows that forty-one percent of patients have delayed discharges due to delays in receiving their medication. Some felt this could be overcome by giving patients prescriptions to take home. Another interviewee suggested that medicines should be prepared the day prior to discharge. This is consistent with advice given in an NHS toolkit on hospital discharge (Achieving timely simple discharge from hospital, Mullally & Alberti, 2004).

Many of the interviewees returned home during the Christmas period when there were severe weather conditions; some returned home to very cold homes with little or no food. One interviewee (Edward) talks about returning home with no food and being unable to walk to buy provisions. In comparison another interviewee (David) describes his experience of being provided with basic food for his return. In contrast Violet explains that she made enquiries about obtaining provisions from the hospital but was told that this was no longer policy. There appears to inconsistency across HEFT for ensuring that patients are returning home to a suitable environment with adequate food supplies. Greater attention is therefore needed to address these concerns as previous research also shows that older people being discharged are worried about practical tasks such as shopping, cooking and cleaning (Cunliffe et al., 2004). Addressing these issues will help to alleviate some of the anxiety older patient’s face when returning home; particularly those with no support networks.

In some cases interviewees describe a ‘seamless’ transition from hospital to home. In such cases interviewees refer to accurate needs assessments and good communication between patient and carers and also refer to good communication between hospital and social care teams. It is important to note that this is highly consistent with HEFTs own policy on discharge. These examples demonstrate the importance of an integrated health and social care system with good communication procedures in place; this is consistent with how discharge policy is outlined in the National Service Framework for older people. Poor communication between health and social care systems has been found to lead to hospital readmissions (Witherington et al., 2008) so has financial implications for the NHS. Research suggests
that in most cases poor communication is caused by insufficient information being passed onto social care agencies. Therefore improved communication between HEFT and social care agencies will not only reduce costs associated with avoidable re-admissions but will also alleviate the anxiety experienced by carers and patients who commented on the difficulty of seeking support from social care agencies after being discharged.

The provision of information prior to discharge was seen by many to be a major shortfall of their discharge experience. Some patients were not given any information about their health condition; some wanted information detailing actions to be taken if complications or relapses occurred. These findings are in line with recommendations made at the Stroke Associations carer and patient event (2011) and from BACOPs survey data. Bull and Roberts (2001) and Huby et al. (2004) suggest that access to information about their condition, treatment and available services is crucial for both patients and carers; such information can avoid unnecessary readmissions but also avoid unnecessary suffering. Additionally the provision of information can empower patients and give them the confidence to manage their own conditions.

Both patients and carers refer to returning back to a community setting with no information about agencies or organisations who could offer support. A consultation carried out by the Stroke Association on patients in Birmingham, Solihull and Sandwell found that many patients and carers want a review to take place prior to discharge explain what will happen after their return home along with information about local agencies (Stroke Association, 2011). This is an important issue to address because many patients and carers talk about the stress and the isolation caused by not knowing where to go for support and advice.

Finally, many interviewees commented on how the process of being discharged from hospital made them feel. Many refer to feeling rushed to leave their bed; often with little notice and felt that this was handled in an insensitive manner. Hospitals are under a great deal of pressure to manage the mismatch between when a bed is needed (patient admitted) and when a bed is available (patient discharged) to avoid incidents of bed-blocking. It is clear from patient testimonies that they are aware of this issue; therefore it is important that health teams improve how patients are informed about their discharge.
Some patients perceived the conduct of hospital staff to be very poor and stated a preference for a more person centred approach to their discharge. In one incident a patient whose speech was severely impaired by his stroke felt as if he was being spoken to like an ‘animal’. Others feel because of their age they are made to feel ‘invisible’ and are not treated with respect. Greater awareness is therefore needed among staff involved in discharge about how current discharge practice (particularly communication) impacts upon older people’s perceptions of the treatment they receive. All patients have the right to make decisions about their own health, particularly about their treatment and their on-going care. Many older patients in this consultation did not feel they were given any choice about their care and some felt they were not treated with dignity and respect. Agencies involved in discharge therefore need to consider how they communicate with older patients and ensure that they involve patients as fully as possible in decisions about their care.

Suggestions for improving hospital discharge

1. Discharge lounges should have a variety of seating/reclining options.
2. Patients should receive support in staying mobile whilst waiting in discharge lounges.
3. Medicines should be prepared the day prior to discharge or patients should be given prescriptions to take home.
4. Checks should be made on whether patients will have support upon their return home; where appropriate patients should be given basic food supplies or referred to social services.
5. Information about ongoing treatment should be given alongside instructions should complications occur.
6. Both carers and patients should be given an information pack containing details of organisations who offer support.
7. Hospital staff should improve the way they communicate with elderly patients; especially for patients who have difficulty communicating.
Community Support

Some interviewees received care at an intermediate care centre before being discharged home. Both carers and patients talked positively about their time in intermediate care and discuss the good relationships they built with staff. For some, intermediate care provides a motivational effect whereby observing other residents reaching milestones spurs them on. Intermediate care was also seen to provide residents with the confidence to return home.

Some patients returned home without a care package in place or follow up care arranged. In many cases patients were eligible for funding which should have been arranged prior to discharge. In some cases patients and carers were able to identify poor communication between health and social care and recommend better communication between the two systems.

In 2002 the Health and Social Care agent team was created to support the implementation of the National Service Framework for older people. The aim of this framework was to develop a single health and social system and partnership working with local agencies. It was evident from many carer and patient testimonies that this did not occur; some patients returned home without any contact with the social care system. When support and funding was arranged prior to discharge interviewees tended to see a social worker prior discharge. However some patients and carers highlight that this only took place because they ‘learnt how the system works’ so arranged this for themselves. Carers especially feel that this should be happening automatically and talk about the frustration of ‘fighting for everything’.

The DoH has also issued guidance on the discharge and care of elderly patients and advocates carer and patient consultation. The aims are ‘to ensure that older people are treated as individuals and that they receive appropriate and timely packages of care that meet their needs as individuals, regardless of Health and Social Care boundaries’.

A common concern in this consultation was the difficulty in obtaining support from social services after returning home if it wasn’t discussed and arranged in hospital. However, for a variety of reasons some patients actually declined offers of support from social services. Some did so because they feared that it would be regarded as an admission of being unable to cope which may result in them being transferred to residential care. Others felt
that the involvement of social services would have delayed their return home whilst others felt that they or their family/carers were able to cope. Social care teams therefore need to be aware of these perceived barriers to accepting support and establish new techniques for providing this information.

It is also important to note that some patients and families will not need to see a social worker because they do not meet the criteria for substantial or critical access to services. However for some there was still an expectation that they were entitled to this support. It is therefore important that communication is improved with patients and families so that they have more realistic expectations. This is in line with recommendations made in the report on delayed discharged produced by the Health and Scrutiny Board; it recommends that communication about discharge with families should start as early as possible.

**Suggestions for Improving Hospital Discharge**

1. Better communication between health and social care should take place.
2. Patients who need the support of a social services should see a social worker before being discharged.
3. Patients and carers should be given contact information for social services and/or community support agencies before returning home.
4. Perceived barriers to accepting social support need to be reduced; Social Services need to consider current communication methods.

**Limitations of this consultation**

There was a great deal of difficulty recruiting participants for this consultation. Many who had recently been discharged did not feel able to take part in this consultation; especially if they were still receiving care. Those participants who did take part often did so because they were dissatisfied with their experience; this is common with consultations of this
nature. Therefore feedback can often be negative; however we have balanced this with examples of good practice highlighted by participants.

Another limitation of the consultation is the omission of staff testimonies; this was because the remit of this consultation covered the inclusion of patients and carers only. Whilst recruiting participant’s we contacted several agencies whose staff recalled stories and made recommendations that did not appear in any patient and carers feedback. For instance some agencies commented on the high number of patients discharged over the Christmas period to cold and homes. A sheltered housing scheme manager commented that hospital staff mistake sheltered housing (independent living) for care homes and therefore discharge patients without conducting needs assessments. Future work should include consultation with staff to consolidate findings and recommendations found in this report.

Conclusions

Communication and the provision of information was the dominant theme to emerge from this consultation and mentioned at every stage of the patient journey.

Older people are not always consulted about the planning of their care. It can be difficult to develop procedures for the greater involvement of older people because they are far from being an homogenous group. This is partly because of the sheer diversity of their care needs, partly because different people may want different levels of involvement, but also because different people have different needs and can experience a range of problems in communicating their needs. It is therefore important to develop the means of effectively ascertaining the views and preferences of individual older people and their carers in decisions about their care, whilst ensuring that they are treated with dignity and respect. Patients and carers experiences will be improved if they have more information about their care and are involved in making decisions. Patients’ perceptions of the NHS are influenced by experiences of their journey through the system. Negative experiences of hospital discharge may deter them from seeking early medical treatment on future occasions, so it’s important to understand what aspects of the patient journey work well.
We have an ageing population and it is anticipated that by 2030 there will be over 73,000 older people living in Birmingham East & North and 53,000 living in Solihull which will put considerably more strain on the health and social care system. It is therefore important to explore the current system from a variety of angles; including the service user perspective.

Despite a plethora of research and changes in policy many of the issues and concerns raised in this consultation echo those found in earlier studies. As we strive to deliver more efficient and cost efficient services we must not forget the user voice. Consulting with patients and carers about their journeys is crucial to improving the patient experience and making the best use of limited resources.

**Summary of recommendations**

1. Discharge planning must include greater patient & carer involvement. Where appropriate a family centred approach to discharge planning and decision making.
2. Better communication around assessing needs, discharge notice and the timing of discharge.
3. More accurate methods for assessing patients need to be carried out, for instance some suggested that assessments could be carried out in patients homes prior to discharge.
4. Discharge lounges should have a variety of seating/reclining options.
5. Patients should receive support in staying mobile whilst waiting in discharge lounges.
6. Medicines should be prepared the day prior to discharge or patients should be given prescriptions to take home.
7. Checks should be made on whether patients will have support upon their return home; where appropriate patients should be given basic food supplies or referred to social services.
8. Information about ongoing treatment should be given alongside instructions should complications occur.
9. Both carers and patients should be given an information pack containing details of organisations who offer support.
10.
11. Hospital staff should improve the way they communicate with elderly patients; especially for patients who have difficulty communicating.

12. Better communication between health and social care is needed so that patients experience a seamless transition.

13. Patients who need the support of social services should see a social worker whilst in hospital.

14. Patients and carers should be given contact information for social services before returning home.

15. Perceived barriers to accepting social support need to be reduced; Social Services should consider current communication techniques. Further investigation into perceived barriers is recommended so that suitable communication methods can be found.

References


HEFT survey Data (July 2010).


Appendix 1

Demographic Information for focus group participants

All demographic data relates to patients; when carers were interviewed they were asked to give details of the patient.

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**Reasons for hospital admittance**

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**Locations patients were discharged to**

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Appendix 2

Demographic Information for interviewees

All demographic data relates to patients; when carers were interviewed they were asked to give details of the patient.

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*for 2 carer interviews 2 or more carers were presented. In total 57 people were consulted.

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**Hospital sites**

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*Other includes breathing difficulty, hip replacement, bypass, eye operation, pneumonia and lung infection

**Locations patients were discharged to**

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**Ethnicity of patients**
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