healthwatch
Nottingham & Nottinghamshire

Discharge of over 75-year-olds from Nottingham hospitals

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Comment from patient

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Executive Summary

Between June and December 2019 Healthwatch Nottingham and Nottinghamshire (HWNN) interviewed older people to explore the issues they were facing as they transitioned from health into social care. HWNN did this by interviewing older patients and their family members before, during and after discharge from Nottingham University Hospitals (NUH).

HWNN interviewed 21 patients and 17 relatives. The number of interviews was 48: 29 before discharge, 13 during transition (a few days after discharge) and six a month after discharge. The patients were all admitted to acute wards at NUH and had varying lengths of stay.

The interviews showed very mixed experiences of the transition from health to social care. Whilst the care in hospital was good, most of the patients and relatives interviewed did not feel that they were well enough informed or involved in discharge arrangements. They generally did not have written information explaining the options available to them. Realistically, they need this in all cases, to allow a considered choice. Options available also need to reflect ideas of how long they might take to organise. Patients and relatives have shown that they are willing to compromise in care arrangements on discharge, but they need to understand the trade-offs involved.

Patients and family were often not sure who was organising the discharge and/or social care support. In some cases this led to time-sapping back-and-forth discussions with staff attempting to clarify what was happening. At other times, they have avoided asking, to spare staff, but creating worry over future arrangements. It was “the little breaks in communication” that often caused confusion and anxiety. These breaks related to continuity of healthcare as well as transition to social care. Of particular concern are issues around changes in medication not being successfully communicated to GPs and pharmacies. Whilst some patients are well able to manage their own medications, others need support, and this support is of limited value if there are uncommunicated changes in prescriptions. These issues could be reduced by having a Discharge Co-ordinator involved in all discharges and by introducing a ‘Leaving hospital – what do I need to know’ checklist similar to the one created by Healthwatch Surrey.

Related to this, delays to discharge due to waiting times from the hospital pharmacy cause specific worries for relatives over timings. Delays can clearly be several hours, and where relatives are either transporting patients or waiting to receive them, this is an added and unneeded burden.

The interviews in this project have demonstrated very clearly the effects on mental health and confidence of the long time some patients waited to go home. Patients do often regain resilience once they are home, but inevitably it takes longer after extended stays, adding to the burden on care services at home.

Social services assessed people for short term support, care packages or admission to a care home, initially on the wards and then, at home, for ongoing care after reablement. Most people understood that the short-term support was free but were uncertain how long it was for and what would happen afterwards. Service users, and their families, need to understand “what happens next?” before the current support ceases to be delivered. In addition, for patients who are living with dementia, it is vital to consult with family members to get a rounded view of their care needs on discharge.

There are many challenges involved in the delivery of services to make the transition from healthcare to social care seamless, but where the system works it makes a large difference to the happiness and wellbeing of vulnerable elderly patients and their families that support them.

Recommendations

- Consider using a discharge checklist such as Healthwatch Surrey's Leaving Hospital (NUH)
- Ensure everyone who needs the Home First factsheet receives one and understands what it is for (NUH)
- Improve the process around medications on discharge to reduce considerable delays on the day of discharge from hospital (NUH)
- Ensure relatives and carers are included in discharge planning where needed (this is Question 1. in Leaving Hospital) (NUH)
- Ensure patients and their relatives are clear about the difference between reablement, short term support and care packages, including payment and timing (Social Services)
- Improve communication between NUH and community health services to ensure continuity of care where it is needed e.g. continence, GP surgery (NHS)
- Consider ways in which the VCS can support people being discharged, in particular, those who live alone (whole system)
- Note how patients and family value people and services such as the Discharge Co-ordinator (NUH), the ward receptionist, the Hospice and Connect (whole system). In supporting patients and smoothing the pathway of the discharge process, such services and help will save time and improve outcomes

Introduction

Between June and December 2019 Healthwatch Nottingham and Nottinghamshire (HWNN) began interviewing older people to explore the issues they were facing as they transitioned from health into social care. HWNN did this by interviewing older patients and their family members before, during and after discharge from Nottingham University Hospitals (NUH).

The project aimed to understand and share with decision makers the experience, of people aged 75 or over, of discharge from NUH through to receiving care at home for the first time.

The questions the project aims to answer are:

- What are older patients' experiences during transition from Health into Social Care Services and the effects of such transition on themselves, carers, family and friends?
- How older patients feel about the transition from Health into Social Care Services; in particular, were they aware why certain arrangements had been made? Were they kept informed with what was happening and did they know what their patient journey would be?
- How the transition from health into social care services can be improved to be more patient-led and better serve older people undergoing this change.
- Were assessment processes aligned, integrated and timely?
- Were patients and carers consulted or involved in any aspect of the transition process?

Background

Discharge from hospital is often a complex process for older people and can be delayed. Nationally, according to NHS England's definition, approximately two thirds of all delays are attributed to the NHS and one third to social care. Monitoring by NHS England shows that 20.8% of all delayed transfers of care were due to patients awaiting a care package in their own home. Delayed Transfers of Care Annual Report 2018/19

Delays can mean that beds are not available for other patients, including those admitted in an emergency. While it is important that patients are not sent home before they are ready, the effects of people staying longer in an acute hospital bed can lead to an increased risk of infection, low mood and reduced motivation. Kings Fund Guide to Delayed Transfers of Care

Research by the Royal Voluntary Service also showed that although most people want to get home as soon as possible, many also feel anxious, depressed and frightened. This was found to be especially true of people living alone - nearly half of people aged over 75 (46%) who had been in hospital within the last five years were living alone. Going Home Alone

The Nottingham and Nottinghamshire Integrated Care System (ICS) is committed to joining up work between health and social care teams, providing the right care in the right place and acting on the needs of local communities. The ICS Primary Care Strategy Nottingham and Nottinghamshire ICS Primary Care Strategy 2019/20 – 2023/24 says that there has been a 17% increase in inpatient episodes in those aged over 75 in the last 3 years and recognises that many patients have more than one health or social care need.

This report describes the experiences collected by HWNN of people 75 or older being discharged from hospital and their family/friends around them, to having care at home for the first time. These experiences will help inform what can be done to improve the transition from health into social care.

Our approach

Experiences were collected by interviewing a patient and their family or friend before, during and after discharge from hospital. HWNN developed a structured interview questionnaire based on a review of national and local policy and plans about hospital discharge; also a helpful checklist designed by Healthwatch Surrey, Leaving Hospital; in consultation with the Nottingham and Nottinghamshire Integrated Discharge Board and older people.

HWNN were guided by NUH staff who identified patients, family and/or friends, who met the criteria and were willing to be involved. The criteria for taking part in this project were:

- Inpatient at NUH aged 75 or over
- Patient willing and able to take part in three interviews: one in hospital, one a few days after returning home and another 4-6 weeks after discharge
- Two other people 'around' them (family members or friends) available for three interviews (as above)
- Patient discharged and going home or to residential care

HWNN interviewed six patients and their family members, a total of 54 interviews. The project included patients from across south Nottinghamshire, that is: Nottingham City, Gedling, Broxtowe and Rushcliffe. Due to the logistics of organising the interviews, only three family groupings took part in all three interviews. Patients and family often did not wish to take further part after discharge; they were focussing on getting on with their lives and didn't necessarily want to look backwards to the process that got them that far. Further, some patients inevitably became ill and were readmitted to hospital, interrupting the chain of interviews. Finally, family and friends sometimes demurred, feeling they did not have sufficient involvement with the family member's care to be able to meaningfully comment.

The project increased numbers by continuing to recruit people over a longer period and asking people through a radio call out, who met the criteria, to take part:

- The number of patients was added to over the time of the study and in some cases only relatives were interviewed
- The total number of people interviewed was 21 patients and 17 relatives
- The number of interviews was 48: 29 before discharge, 13 during transition (a few days after discharge) and six a month after discharge
- The interviews took place between June and December 2019
- Members of staff were very helpful in identifying patients; however, they did not have time to be interviewed themselves
- At least three patients were readmitted.
- The age range was wide: three patients were aged 65-74 and three were over 90 years old
- 10 patients were female and four were male (there were more females than males able and willing to talk. Also, older males tended very much to be going into care homes rather than going home, from comments by the Discharge Coordinator)
- Five patients were from Nottingham City and eight from Nottinghamshire, including one patient from North Nottinghamshire. One patient was from outside the County.
- 12 out of 14 had a disability

A table showing the demographics of the patients interviewed is included at the end of the report in Appendix 1. Demographic information was collected for 14 out of the 21 patients interviewed. In addition, following the radio call out, relatives only were interviewed for a further five patients.

Summary of findings

The findings are discussed under four headings: before discharge, during transition, after discharge, and patient and family members journeys.

1. Interview One: Before Discharge

Most people (29 out of 38 patients and relatives) took part in interview one which asked questions while patients were in hospital waiting for discharge. All the people interviewed were asked if they had been given the Home First factsheet, explaining about social care support to help patients get home from hospital more quickly. Only three out of 29 people said they had.

Patients described having differing needs in terms of health and social care support on discharge and therefore different expectations about the process. For example, one person said *"I haven't actually been told I will be given any care at all. I'm not complaining, I haven't expected any."* Similarly, another said *"They just said they'd send me home and see what I can do."*

The findings below focus on patients who did require and receive social care at home or were moved to a care home. Patients' and relatives' experiences of transition from health into social care, and consultation about the assessment and transition process, centred around several themes:

- Communication about discharge and the transition to social care
- Feelings about discharge
- Delays to discharge
- Medication
- Dementia

Communication about discharge and transition to social care

Several people interviewed were happy about communication and their involvement in discharge planning. One person said: *"I think they've communicated with us pretty well."* Another relative said they were happy with the help they had received from the social worker: *"Having the name of the social worker, who I've met and spoken to and have been able to talk to by phone. That's the good bit."*

Eighteen people out of 29, however, felt that they had not been consulted or involved in discharge plans. For example, some patients had not been spoken to: *"I don't know what's going to happen. I think I should go in a home but I'm not sure that it will work out like that. Nobody has done anything about it. No one has talked to me properly about it."* Another said: *"I don't know. I've not heard anything about it, but they said something about social services. Yes, but I've not seen anybody."* Sometimes the relatives were asked whether the patient had support at home: *"We've been asked some questions about will he have support when he goes home. But other than that, no."*

Overall, people wanted more communication and involvement in discharge planning and for relatives to be included in this. One person said they wanted: *"a bit more communication. It would be nice for them to come back to you."* Another relative spoke about the need for *"transparent communication to key family members … for the patient. So, because she may need to go into rehab. I don't know where the rehab would be… nothing's been communicated at all."* Patients themselves wanted family members to understand the arrangements being made: *"It's a good job my [relative] came to see me today or she wouldn't know anything about it."*

One relative was concerned about pressing the staff: *"…because they might think I'm being abusive. You know they've got zero tolerance policy and all this business. I don't want to be having a go all the time at her because it might get on their nerves you see."*

Another relative talked about the use of language and whether people understood different roles and job titles: *"I think the communication was quite difficult. It was quite confusing as to who was doing what. So, I would go into the hospital or ring my [relative] and I would have different stories, some of which, I think, were about his confusion and misunderstanding. My other [family member] is also heavily involved, and I don't think they realize that people don't understand some of the things being told. For example, my [family member] contacted me to ask me what an OT was."*

There was some acknowledgement that ward staff themselves did not always have the full picture. *"I think they know what's going to happen, they just don't know when it's going to happen."* Patients did also acknowledge that their journey could be unpredictable, for example: *"I think we were told as much as anybody knows. So, yes, it's a step-by-step processing, isn't it, because it's dependent on the results of various tests and investigations, and nobody knows in advance what they're going to throw up."*

People especially valued the role of the Discharge Co-ordinator where this was available. *"Well it's very good. There's a lady that's a sort of a co-ordinator. She'll inform me when social services are ready to get a package. That's good, because it doesn't leave me to ring them up all the time to find out what the situation [is]. So I think they're very good in that respect. They're going to sort it on my behalf."* One patient also said: *"The Discharge Coordinator was here, and so was my [relative]. They sorted it out between them, so now I just go along with it to be honest."* The Co-ordinator was available on one ward and when away, the Deputy Ward Managers had to undertake this in addition to their own role, which they said could cause delays.

The role of the Ward Receptionist was also valued by family members, as she was approachable and capable of explaining issues and terminology that they hadn't understood when approached my nursing staff.

One family also particularly valued help from the mental health team who were assessing their relative for hallucinations: *"The mental health team, I spoke to them this morning. They have been doing an assessment. They do want to do follow-ups. To be fair, they've been really good, the mental health."*

Feelings about Discharge

Altogether 29 patients and family members were asked whether they/their relative felt ready for discharge: of these 16 said they did feel ready, five said no and others had mixed feelings. Some patients wanted to get home as soon as possible: *"I want to get back. The feeling of wanting to, should give you enough reason to. You've got that incentive really that you want to get back to your home."* Another patient wanted to see her cat: *"I can't wait to get home - get my cat back."*

However, some patients did not feel ready, were anxious, depressed or did not feel confident. In some cases, patients felt they were being discharged too early:

"I don't know yet because my legs don't work very well"

"I can't walk at the minute properly. I'm not able to look after myself properly at the minute. I'm now at Lings Bar."

"I just don't feel competent at the moment to go on my own to the toilet."

For others, their feelings showed a lack of confidence or fear of going home:

"I don't feel poorly still, but I'm still anxious to work out how I'm going to get on with things."

"She is getting depressed and so may go downhill"

Others acknowledged they could go home with support:

"If I get a little bit of help, I can cope"

The feelings expressed in these quotes underline the effects of inpatient admission on older people highlighted by the Kings Fund, including low mood, reduced motivation and a decline in muscle strength due to long periods of immobility in a hospital bed. While people need help when they get home, the delay in arranging care can worsen their general physical or mental health.

Delays to discharge

Many patients were keen to go home, and disappointed when they felt their discharge was delayed. It is not possible to discern from the survey how many patients' discharges were delayed according to the NHS definition, however some patients and relatives did feel that their discharge was delayed. Of the 15 patients who said they had a planned discharge date, six definitely went home on that date and at least seven people said they were ready to go home but were waiting for a care package and/or reablement, as described in the examples below.

"I spoke to a guy, last week about Wednesday, Thursday and he said he'd sort my [relative's] discharge out and he was going to organize carers morning and night. I said to him, 'How long will this be?' He said we should do it by the weekend and we're still no nearer to that date and my [relative's] well peeved off because [they] could be at home and could walk about at home."

"We're waiting for them to organize a package, a care package. I just want to get out. I've got a nice home. I've got a nice garden. I want to get out to enjoy them."

"… it was a plan that they wanted five days a week with three home visits and I left it with them to sort out, but it took a while. Now, we've had to cut it back and we're back to a shorter package which I have accepted. I feel happy about it because it's going to get me home sooner."

"Well there are two things. One is when [they're] ready, which is a medical thing so that's not to do with me, but I was aware of it, and the second thing is the type of support [they'll] need. Again, yes and then it's just basically it's a black hole of waiting, and I have had to chase that because they just go quiet."

People said what they would have appreciated was *"a plan with timescales would be helpful."* Even those patients who were hesitant generally recognised they would be better off at home: *"Let's put it this way, could be a lot faster."*

Medication

Medication and changes to medication were often particularly confusing. Some patients did not have a lot of medication or had had no changes. At least 14 out of 29 people said that there were changes and several of these said they were unclear. One patient said: *"I don't have a lot - don't know how to take them."* Another said that the hospital had tried to reduce their medication and that whilst they knew what to take: *"I don't know what the names are or anything like that, you see. I can take them, take the whole lot because that's what I'm supposed to do, but whether there's a particular way of doing it, I don't know."*

Family members were concerned that patients did not know how to take their medicines: *"[My relative] needs somebody to give it to her. It's a blister pack, she gets a blister pack. She doesn't understand it. I tried to explain it one time to her, she still can't understand it. I've had to do it for her."* Some other family members and carers took care of patient's medicines themselves: *"I actually can't tell you the truth of that because my family deal with it"* and *"It hasn't been discussed yet, but the carers do my medication. I don't touch it."*

Dementia

All the patients interviewed were on acute wards at NUH; six patients were described as having been diagnosed with dementia. There were sometimes differences in the views of relatives and services. One family whose relative had been diagnosed with dementia several times said that social services did not agree: *"I think it was the fact when I told them that we're in this situation because social services think she has capacity, I think we got the eye roll at that particular time."*

People with dementia may also present well and say that they can do their own cooking, cleaning, washing, shopping, etc. *"That is not the case. She is totally reliant on us. I understand that, obviously, my [relative] has to be listened to as an individual, but we find that quite often we're not listened to as carers."*

Findings nationally, by the Alzheimer's Society in 2009, showed that people living with dementia often need a higher level of care and are more likely to be discharged to a care home. One relative said: *"I'm concerned about her getting dementia-type attention that she needs."*

2. Interview Two: During Transition

The number of people who took part in the second interview, during transition, was 13. Most people preferred to deal with the follow-up interviews by telephone rather than be visited. The themes which emerged from the second interviews were similar to interview one, although the period of transition did raise the most difficulties. The key themes were:

- Communication about discharge and the transition to health and social care
- Delays to discharge
- Aids and adaptations
- Medication
- Care at Home or in a Care Home
- What was good and what could be improved about discharge
- Living alone

Communication about discharge and the transition to health and social care

The second set of interviews, during transition, gave the following six examples of the confusion patients and relatives experienced in terms of continuity of health and social care. The first three examples are about referrals for health care. First, one patient needed a district nurse: *"I was supposed to get a district nurse. She didn't seem to arrive and because I've used district nurses before, … I knew that you could speak to them. I rang up the surgery. They gave me an emergency hot number, I rang that and told them. They said they haven't received a referral, but they would send an emergency district nurse."*

A second family said they were waiting for the community nursing/continence service because their relative had a catheter: *"Presumably, they will have to assist [our relative] in managing that and just keep an eye on it, but they've not been as yet... A constant question I am asked by my [family members] is, Will the hospital know this? Will the GP know that? Will the community nursing service know the other?"*

There was also some general confusion about whose responsibility it was to contact the GP surgery. *"Her blood pressure should be checked the first week she's back, but she said that no one's done that. Now I don't know if I've got to ring the doctors and arrange it or - I'm guessing I've got to ring up and arrange someone to see her."*

Patients experienced similar problems in communication between the hospital, care homes and relatives. One person described how her relative was discharged twice to the care home which then sent her back to hospital. *"They sent her back to hospital, and then the hospital has now released her to go back into the home again. I was on my way to the care home; I had a phone call to say they sent her back into hospital in the same ambulance that they dropped her off in. I said to them, 'Somebody somewhere has not done their job properly'."*

Another relative said they were not told when the patient was being moved. *"There's no communication at all. The ward got the phone call to say my [relative] was being moved on Friday, the respiratory nurse had the phone calls to go and do this assessment so the oxygen could be waiting*

at the care home. The people that should have known, like [us] weren't told. So, I didn't know until five o'clock on a Thursday that the next morning she was moving out."

And again, some relatives said that they had not been consulted and that the discharge was rushed: *"I think it was rushed quite a lot. Like I said, nothing was discussed really much with the family as to when she was discharged to what needed to be done. They did before that, as we were sort of looking at being discharged, but I think as soon as she was found medically fit, it was 'right, we need her out of the bed.' Then, everything got rushed sort of."* Better communication between hospitals and GPs, health and social care staff and health and social care staff and patients and relatives would alleviate these issues.

Delays to discharge

Three of 13 people complained about delays to discharge, mainly due to waiting for care packages and of these, two patients did not take part in interview one, meaning that nine people altogether felt their discharge was delayed. One relative explained: *"… my [relative] has been stuck in hospital eight weeks, her mobility is going, her mental state is going. Then I don't like to ask but is there anything you can do to push this situation along because at the moment she wouldn't be able to go home, she just needs that support to get some mobility back?"* This person was not happy with the response she received: *"I've made umpteen phone calls to social services and I cannot get anybody to pick that phone up. I've even gone through to their head and I got so abused it was surreal. Verbally abused."*

One patient said that they were not getting any care: *"Stayed in hospital an additional week for care to be set up. Not happened, been forgotten about, promises of help not fulfilled. Would like help in morning to get dressed and washed, can't put socks on. Manage during the day and able to cook etc. Not received anything from social services."*

Another relative talked about the effect of staying longer in hospital. *"She's not improved. She's gone downhill. It's nothing to do with the medical health that she had. That was fine. It's just the length of time that they are actually sitting in hospital waiting to get out. It's also affected her mentally as well. She is very low, very depressed and that we just can't get her out of that. At the moment she's starting to improve these last couple of days [after being discharged home with carers]."*

Some of these comments again suggested patients needed to regain confidence – delays to discharge have led them to lose confidence, meaning they have a harder time readapting once home.

Aids and adaptations

Some people were already using aids and adaptations before going into hospital: *"Well, yes, I have a walking stick and I've got a walker, one of those four wheels walkers."* One relative however observed that: *"Yes, she has. She's got everything. They gave her everything that she needed, unfortunately she just doesn't use it, hence the reason why she ended up on the floor."*

Most people who responded (9 out of 12) did receive the aids and adaptations they needed, and one person mentioned the Red Cross specifically: *"the Red Cross came and they put some more in the house for her. She's got something on side of the bed for her and she's got another tray that's come as well, she's had the new walker as well."* Similarly, a family member said *"Yes, she's been given a frame. They're coming to do a new bathroom for her tomorrow. Two weeks."* However, there were exceptions: *"Ordered walking stick, stool for bath but not received. Ended up buying walking stick."* In one case this meant the patient was unable to get to the toilet: *"There was a commode to be delivered and they delivered the frame and they didn't deliver the bucket, which was great…then, I get a phone call at three o'clock in the afternoon,… saying, 'You're going to have to come home, because I'm going to have to use the outside toilet because I've come home and there's no commode bucket yet'."* Therefore, it is important to offer this type of support before it becomes critical and leads to delays in discharge.

Managing Medication

Six patients and family members out of 13 felt they or their relative was very able to manage their medication: *"She has all of them at home with her, and she knows exactly what she takes. She knows when to take them, she knows how much. She knows them better than anybody."*

Patients and relatives often felt that help was needed with medication: *"Yes. Obviously, he's fairly alert, he's fairly intelligent, but he's worried that he'll forget to take some of the medication."* Another relative said: *"Yes, well, I've written on the box when she needs to take it. Yes, otherwise, she won't know."*

Where medication had changed, this also caused confusion: *"I reckon I've got too much. The hospital gave me a load of meds, we checked that they've got it in … Trying to sort out, I think it's about 10 tablets a day, some have got to be taken in the night and some in the day. It gets very confusing."* Again, it therefore is important that there is communication with relatives to make sure they understand the medication.

Care at Home or in a Care Home

Immediately after discharge, most patients (five out of nine) received care at home or had moved to a care home (one person). Some people were very happy with the care: *"I think it's a good level of care that she's getting at the moment in the rehab home."* And *"Yes, she really likes the one coming in the morning because she gets her out the bed and helps her to shower. She was obviously a bit frightened of falling over again, so that works well in the morning."*

Several people were receiving reablement: *"They're not going to do everything for somebody that - we're trying to rehabilitate them, but I think some of it might be pushing a little bit too far when they've only been home two or three days."*

People were not always clear when the reablement (which was for a limited time) was due to finish: *"Probably more communication with somebody that's involved with the family member because I have doubt that she spoke to any carers. Yes, because I was actually going to make a call to the person that's providing the care and ask him when it's due to finish."*

Most people did understand that reablement was paid for by Social Services but that, if they had money, they would probably have to pay for ongoing care: *"The guy said … he wouldn't know until after they finished and Notts County Council worked out how much it was. They will do but I don't think she'll have to contribute."*

Others did not need ongoing care: *"she does everything herself. That's why the carers finished because she was doing everything herself."*

What was good and what could be improved about discharge

There were some very positive comments relating to the staff on the wards: *"I think the staff on the ward were lovely. The nurses and healthcare assistants were really lovely. Told us what they could tell us, but it felt like they didn't know what was happening. They were very polite, always very apologetic, always trying to keep us informed. You couldn't fault the care we got on the ward at all."* Another relative said: *"It went very smoothly. They were helpful, and they gave her a nice send-off, I think. The ward, the staff."*

One patient talked positively about the discharge lounge and Arriva: *"Once I was in the [discharge] lounge, the people there were all right because you could get coffee, water, they were serving lunch. I could get to the ladies. I just had to ask where it was. The only thing that I bothered about was, was I going to get home in time. When I asked, it got sorted… Arriva, they were very good."*

One relative particularly mentioned Ward B49: *"The lady who refers to herself as a receptionist is also very helpful on B49 … I was particularly impressed this time with B49. When she was in the last time, it was not a nice experience for me. This time the staff were very open with me. Last time I felt as if I was in the way with the other ward, but this time it was good."*

However, there were also many comments about what could be improved about discharge on the day.

Waiting for medication: *"It's like waiting for your medication. You can be there hours waiting for that, and yet, everything else is in place for you to come home if medication is not there. I think if they know you're going to discharge the next day, why don't they put in for your medication the day before you're being discharged?"*

Knowing what time a patient was being discharged: *"Let us know, for definite, what time they're likely to be coming out. Because they told me they were booking her a taxi at 10:00, and then they rung me and said, 'Are you okay for her to go in a taxi?' and I said, 'Yes.' So, then they said, about 2:00, that she couldn't come in a taxi, she'd got to go in the ambulance, so it was a lot of mixed messages."*

Time spent in the discharge lounge and lack of understanding of the role that discharge lounges play: *"It's very hard to say this because we get the opinion that she's actually in the discharge lounge for quite a while before they release them. I understand there's a waiting list and things to leave the hospital but we understood … that she went down there to sort of - we was told roughly around 10*

o'clock, she went down to the discharge lounge and she was there till they released her about 5 I think."

Sometimes there were unforeseen events: *"It didn't go according to plan because they discharged my [relative] on the computer and then they realized they'd got a flu epidemic going on in the ward, so they wouldn't release her until a doctor had been to see her and this doctor had to come from Queens to get to City. So, it was two or three hours later than it should have been but that can't be helped."*

Living Alone

It is clear from the interviews that the nine patients represented in interview two live alone which is consistent with the Royal Voluntary Society report Going Home Alone found. *"She's not been out of her flat for two years. She doesn't interact with anyone at all. I'm the only person she sees. Yes, so she's pretty cut off from everyone, but that's how she likes it. She's is in a warden aided flat, so he calls her every day."*

It could be difficult to join in with things: *"When I've gone up there [church] they said, 'Where have you been?' but it doesn't go any further because lots of the friends have still got a partner, they're retired and they're doing the things that they planned. It's only when there's one person left that they realize what it's like to be one person out of a partnership. There's a big difference in that."*

Being in hospital also affected people's confidence to join in socially: *"I still think he's lost a bit of confidence, mentally and socially. He was usually fairly busy - he'd go to coffee mornings and things. [We] are trying to encourage him to get back into doing that. He's got a little bit into, 'I need to rest,' probably more than is good for him."*

Many people were able to rely on family, friends and neighbours: *"I've got good neighbours… to be honest with you, I think I've got a lot of support with my [family and friend] who would definitely come anytime."* However, family are not always available: *"I've got [children] who have got their own family. They try and visit once a week. That's mainly at the weekend, obviously, because they work. Then they've got their children at school as well you see."*

3. Interview Three: After Discharge

Six people took part in the third interview: two patients and four relatives. These interviews took place about one month after discharge and by this time, all these patients were managing well at home.

Themes emerging from interview three were:

- Patients managing well at home
- Medication
- Care at Home or in a Care Home
- Living Alone

Patients managing well at home

The patients and relatives who took part in interview three said they were managing well at home: *"I think he's managing quite well at the moment."*, *"Yes, she's settled back home, exceptionally well."* and *"I'm fine, thank you. My cat has now calmed me down again. Yes, I'm doing everything I need to."* Similar comments were:

"She is great at home now, yes. We have a carer who comes twice a day, morning and night, but the carer in the morning is better because she gets her up out of bed."

"Very well thank you. I don't seem to have any problem as such… As long as it's a slow progress, I'm all right with that."

"She's fine. She's doing really well. She's a lot, lot better than what she was. Like I said, she's still getting around slowly, and I don't think that will ever get better because of the back, but she is getting better."

One was already improving in a nursing home: *"She's eating well and the difference, actually, from the day she arrived to how she was from the first to the fifth when we went back up you could see she's eating well, she's looking better."*

Medication

Two people were concerned about how long they had waited for medication before they could pick their relative up at discharge: *"They say you're going to pick them up at such time, so you go up and the medications aren't ready. I think that's just a general thing at the City hospital."* Another person said: *"The golden oldie, of course, hanging around for your medication and I think nothing new."*

Again, changes to medication caused some confusion for two patients, especially where there was a breakdown in communication between the hospital and the GP: *"The medication was something that was a bit of an issue because he was discharged with some additional medications … the GP then issued a prescription that missed off a great number of the medications. That caused him some distress. I think that was just a mistake… the transition between hospital and community didn't happen very well."* Another patient: *"used to be on a lot of medication and that needs assessing because she's on hardly anything at the moment."*

Care at Home

Overall, after a month, all those interviewed were happy with the health and social care they were receiving at home. The health service had now put in place reviews to manage one patient's catheter and they had: *"…a way of contacting them any time of the day or night if [there is] a problem..." I think it's appropriate and proportionate at the moment..."*

People were also happy with their carers: *"I know they get a breakfast ready for her. I know one helps her get a shower, and then while the other one gets her breakfast ready for her. I know she says they come in the morning and she says she is a really, really nice girl. She says she's really nice and she's really friendly."* Another patient made a similar comment: *"Oh, the carers, yes, they are both nice girls as to that. I've seen two, and they've both been very good, very nice. They've helped me with a lot."*

However, people were not always sure what was going to happen after the short term support ended: *"Don't know after 6 weeks."* and: *"All she says was that they'd come around, they'd assessed the house, the way she lives, and one thing and another, and then they left. She says then they said to her, 'We'll be back in touch,' and I presume that will be when the six weeks are up."*

One patient had moved to a care home and the relatives felt that: *"they know how to care for her, so there's peace of mind that she's not going to be on her own or fall over."* Although they were also concerned: *"…in terms of stimulation, I'm really not sure because they've lost their activities person. I remember one time seeing her sitting and there were only three of them in this room, it's done in various pods so it's not a huge room, but they're just sitting there with the TV on, or without the TV on with two carers in the room and I'm just not sure the mental stimulation is there yet."*

Living Alone

As with interview two, the patients lived alone, except for one person who had into a nursing home. One relative lived elsewhere in the country and said: *"When I disappear, I'm a little a bit unsure as to whether she's going to need a bit more support."*

Friends and neighbours were described as very important to those people who live alone: *"Where he lives there's quite a lot of neighbours that are elderly with various health problems and they provide a lot of support for each other like care to care for each other."*

One person relied on the Hospice: *"Nottinghamshire Hospice one day a week. She did mention a while ago that she would like to go another day there, but I think that's quite difficult to get another day to go to. She did enquire, but I think the waiting list to go is hard to get even onto. Yes, she goes there and then she goes and does her shopping."*

Another patient had had support from Connect: *"There is an organization called Connect. Their leaflet says, 'Stay independent, active and well' It's funded by Nottinghamshire County Council. Initially when [I] came out of hospital, a lady came along and then a couple of weeks ago, another lady came along…she helped fill out an attendance allowance form... If there was anything needed, I think they would be quite helpful actually"*

4. Patient and family member journeys

Three family groupings (one patient and one relative each) took part in all three interviews and five others in two interviews. One of these patients was discharged to a nursing home and the others home with various levels of support, including the START team, reablement or carers.

For the three patients and their relatives who were interviewed three times, they all said they were very happy with the treatment they had received in hospital, particularly in reducing and managing pain.

The experiences of the eight patients (three plus five) and their relatives, during transition and its effects on them, focussed around three key themes which reflect the views given in the interviews generally: communication, delays to discharge and what was good about discharge and their return home.

Communication

Lack of communication is a theme that has emerged throughout transition from hospital to care at home. This is also the case for people who took part in two or three of the interviews. Examples of where people had concerns were:

Between the hospital and primary care: *"There was a little bit of a hiccup because 10 days after he was discharged, he had a bit of a problem with the catheter that he was fitted with and I rang the community nursing service, Continence Service on a Sunday. They were very, very distressed and angry that he'd been discharged and that QMC hasn't alerted them to the fact."*

People were not clear about who was co-ordinating their discharge: *"It's the hospital, they do, don't they?"* or *"I know it's somebody named J., but I'm not sure of his second name. I've only met him twice and he has been in touch with my daughter about it."*

Confusion about language and roles. For example, one family said: *"I think that everybody wouldn't understand what reablement means, what OT is… the distinction between nurses and healthcare assistance and who does what"*

Communication about discharge and transport. One patient had been taken back home when she should have been taken to a care home: *"It wasn't checked through that she was going home. She should never have gone to her old flat. They were supposed to start taking her out of there. If she'd had gone back into her flat before they realised, then they'd never have got back in. It would have been a nightmare."*

Delays to Discharge

Patients were keen to get home and were unhappy when they felt their discharge was delayed. *"Well, I was annoyed because I was bored stiff in hospital - I'd spent six days there."*

The most common reason for a delay was agreeing a care plan: *"Well, at first to me, I was a bit unhappy about it because it went so slow, but then all of a sudden they've offered me this care plan, I've accepted and within two days it's all done sorted and I'm going to go home."*

What was good about discharge

It was good that when people were discharged, the heating was on at home, family had provided food or the hospital an emergency pack, people did not lose any of their personal belongings (keys, clothes, dentures etc.) and they had the right mobility aids. It was also good that by the third interview all three patients who were interviewed three times were settling in at home either *"quite"*, *"really"* or *"exceptionally well"*.

Conclusions

The interviews showed very mixed experiences of the transition from health to social care. Whilst the care in hospital was good, most of the patients and relatives interviewed did not feel that they were well enough informed or involved in discharge arrangements. They generally did not have written information explaining the options available to them. Realistically, they need this in all cases, to allow a considered choice. Options available also need to reflect ideas of how long they might take to organise. Patients and relatives have shown that they are willing to compromise in care arrangements on discharge, but they need to understand the trade-offs involved.

Patients and family were often not sure who was organising the discharge and/or social care support. In some cases this led to time-sapping back-and-forth discussions with staff attempting to clarify what was happening. At other times, they have avoided asking, to spare staff, but creating worry over future arrangements. It was "the little breaks in communication" that often caused confusion and anxiety. These breaks related to continuity of healthcare as well as transition to social care. Of particular concern are issues around changes in medication not being successfully communicated to GPs and pharmacies. Whilst some patients are well able to manage their own medications, others need support, and this support is of limited value if there are uncommunicated changes in prescriptions. These issues could be reduced by having a Discharge Co-ordinator involved in all discharges and by introducing a 'Leaving hospital – what do I need to know' checklist similar to the one created by Healthwatch Surrey.

Related to this, delays to discharge due to waiting times from the hospital pharmacy cause specific worries for relatives over timings. Delays can clearly be several hours, and where relatives are either transporting patients or waiting to receive them, this is an added and unneeded burden.

The interviews in this project have demonstrated very clearly the effects on mental health and confidence of the long time some patients waited to go home. Patients do often regain resilience once they are home, but inevitably it takes longer after extended stays, adding to the burden on care services at home.

Social services assessed people for short term support, care packages or admission to a care home, initially on the wards and then, at home, for ongoing care after reablement. Most people understood that the short-term support was free but were uncertain how long it was for and what would happen afterwards. Service users, and their families, need to understand "what happens next?" before the current support ceases to be delivered. In addition, for patients who are living with dementia, it is vital to consult with family members to get a rounded view of their care needs on discharge.

There are many challenges involved in the delivery of services to make the transition from healthcare to social care seamless, but where the system works it makes a large difference to the happiness and wellbeing of vulnerable elderly patients and their families that support them.

Recommendations

- Consider using a discharge checklist such as Healthwatch Surrey's Leaving Hospital (NUH)
- Ensure everyone who needs the Home First factsheet receives one and understands what it is for (NUH)
- Improve the process around medications on discharge to reduce considerable delays on the day of discharge from hospital (NUH)
- Ensure relatives and carers are included in discharge planning where needed (this is Question 1. in Leaving Hospital) (NUH)
- Ensure patients and their relatives are clear about the difference between reablement, short term support and care packages, including payment and timing (Social Services)
- Improve communication between NUH and community health services to ensure continuity of care where it is needed e.g. continence, GP surgery (NHS)
- Consider ways in which the VCS can support people being discharged, in particular, those who live alone (whole system)
- Note how patients and family value people and services such as the Discharge Co-ordinator (NUH), the ward receptionist, the Hospice and Connect (whole system). In supporting patients and smoothing the pathway of the discharge process, such services and help will save time and improve outcomes

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Appendix 1 Demographics of respondents

Demographic information was collected from 14 patients. Survey respondents n=14

Age groups	No.
65-69	1
70-74	2
75-79	4
80-84	1
85-89	3
90+	3
Total	14

Gender	No.
Female	10
Male	4
Total	**14**

Ethnicity	No.
White	13
Prefer not to say	1
Total	14

District	No.
Nottingham City	5
Broxtowe	3
Gedling	2
Rushcliffe	2
Other	2
Total	14

Illness/impairment	No.
Hearing	5
Mental health condition	2
Physical impairment	11
Visual impairment	1
Other	2
Total	21[1]

Note 1. Includes respondent/s with more than one condition

Disability Count	No.
Number of respondents	12[2]

Note 2: Survey respondents (n=14) – note number of respondents who indicated they had a disability

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