healthwatch
Brighton and Hove

“Let’s Get You Home”

The experiences of older people being discharged from the Royal Sussex County Hospital, Brighton from July to September 2018

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1. "Make it Real" – Executive Summary by David Liley, Healthwatch Chief Executive

The NHS and Brighton City Council are making plans to better integrate health and social care in the City. The way the NHS is managed in Sussex and East Surrey is changing with much closer alignment of Commissioning - purchasing health and care services, over that region. The whole health and care system is dealing with higher demands and funding pressures, many quality and performance targets are not being met and GP's in the City have much higher numbers of patients to treat than in other parts of the country.

In this context Healthwatch asked local older people about their experience of getting advice and support when being discharged from hospital to home. Healthwatch interviewed 80 people in hospital and followed up on 49 people two months later at home. 41% of those who took part were over 80yrs old.

This review raises serious concerns about the quality and consistency of care planning and a lack of coordination and personalisation of care.

Personalised care – "make it real…"

- ✓ 59% people felt they were not involved or only partly in decisions about their care. Over half of these patients 53%[1] felt they had not been asked for their opinion

Integrated health and social care – "make it real…"

- ✓ 39% of all patients[2] felt the advice they had received while in hospital was not good enough to prepare them for being at home. 44% of all patients[3] felt they were either not ready or only partly ready to return home.

Being in control of your own health and social care – "make it real…"

- ✓ At the time we spoke to hospital patients, only 3%[4] had received written advice on discharge planning, 11 people[5] had received a hospital discharge letter, and only two people[6] had received a written care plan.

The NHS 'Let's get you home' hospital discharge cornerstone initiative of 2017 seems to have failed to gain traction in implementation. Healthwatch Brighton and Hove have heard much from local system leaders about integration,

[1] 18 patients, Table 9
[2] 21 patients, Table 51
[3] 26 patients, Table 52
[4] Two patients, Table 14
[5] 17%, Table 14
[6] 3%, Table 14

personalisation, and people taking more responsibility for their own health. These are all fine words and great intentions but how can we “make it real”. The issues and failures might be in policy, practice or funding but wherever they are the system is not delivering what it promises for older people.

In December 2018 Healthwatch Brighton and Hove provided an Interim Report to the local NHS and City Council. We welcome the response from the Brighton and Hove Clinical Commissioning Group CCG (printed in section 4 of this full report). They have pledged to act to improve the information and advice given to people on discharge from hospital and on other Healthwatch Brighton and Hove recommendations.

2. Summary of Findings

What we did

Healthwatch ran a project to seek the views of older people (65 years and older) about their experience of hospital discharge. The project collected patient experience from 80 people at the Royal Sussex County Hospital, Brighton, between July and September 2018. Healthwatch volunteers interviewed people in hospital and again post-discharge in their home or other residence.

Our findings

Experience in hospital

High quality of care in hospital:
Healthwatch found that 86%[7] of patients spoken to, felt that overall staff had treated them well while in hospital. When asked in hospital, the majority of patients spoken to (71%[8]) were happy with the arrangements being made for leaving hospital.

Inconsistent Information provided to patients:
Almost half the people we visited in hospital (44%[9]) had not been spoken to about what would happen to them after leaving hospital. Two thirds of people (66%[10]) had not received any *written* information at the time we spoke to them.

Lack of personalised care:
The majority of all people felt they were not involved or only partly in decisions (59%[11]) about their care. Over half of these patients (53%[12]) felt they had not been asked for their opinion.

Lengthy stays in hospital:
58% of the people we interviewed in hospital had been admitted for more than six days. 16% of these people had been admitted for over 20 days.

Experience at home

General satisfaction with discharge arrangements at home:
70%[13] of all patients reported that overall, they were satisfied or very satisfied with the discharge arrangements made for them at home.

Inconsistency in service provision at home:
Five patients[14] reported that they did not know who to contact should a problem arise. Four patients did not receive services at home, that they had been told to expect, while in hospital.

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[7] 79 patients, Table 2
[8] 35 patients, Table 19
[9] 34 patients, Table 3
[10] 43 patients, Table 14
[11] 41 patients, Table 8
[12] 18 patients, Table 9
[13] 40 patients, Table 54: A combination of patients asked at home and online
[14] 24%, tables 43 and 44

Lack of preparation for returning home:
Once home, 39% of all patients[15] felt the advice they had received while in hospital was not good enough to prepare them for being at home. 44% of all patients[16] felt they were either not ready or only partly ready to return home.

The importance of involving a patient's support network in the discharge process:
Half of patients (52%) spoken to at home mentioned the importance of the support of family and/or friends in their discharge experience.

[15] 21 patients, Table 51
[16] 26 patients, Table 52

3. Recommendations

Healthwatch has identified recommendations in four areas:

- Communication
- Personalised care
- Delayed transfers of care (DoTC)
- Independent living.

Patients and staff highlighted the need for a consistent and standardised approach in discharge planning. People asked to be more involved and to have their opinions considered in the decisions made around their discharge. The majority of people are likely to return to their own homes. It is important that those living alone and unsupported are distinguished from patients who have a strong supportive network of friends and/or family. The following recommendations might help to reduce delayed transfers of care.

Communication

1: Improved patient communication from hospital to home: discharge planning to start within 24 hours after admission; written and verbal communication with every patient, consistent use of one document covering hospital to home patient advice.

Discharge planning should start within 24 hours after admission[17].
Informing patients early on about plans for discharge and giving patients an idea of how long they are likely to be in hospital, could help people and their families make their own plans, and be more involved in planning care with hospital and community care staff. Improving information could include sharing potential discharge dates as early as possible with patients and providing detailed information at the point of discharge.[18]

Written discharge information should be provided to all patients, rather than relying on verbal advice only. Amongst this group of people, some are suffering from memory loss and written information would help ensure that it can be shared most effectively with family members, support networks and professionals who visit the patient.

Communication should be consistent for all patients. Prior to our review, Healthwatch were made aware of two patient leaflets, "Let's get you home" and 'Planning your discharge'. We were advised that the hospital is in the process of combining both into one booklet that meets all discharge information needs. Healthwatch recommends that patients are fully involved in the development of this booklet.

Every patient to receive one document covering all patient advice. The majority of the patients interviewed had not had sight of either of the available leaflets.

[17] In line with the "Let's get you home" campaign priorities, Sussex & East Surrey Sustainability & Transformation Partnership
[18] See Alan's story in Section 4.

This is disappointing as one of the key recommendations Healthwatch made in 2015 was that the 'discharge booklet' was given out 'as a matter of course for all patients being discharged from the [Royal Sussex County] hospital'.[19]

2: Improved communication between hospital and community-based staff. Information to be consistent, complete and timely; One person should be appointed as having responsibility for the overall discharge planning.
Hospital and community-based staff should share consistent, complete and timely information. To encourage a joined-up approach, one person should be appointed as the main person to ensure safe and sustainable discharge for the patient. With the person, family friends and other support agencies made aware of who this person is.

3. Hospital staff should maintain a written or electronic record of all discussions taken place with patient and family member/carer about the patient's discharge. This information should be held in one form and patients and family members/carers should be given a copy of this form; the *Discharge plan extension form* should be redesigned to allow this information to be recorded.
As recommended above, each patient should receive one written/electronic document containing patient advice. In addition, the written record of all communication between patient, family/carer and hospital staff should be given to patients and shared with community staff.

Personalised Care

4: Patients and family members, carers or those in their support network should be involved in the decisions about the patient's care both during their stay and also regarding what will happen to them on leaving hospital. They should be made fully aware of any choices and given the opportunity to say for themselves what kind of care they might need at home. Where possible, practical and safe to do so these views should be factored into pre- and post-care arrangements; and where not achievable, explanations should always be provided.
Patients and family members should be more involved in decisions around what will happen to them after hospital. Both patients and family members can provide a context for patient need that can inform the type of provision made. While choice cannot be guaranteed, if the patient is aware of the situation, they are less likely to be anxious about the future. People should have an opportunity for their personal preferences to influence the planning and delivery of care in the hospital and at home in line with personalised care.[20]

5: Hospital and community care services should differentiate between patients living with, or regularly supported by family and/or friends, and those living alone and unsupported.
Hospital, Community and Social Care staff should take active steps to identify each person's support network and ensure that family members, carers and friends are

[19] This followed our review of discharge in the Royal Sussex. Please read our report for further information.
[20] See NHS website for more detail on the importance of personalised care.

involved in decisions. All of these groups can provide essential context to the patient's home environment. Staff should actively consider which networks to directly engage with where the patient does not have any immediate family or a named carer.

People who are living alone and unsupported could be provided with additional visits from support services, and they could receive phone-calls to check that post-discharge arrangements are working well or whether the patient requires anything different. Their GP should be made aware of the persons circumstance so that they can offer additional support where needed. As well as professional support, patients should be advised about local community activities and support groups via the Ageing Well service.

Some people will have a partner or primary carer who is also vulnerable, frail and in poor health. Care plans for hospital discharge and care at home should take that into consideration.

The British Red Cross assisted discharge service[21] brought in for the Winter period 2018 could be extended to around the year. This would assist with the transition from hospital to home. The service could also help with provision of additional phone calls and visits for those living alone and unsupported and those being cared by someone who is also older.

Reduction of delayed transfers of care

6: The hospital should identify and implement workable actions that reduce the number of stranded patients, particularly for this age group (65 years old plus).
Involving people (and their support network) at an early stage in their discharge plan would help identify the patient's needs both in hospital and post discharge. This may also reduce the length of time that patients wait for care packages to be arranged. Nursing staff mobilizing people, or providing physiotherapy in hospital, may help patients to be physically able sooner and this may enable patients to leave hospital earlier.[22]

7: The hospital should maintain services such as blood tests, x-rays and access to medical prescriptions during the weekend at the same level of service as during the week.
Maintaining services at the weekend that reflect those offered during the week, could support the hospital in reducing the number of delayed transfers of care.

[21] The British Red Cross assisted discharge service aims to ease the pressure on hospital services over the busy winter months, and offer extra support to people who might struggle to cope with the transition back to home life.
[22] For example in the case of Alan's story

Independent living

8: All patients who are discharged home, should receive an assessment for independent living and where needed, provided with the appropriate support structure (adaptation) to enable independent living.

Where possible, every patient should be enabled to live independently, with the provision of the right support structure, adaptations, and appropriate advice.

9: All patients should be provided with written advice about living independently post-discharge. This should include advice about how to maintain good hydration and nutrition and how to access local support groups and activities e.g. the Brighton and Hove Ageing Well service.

More advice could be given about living independently, considering the majority of patients were expected to return home. The patient discharge document should include advice about how to maintain better nutrition and hydration.[23] Patients should also receive advice about accessing local support groups and activities via the Brighton and Hove Ageing Well service.

10: Better follow-up arrangements: Every patient to be provided with advice on who is likely to contact them and who they should contact should a problem arise. Each patient to be provided with a suitable support structure at home. Service provision discussed in the hospital should be followed through to service provided at home.

On leaving hospital, all patients should be given information on who is likely to contact them and who to contact should a problem arise at home. Some patients, particularly those who live alone and are unwell, may be fearful of letting people into their homes. This should be included in the patient discharge document.

While in the majority of cases, patients felt ready to go home, there were those who didn't. With these patients, reassurance could be provided by better information and ensuring the appropriate support structure is at home.[24]

Unfortunately, there is a recognition that some patients will never feel ready to go home despite reassurance. Amongst this group of patients will be some that are unable to live independently. It is recognized that sometimes a patient's inability to live independently may not be possible to predict prior to the patient returning home.

[23] Baden have demonstrated the potential for malnutrition in this age group. The Food Partnership have highlighted the importance of ensuring good nutrition and hydration amongst older people. Age UK are amongst a number of organisations who provide social networking opportunities for older people. They have also highlighted the prevalence of lonliness amongst this age group and have carried out research into ways to prevent isolation through participation.

[24] See John's daughter's story in Section 4.

4. Clinical Commissioning Response to the Interim Report[25]

PRIVATE AND CONFIDENTIAL
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Dear David

Re: Healthwatch Brighton's Interim Report on Let's Get You Home

On behalf of Adam Doyle, CEO of the eight Sussex and East Surrey CCGs, I would like to thank Healthwatch for the Interim Report on "Let's Get You Home" which will inform our ongoing improvement journey.

In recognition of the importance of ensuring that patients don't stay in hospital longer than they should the System held a chief officers Delayed Transfers of Care (DToC) summit in August 2018 and agreed to strengthen a number of areas such as the Let's Get You Home (LGYH) policy.

As I am sure you know we have seen significant improvement in DToC from Brighton and Sussex University Hospitals NHS Trust, since that summit, which has seen a reduction from 6% to 3.2% between August and December 2018
The areas from the emerging recommendations (extracted below) we will be taking forward are;

Improved communication

Discharge planning to start within 24 hours after admission; written and verbal communication with every patient, consistent use of one document covering all patient advice.

[25] Healthwatch produced an Interim report for key stakeholders distributed at the end of November 2018 with some headline findings and recommendations.

The BSUH LGYH document is being improved and adapted based on one used at Western Hospitals NHS Trust, where they have successfully combined their LGYH and Planning your Discharge booklet, which is a very good document. This will support improved communication and discharge planning with patients and their families.

Patient involvement

All patients (and/or family members) to be involved in decisions and being made aware of any choices. There will be on-going education with ward teams, by the end of quarter one 2019 present at Medical and Nursing Inductions, and the increased discharge team will be able to spend more time on the wards and be able to participate and encourage ward staff to have these early conversations with patients and their families.

Better preparation for independent living post discharge

All patients to receive advice on nutrition and hydration and accessing community groups. BSUH dietetics will provide some information to go into the Discharge Information Leaflets by the end of quarter one 2019.

Better follow-up arrangements:

Every patient to be provided with advice on who to contact should a problem arise and to be provided with a suitable support structure at home. This will also be included in the new Discharge Info leaflet.

'Alan's Story' – BSUH are aware that the Discharge Lounge is not an ideal environment for patients/families or staff. The redevelopment of the discharge lounge will be reviewed by the end of quarter one 2019.

With regards to the manner used by staff members, BSUH will share the report when the final version is released, and discuss patient/customer care with all staff as this is not acceptable that members of the public take away this perception from BSUH.

BSUH have requested more information about Alan's Story, e.g. a date so they can investigate as ordinarily if we have a patient who is unsettled in the discharge lounge they would usually deploy a health care assistant to be with the patient, also it is unusual for the Discharge Lounge to have patients who are very confused as it is deemed not always in the patient's best interest to move multiple times before discharge, because it does unsettle them.

I would like to thank you again for the interim report and we look forward to seeing the final document. In the meantime we will ensure that your recommendations are put in place as part of our work to continually improve care for patients.

Yours sincerely

Wendy Carberry
Managing Director South
Central Sussex and East Surrey Commissioning Alliance

Cc Adam Doyle

5. Introduction

Background

The problem of lengthy stays in hospital is an issue that has been widely recognised by a number of commissioners, providers and researchers. The Department of Health has identified that delayed transfer of care (DToC) is problematic for both patients and hospitals.[26] Muscle-waste has been widely recognised as a result of lengthy stays in hospital;[27] For hospitals, the effect is shortage of beds and their lack of availability to admit Accident & Emergency patients who are requiring admission.

Healthcare providers have made a concerted effort to respond to these concerns. Locally, the Sussex & East Surrey Transformation Partnership created an initiative around "Let's get you home" to prioritise speedy and safe discharge of hospital patients.[28] The NHS Clinical Commissioning Group Brighton and Hove (CCG) have prioritised the reduction of DToCs as a key issue for the local area.[29] In addition, the CCG have identified "frail older people" as a particular group of people they are concern about in their "Caring Together" programme.[30]

Objectives

Healthwatch aimed to gather patient experience of hospital discharge with these issues in mind. In discussion with key stakeholders, the following concerns were raised, namely:

- Increased delayed transfers of care;
- Poor quality of life post-discharge, particularly for older people (65 years of age plus);
- Older people were not receiving the care they required post-discharge, and this included concerns about their diet and well-being.

Project Scope

In developing the project, we chose to speak to older people (65+ years) including those who were considered frail, about their experience of discharge. We considered that this group included a higher number of vulnerable people who were more likely to be adversely affected by delayed discharge. We planned to

[26] The Kings Fund highlights the issues in 'Delayed transfers of care: a quick guide' including a link to the NHS' *National Audit of intermediate care*. Also worth looking at is The Telegraph's article on a Department of Health pledge to free up beds.
[27] See this article by the British Geriatic Society.
[28] See the "Let's get you home" campaign for further details.
[29] The Brighton and Hove CCG Quality Report in April 2018 stated that DToC's were above target at 9.3%. The CCG Governing Body Meeting (Public) in May 2018 and the Local Accident and Emergency Delivery Board in November 2018 both highlighted the reduction in DoTCs as a target for the current year.
[30] 'Caring Together' programme and more details on 'Caring Together objectives'.

speak to patients prior to discharge (in hospital) and after leaving hospital, wherever they were located.

Our aim was to identify what worked well in the existing discharge process, and what improvements could be made that might decrease the likelihood of the issues mentioned above.

Context

This was a challenging project to manage due to a number of considerations. We interviewed patients in eleven areas of the hospital (ten wards and the discharge lounge)[31] and this needed cooperation from a number of ward managers and other staff. Due to the cohort of patients, we had to consider potential memory loss, fragility, long-term physical and mental conditions and therefore sensitivities in speaking to these patients. We needed to gain consent from the patients to visit them after discharge, and this process took time to work out.

As with all Healthwatch projects, anonymity was important to maintain and we had an added challenge of linking anonymous hospital interviews with anonymous home visits. In addition, we conducted three online surveys, one for patients/carers, and two others aimed at staff who are involved in patient discharge, hospital and community-based staff respectively.

Clinical Commissioning Group Response

Prior to this report we produced an interim report at the end of November 2018 which was circulated to key stakeholders. The Clinical Commissioning Group responded positively to the interim report and their response to our recommendations in that report is attached as Section 4.

[31] Volunteers interviewed patients in the following wards: Catherine James; Egremont; Bristol, Chichester, Jowers, Valance, Overton, Donald Hall, Solomon, Bailey. We also visited the Discharge Lounge. Wards were chosen, as the ones most likely to have a high number of patients aged 65 years and over.

6. Methodology

The project took place between July and September 2018. Healthwatch volunteers interviewed 80 patients (and their family members) in person in the Royal Sussex County Hospital. The majority of patients (76.5%)[32] were from Brighton and Hove and 41% were over 80yrs[33]. Volunteers asked patients whether they had received discharge information and in what format, written or verbal. Patients were asked what type of information they had received (advice, information on support they would receive after hospital etc). We also asked patients what type of support they were expecting and where they expected to go after hospital.[34] With the patient's consent, we also asked the hospital staff some questions on the patient's condition, how long they had been in hospital, where they were likely to go after discharge and what discharge information had been given to the patient.[35]

Gaining consent from the majority of patients, our volunteers successfully visited 49 patients in their homes or other community residence ("home").[36] Patients were visited one – two months after discharge as we felt this would give time for the patient to reflect on their "home" experience. We had also been advised by key stakeholders that patients already received a high volume of professional visitors in the first few weeks after discharge. During these visits, patients were asked if the arrangements they had expected while in hospital, were provided for when they returned "home". They were asked if the arrangements had gone well and they had received the support they needed or if there were any problems with the arrangements made. Patients were also asked if they had been readmitted to hospital since the time our volunteer had visited them in hospital. They were asked what factors had made their discharge arrangements successful or not.[37]

In addition, Healthwatch promoted an online survey to capture the experiences of patients who had been discharged from the Royal Sussex in 2018. This survey asked similar questions to those asked in person, and was available to patients and their family members to respond to. We received 21 responses from the online survey.

The data tables at the end of the report show all questions that were asked of patients and family members/carers and the responses we received.

[32] From 81 patients interviewed in hospital, 62 were from Brighton and Hove. Other patients were from Lewes, Newhaven, Peacehaven, Hassocks, Haywards Heath, and two patients were from outside Sussex. We did not ask this question of those patients who completed the online survey.
[33] See Demographic questions for breakdown of all patient ages including those who responded to the online survey.
[34] See Tables 1 – 19.
[35] See Tables 20 – 32.
[36] See Table A (Supplementary analysis) for where patients went after hospital.
[37] See Tables 33-58.

In addition to patient experience, we promoted two staff surveys, one aimed at the hospital staff and the other, aimed at staff working with patients in the community. Both surveys asked staff whether they felt the discharge process was successful, and what factors made it work or not. We also asked staff for best practice suggestions for a good discharge process. We received seven responses to the community staff survey and two to the hospital staff survey. While this was not enough to provide valid data for full analysis, we have captured staff experience in our section on Systems and Processes.

Our findings are based on all the observations and conversations with patients, carers and staff, supported by the statistical data captured during interviews with patients. The supplementary analysis section under data tables, contains additional analysis including where we compared two questions to identify if there was any relationship between them. We have also included case studies and comments (within the report) directly gathered from patients and some staff, who wanted to tell us their story.

7. Key Findings

Healthwatch identified a number of key findings from the surveys and interviews conducted. We have grouped these into experience in hospital and experience at home and also included a section drawn from the staff surveys we conducted.

The majority of patients spoke highly of hospital staff and the quality of service. However, either lack of or inconsistent communication was the main reason for negative feedback from patients, family members and staff.

Patients felt they wanted more involvement in discussions around discharge plans and by being more involved, they would feel better prepared for going home. The patient experience at home, was dictated by patients having received appropriate advice so they knew what to expect and receiving appropriate service provision. Often the patient experience was positively influenced by a good support network of friends and family.

Experience in hospital

1: Quality of care and overall arrangements.

86%[38] of patients spoken to, felt that overall staff had treated them well while in hospital. Good care and attention can ensure a positive experience for the patient even where the context is difficult (see Charlie's story). Alternatively, patient's can experience a poor discharge where they are not treated appropriately, as with Alan's story.

> *[I] couldn't praise the staff highly enough for the care received.*
>
> *Patient*

> *[The staff] have been fantastic.*
>
> *Patient*

When asked in hospital, the majority of patients spoken to (71%[39]) were happy with the arrangements being made for leaving hospital. However, improvements could be made in a number of areas.

> *[I was treated] like a human…not like a patient.*
>
> *Patient*

2: Advice and information

Sussex & East Surrey Sustainability & Transformation Partnership (the NHS and local council partnership for this area)[40] created an initiative called the "Let's get you home" campaign.[41] This initiative sets out to *"ensure that patients spend no longer than they need to in hospital. It supports people to return home safely or, if this is not possible, to move to a care home or supported housing once their treatment in hospital is complete"*. The initiative includes *"Staff having earlier conversations with patients about how they will leave hospital - usually within 24 hours of being admitted - and being given clear information about their choices."*

[38] 79 patients, Table 2
[39] 35 patients, Table 19
[40] See SES Health and Care for further information about Sussex & East Surrey Sustainability & Transformation Partnership
[41] See the "Let's Get You Home" campaign for further details.

She is happy that her Mum can go home and be adequately cared for.
Patient's daughter

Some of the patients we interviewed received good advice and information and felt reassured with the discharge plans put in place.

However, almost half of the patients we visited in hospital (44%[42]) had not been spoken to about what would happen to them after leaving hospital. This was confirmed by the staff we spoke to who reported that 48%[43] had not received any information. Also, 32%[44] of hospital patients had no information on how long they would be staying in hospital. Read Peter's story for a personal experience of this.

It is always me asking about discharge. The staff tell me that they have no idea when I will be discharged…it is patient driven.
Patient

27%[45] of patients who completed our online survey responded that they had not received any discharge information by the time they left hospital.

Two thirds of patients (66%[46]) had not received any *written* information at the time we spoke to them. This included seven patients who had already been discharged (responding to our public survey)[47]. There was a lack of consistency with the information received. While 11 patients[48] received a discharge letter, only 3%[49] were handed a copy of the "Let's get you home" leaflet and only one patient[50] had received 'planning your discharge booklet'. Two had received a copy of their care plan.[51]

When we asked staff the same question, their records showed that more patients had received written information than the patients remembered themselves (26 hospital patients had received something written as opposed to 16 recalled by patients themselves)[52]. However, staff explained that 37% of those who had been given information (13 patients), received it verbally only.[53]

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[42] 34 patients, Table 3
[43] 32 patients, Table 28
[44] 19 patients, Table 6
[45] 4 patients, Table 3
[46] 43 patients, Table 14
[47] Of the hospital patients we spoke to, all had been in hospital at least one day and 94% had been in two days or more. All patients met the criteria stated in the "Let's get you home" campaign. See Table 21 for days in hospital.
[48] 17%, Table 14
[49] Two patients, Table 14
[50] 2%, Table 14
[51] 3%, Table 14
[52] Table 29
[53] Table 29

Our findings show that there is a general lack of standardisation in the way information is provided to the patient. This finding was also reflected in our Healthwatch Complaints Review meeting held in November 2018.[54]

Recommendation: Healthwatch recommends that discharge planning (and communication with patients) should begin earlier in line with the "Let's get you home" campaign pledge.[55] Communication should be consistent for all patients. This should be provided in written as well as verbal form and consist of one document covering all patient advice.

3: Preparation for home living

The majority of patients (85%[56]) expected to return home after hospital. Of those patients we visited, 80% (39 patients) did return home, with a further four patients (8%) who went to live with family.[57] However, there were variances in the completeness and quality of advice given that would enable a patient to live independently at home. Of the 39 patients who responded to this question in hospital:

- Nine patients (23%) had been provided with advice on home help (with shopping, cleaning etc);
- Two patients (5%) had been advised about Telecare;[58]
- Another two (5%) had received advice about District nurses;
- One patient had received advice on diet and liquid intake;
- No one had received advice on social groups and local activities.[59]

With concerns about the potential for malnutrition in this age group[60], it is important that discharge information includes advice about good nutrition and hydration. Also, that it includes suggestions on how to access local groups that can support the patient with these needs post discharge.[61]

With those who responded to this question in the public survey, only a small proportion had received any advice.[62]

Recommendation: All patients should be provided with written advice about living independently post-discharge. This should include advice about how to maintain good hydration and nutrition as well how to access support groups and activities via the Ageing Well service.

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[54] The Healthwatch Complaints Peer Review meeting was held on 27th November 2018. Four complaints presented at the meeting demonstrated that the discharge procedure was dependent on the capability of the individual staff and recommended that more standardisation was required.
[55] "Let's get you home" campaign priorities, Sussex & East Surrey Sustainability & Transformation Partnership
[56] 62 patients, Table 4
[57] See Table A in Supplementary Analysis.
[58] A Telecare Alarm service provides elderly people who live alone with 24-hour access to somebody to call for help if they suffer a fall, feel unwell or need some reassurance.
[59] All Table 7
[60] See the Bapen website for more information on this.
[61] For example, The Food Partnership.
[62] Two patients, 29%, Table 7

4: Personalised care

"Personalised care means people have choice and control over the way their care is planned and delivered" as stated by the NHS England website.[63]

The majority of all patients felt they were not involved or only partly in decisions (59%[64]) about their care. Over half of these patients (53%[65]) felt they had not been asked for their opinion.

> *[I felt staff were] treating the illness and not the patient.*
>
> Patient

Half of all patients (50%[66]) were either not helped to understand their options or only partly helped. Of these patients, only just over a third (37%[67]) were given the option to clarify anything they had not understood. Being given the chance to raise questions, and being helped to understand that information is critical to the patient discharge experience as is shown in the positive story from Charlie.

> *I am Italian and they helped me to understand [the information].*
>
> Patient

Patients and family members can provide a context for patient need that can inform the type of provision made. While choice cannot be guaranteed, if the patient is aware of the situation, they are less likely to be anxious about the future. People should have an opportunity for their personal preferences to influence the planning and delivery of care in the hospital and at home in line with personalised care.[68] It is important to recognise that despite a need for physical support, many amongst this patient cohort are independent and are very capable of stating what care they require once leaving hospital.

> *I have been through this before several times and didn't need much advice.*
>
> Patient

Recommendation: Patients and family members, carers or those in their support network should be involved in the decisions about the patient's care both during their stay and also around what will happen to them on leaving hospital.

They should be made fully aware of any choices and given the opportunity to say for themselves what kind of care they might need at home. Where possible, practical and safe to do so, these views should be factored into pre- and post-care arrangements; and where not achievable, explanations should always be provided.

[63] See NHS Website for further details.
[64] 41 patients, Table 8
[65] 18 patients, Table 9
[66] 29 patients, Table 10
[67] 11, table 11
[68] See NHS website for more detail on the importance of personalised care.

5: Delayed Discharge – "Stranded Patients"

NHS England defines "stranded patients" as those patients who have been in hospital for more than six days. They also discuss long stay patients as those who have been in hospital for more than 20 days and this is commonly known as "super stranded".[69]

58% of the patients we interviewed in hospital are considered "stranded" by this definition and 16% of these patients were "super stranded" at the time of interview.[70] By adding on the likely time they had remaining before discharge, the stranded numbers increased to 88% in total (with 39% of these super stranded).[71] These high numbers suggest extended hospital stays are an ongoing issue. The hospital should take action to reduce these numbers and achieve the commitment made in the "Let's Get you Home" campaign.

It is well-documented that "bedrest in hospital over 10 days leads to 10 years of muscle ageing for people over 80."[72] From all patients surveyed, 41% (34)[73] were in this age group. Particularly poignant is one patient's story, where his wife felt his long stay in hospital had been detrimental to his progress, both physically and mentally (see Clarissa's story).

Recommendation: The hospital should identify and implement workable actions that reduce the number of stranded patients, particularly for this age group (65 years old plus).

> *They have lost test results which has meant it has been repeated and delayed potential discharge.*
>
> *Patient*

24% (14)[74] of all patients felt their discharge was later than expected. In the majority of cases this was less than five days.[75] Reasons were various and included waiting for care packages to be put in place.[76] Some patients referred to delayed discharge due to *"lost tests"* (one patient) and waiting for medication (one patient). Another patient commented that they were not given enough time to make arrangements. After a period of no information, there was a *"sudden announcement that [I was] going home that day."* The result was a delay of one day to ensure the patient could make appropriate arrangements.

[69] See the NHS June 2018 paper 'Guide to reducing long hospital stays' for more details.
[70] See Tables B and 21 in supplementary analysis. 42% (29 patients) were stranded and 16% (11 patients) were super-stranded.
[71] See Table B in supplementary analysis.
[72] See "Guide to reducing long hospital stays", page 44.
[73] See Demographic questions.
[74] See Table 16
[75] 85% (11 patients), Table 17
[76] Table 18

I was told on the Wednesday that I was ready to go home …nothing happened over the weekend so it dragged on until the Monday. I was told not a lot happens over the weekend - why not?

Patient

Several patients we spoke to commented on delays due to lack of service provision at the weekend. One patient commented: "[It] all happened at the weekend and they don't do blood tests at the weekend" so they had to wait until Monday. In two cases, patients felt they were sent home too quickly.

Recommendation: Hospital staff should keep patients informed as early as possible about potential discharge dates.

The hospital should maintain services such as blood tests, x-rays and access to medical prescriptions during the weekend at the same level of service as during the week.

Experience at Home

6: Overall experience at Home

70%[77] of all patients reported that overall, they were satisfied or very satisfied with the discharge arrangements made for them at home.

The main reasons patients gave as to why they felt the home experience had been effective[78] were around:

- Available and understandable information (54%[79]);
- Access to and understanding about medication (58%[80]);
- Suitable arrangements being in place (34%[81]);
- Ability to access support (38%[82]);
- Ability to self-manage (26%)[83].

The majority of patients (71%[84]) reported effective or very effective arrangements. However, where it went wrong, this was related to a number of things.

- Lack of information or understanding of information (10%[85]);
- Inability to access support (6%[86]);
- Incomplete adaptations or absent arrangements at home (14%[87]);
- Lack of ability to self-manage.[88]

[77] 40 patients, Table 54: A combination of patients asked at home and online
[78] Table 36
[79] 27 patients, Table 36
[80] 29 patients, Table 36
[81] 17 patients, Table 36
[82] 19 patients, Table 36
[83] 13 patients, Table 36
[84] 42 patients, Table 37
[85] Five patients, Table 36
[86] Three patients, Table 36
[87] Seven patients, Table 36
[88] Four patients, 8%, Table 36

7: Service provision at home

The majority of patients (76%[89]) felt support at home had been good or very good. For some patients like John (see John's daughter's story) the service provision went above and beyond expectations.

However, five patients[90] reported that they did not know who to contact should a problem arise. Other patients did not receive the care they had expected. In Simon's Daughter's Story, Simon did not receive the follow-up care he needed or the adaptations he required. From those who were interviewed at home, two patients (33%)[91] didn't receive physiotherapy and another two patients (67%)[92] didn't receive speech therapy. All four patients had expected to receive these services when they were asked about this in hospital. One stroke patient had been receiving speech therapy for six months following an earlier hospital admission. After readmission, there *"seems to be a wait before the next sessions begin."* Another stroke patient was due to receive speech therapy but this took two months before the appointment was arranged and then cancelled before it took place. For a third patient, the lack of physiotherapy provision at home is illustrated by Clarissa's experience with Ernest.

> *I cancelled [the speech therapist] after they cancelled me.*
>
> *Patient*

> *I just want a physio to help him walk again.*
>
> *Patient*

For other patients, it was not the lack of provision that was the issue so much as not knowing who to expect or when. The care provision for one patient was not *"joined up"*. She was happy that she was being looked after, but she received *"a lot of unexpected visitors and [is] not always sure who [is] coming and why."*

Recommendations:

As part of the discharge information provided all patients should be provided with advice on who they should contact should a problem arise at home.

All patients who are discharged home should receive an assessment for independent living and where needed, provided with the appropriate support structure (adaptation) to enable independent living.

Service provision discussed in the hospital should be followed through to service provided at home.

Service provision should be "joined up" between community services and the patient kept informed in advance of visitors.

[89] 42 patients, Table 45
[90] 24%, tables 43 and 44
[91] See Comparative Table A
[92] See Comparative Table A

8: Advice and information

Once at home 39% of all patients[93] felt the advice they had received was not good. This included two patients who had not been informed about the option of the patient transport service.[94] 44% of all patients[95] felt they were either not ready or only partly ready to return home. Reasons given for not feeling ready were various:

- Lack of information or understanding about information provided (13%[96]);
- Unable to access support (9%[97]);
- Inability to self-manage (11%[98]).

> *The letter was the same one as [my] doctor was getting and [I] didn't understand the meaning of all the words.*
>
> Patient

One patient who responded to our online survey reported they were 'discharged from hospital in a rush' without any support or information, that their 'head was spinning'.

Of those patients we interviewed at home 26 patients rated the advice and information either good or very good and all 26 (100%)[99] were either satisfied or very satisfied with the discharge arrangements. Similarly, 10 patients we interviewed at home felt the advice and information was poor and seven of these patients (70%)[100] were also unsatisfied with the discharge arrangements. We might expect advice received and satisfaction with arrangements to be linked. However, this strong connection indicates just how important good advice and information is to ensuring discharge arrangements work effectively.

Recommendations:
Communication should be consistent for all patients. This should be provided in written as well as verbal form and consist of one document covering all patient advice.

9: Family and Friend Support

Half of patients (52%) spoken to at home mentioned the importance of the support of family and/or friends in their discharge experience. 10 of these patients (21%) mentioned they were living with a family member (or partner).[101] This context was often reflected in the answers given to how well the discharge process had gone. It is therefore worth recognising that those supported by family and friends

[93] 21 patients, Table 51
[94] One patient arranged for a friend to pick them up. However, the other patient did not have this option and was taken to the discharge lounge from 9am and waited until 5pm when a friend was available to collect them.
[95] 26 patients, Table 52
[96] Six patients, Table 53
[97] Four patients, Table 53
[98] Five patients, Table 53
[99] See Table D in supplementary Analysis.
[100] See Table D in supplementary Analysis.
[101] Patients were not asked explicitly whether they had family or friends support. Therefore, the numbers given here (25 and 10 respectively) are the numbers of patients who mentioned family or friends support within the narrative answers to our home questions (total 49 patients).

may not have the same requirements for professional support as those who do not have a support structure.

Several patients mentioned that family members were involved in hospital discussions speaking *"to the consultant"* about the patient's *"care at home."* In some cases, it was due to the proactivity of the family that discharge information was received at all:

"[My] family had to help a lot to get this information…[as they found it] difficult […] to get the information [they] needed to help [the patient]."
It was also sometimes due to the family member that the patient was helped to make decisions: *"My daughter is involved as well…she helps me to make decisions'.*

At home, some patients were helped with *"acquiring medication and food."* In some cases, a relative *"makes most of the arrangements"* so there was little requirement for professional arrangements to be made. Several patients commented that family members researched the care home options as *"we had to find out information for ourselves." "There was no help from the staff with this."*

> *My daughter has been fantastic and has popped in everyday to see if I need anything. She helps me to stay positive and think about the future. I love it when my noisy grandchildren pop in.*
>
> *Patient*

Recommendation: Hospital staff should differentiate between patients living with, or regularly supported by family and/or friends, and those living alone and unsupported.

Patients who are living alone and unsupported are likely to need additional support post-discharge and this context should be factored into the discharge plan. For example, these patients should be provided with additional visits from support services, and they should receive phone-calls to check that post-discharge arrangements are working well or whether the patient requires anything different. Their GP should be made aware of the patient's circumstances so that they can offer additional support where needed. As well as professional support, patients should be advised about local community activities and support groups via the Ageing Well service.

> *I am a member of the local church and have really good friends who will help me.*
>
> *Patient*

In one case, it was due to friends intervening that ensured the patient received support at home. Described by a friend as someone "who was *used to being independent"*, the patient may not have provided a true picture of their ability to live alone. Friends stepped in, spoke to the Doctor and a short-term care package was provided to get the patient back on their feet again. It should be recognised that family and friends can shed light on the contextual needs of the patient, as in "Simon's Daughter's Story".

Recommendation: Family should be given the opportunity to assist staff in understanding the patient's situation. In the case of no family being available, appropriate friends who are akin to a family connection should be involved in these discussions.

For those without any support, patients experienced "*loneliness*" and even where the discharge process had gone well, a patient may *"just not want to return home."*

> *[I am] most worried about going to an empty house as [my] dog died a few days before admission.*
>
> *Patient*

Recommendation: Home arrangements should include regular visits for those living alone and particularly where the patient has mobility issues. Patients should be advised about local community activities and support groups via the Ageing Well service.

Other patients experienced a change of situation. *"On leaving hospital, [they] were given enough information for [them] to manage."* Once home their main carer *"became ill too"* and the requirement for support changed.

Recommendation: Consideration should also be given to those patients, where the main carer is older themselves and may also have health problems.

10: Systems and Process: Staff views

We did not gain a high enough number of responses to provide valid data for a full analysis.[102] Of those who did respond, one social worker referred to lack of resources, both in *"staffing"* and in *"step down beds [for patients who] are medically fit to be discharged [but require] rehabilitation"* before returning home. Lack of resources in the community was also seen as a challenge to good discharge picked up in the Healthwatch Complaints Review meeting in November this year.[103] The majority of comments, however, were around communication and information.

Poor communication internally and between hospital staff and community-based staff were the main reasons given by hospital staff for the discharge process not working.[104]

[102] We received seven responses from community based staff two from hospital staff.
[103] Healthwatch noted that staff shortages paid a large part in the complaints reviewed and were linked to poor hospital discharge. It was suggested in the meeting that there was a role for voluntary organisations to help more formally in discharge.
[104] Both respondents to the hospital staff survey chose these options as the primary reasons for the discharge process not working.

> *Some referrals have all the relevant information, others have very poor information.*
>
> Hospice professional

Similarly, respondents to the community staff survey felt that information from the hospital was **inconsistent and sometimes incomplete.** One hospice professional commented that some referrals made by *"general staff"* *(rather than the "Hospital palliative care team"*), do not contain all the information. With the specific context missing (e.g. if the patient has *"diarrhoea, confusion"*), the patient could be wrongly placed in the Hospice when *"the patient would have been better off in a care home."* A nursing home professional commented that important information such as *"incidents [including those relevant to safeguarding] that have happened in hospital are [sometimes missing]."* This can affect the ability of the nursing home to put appropriate post-discharge care in place.

Missing information such as next of kin and incomplete medication can create *"a lot of extra work."*(Hospice professional) Reasons behind decisions are sometimes not given: *"why a catheter has been inserted"*(nursing home professional) or why medications have been stopped (GP). The need for better communication between hospital and care home (and care home assessors) was also recommended to staff in the Healthwatch Complaints Review meeting. In particular, providing the care home with a discharge summary containing clear advice about the discharge needs of the patient.[105]

> *We have had occasions when we have not been informed and an ambulance has turned up - on one occasion I was unable to accept the resident and they had to return to hospital.*
>
> Hospice professional

Information from the hospital could be **provided earlier**. *"We get the [discharge] summaries too late […] 2-3 days after discharge [rather than] prior to discharge."*(GP); *"Often we will not know that the patient has been discharged until some days/weeks after discharge."*(Clinical nurse specialist). This can lead to the onward care provision not being ready to accept the patient: The Hospital doesn't *"communicate a time"* with the nursing home and the patient is discharged *"past [the] hours [we can] accept a discharge [patient]."*(Nursing home professional)

[105] The review picked up good as well as poor practice. Staff were reminded of the importance of proper communication between Care homes (and assessors).

Better **joined up communication** between patient, family, hospital staff and community-based staff is important. The process can go wrong, when the *"patient/family are unclear about why the patient is coming to [the] in-patient unit."* It is important that *"patient and/or family have made an informed decision."* (Hospice professional). Equally, involving Social workers can have an impact in the care provided post-discharge. Providing insight to the patient's context, one social worker cited two occasions where their intervention with the hospital meant the patient was discharged to appropriate care in the community.

> *Patients and relatives can have unrealistic expectations of what care we can provide in the community.*
> Hospice professional

Recommendation: Communication between hospital staff and community-based staff should be consistent, complete and produced in a timely fashion.

One hospital staff member should be appointed as the main person to ensure safe and sustainable discharge for the patient. This will also encourage a joined-up approach between the hospital and all community services involved in the patients care, pre- and post-discharge.

In addition to the survey, one of our volunteers spoke in person to hospital staff about the discharge process and this highlighted some interesting findings.

There are a number of patient forms that are completed by hospital staff. These include:

- *The Admission, Assessment, Transfer and Referral Document* completed on patient arrival, which contains existing care arrangements.
- The *Discharge Planner*, described by our volunteer as *"an impressive and comprehensive document."* Used from day one of the patient arrival, this should record every discussion with the patient and family/carer, about the patient's discharge plans.
- The *Discharge Summary Form*, a clinical document for the patient's GP and pharmacist to describe the patient's medication needs.

However, there appears to be a number of weaknesses with these documents, primarily:

1. There is no *one* document containing all patient information.
2. The *Discharge Planner* is not given to patients. Our volunteer spoke to one hospital staff member who realised this *"could be a significant weakness especially for dementia patients or elderly patients […] with poor memories."*

3. If space on the *Discharge Planner* runs out, the *Discharge plan extension form* is used. However, there is no space on this form to record whether the plan was discussed (or with who).
4. The *Discharge Summary Form* given to patients, contains clinical language which *"sometimes [contains] indecipherable abbreviations"* according to one GP.[106]
5. Also as the GP receives the *Discharge summary form* electronically while the patient is sometimes transferred to the discharge lounge without medication, it is possible the patient may go home without medication and therefore there could be an assumption by the GP that the patient is taking medication where in fact they are not.
6. Our volunteer spoke to a number of hospital staff and it seemed as if no *"written discharge plan is given to anybody, whether patient or carer."*

There appears to be good intention in producing forms that contain useful information to hospital staff, community staff as well as patients and their family members/carers. However, the information is inconsistent, sometimes indecipherable and incomplete and not produced in a timely fashion.

Recommendation: Hospital staff should maintain a written record of all discussions taken place with patient and family member/carer about the patient's discharge. This information should be held in one form and patients and family members/carers should be given a copy of this form; the extension form should be redesigned to allow this information to be recorded.

[106] This was in response to our community staff survey.

8. Conclusion

Hospital and community-based staff are often under pressure from lack of resources and high numbers of patients. The majority of patients we interviewed spoke highly of staff and the quality of care they received. However, Healthwatch identified a number of areas that could be improved and we believe that many of these are relatively easy to implement. They should also greatly increase patient's preparation for their discharge and care arrangements afterwards.

Both patients and staff spoke about the need for a consistent and standardised approach in discharge planning. Patients asked to be more involved and to have their opinions considered in the decisions made around their discharge. As the majority of patients are likely to return home, it is important that discharge plans prioritise supporting patients to live independently. These concerns are in line with the "Let's Get You Home" campaign and the local CCG's prioritising of reducing delayed transfers of care.

Within this cohort of patients there are many that are vulnerable, living alone and need a high degree of professional support. The discharge plan should take this into consideration. These patients can be offered additional visits from support services, and/or phone-calls to check that post-discharge arrangements are working well or whether the patient requires anything different. Their GP should be made aware of the patient's circumstances so that they can offer additional support where needed. As well as professional support, patients should be advised about local community activities and support groups via the Ageing Well service. By offering additional support and advice, this could lead to a reduction in patients returning to hospital with conditions related to malnutrition and hydration, or caused by loneliness and self-neglect.

However, there are patients within this group who are independent and who already have a strong family or friendship network and this differentiation should be taken into consideration when putting together their discharge plan. Their support network (friends, family or carers) should be involved in the decisions around the patient's discharge plan, as they can help provide a context that could ensure that appropriate plans are made.

By differentiating patients in this way and providing the personalised care as defined by the NHS, the hospital would improve patient experience of being discharged. The hospital may also be able to reduce delayed transfers of care and prevent repeat admissions.

9. Thanks

We are indebted to a number of people who enabled this project to succeed. Our thanks go to the hospital staff and management, particularly Caroline Davies and Sara Allen, who enabled us to access patients across 11 wards.[107]

To ensure we gathered data both before and after discharge, patients were asked to consent to our volunteers visiting them in their place of residence. As this was often their own home, we are indebted to the kindness of these patients and their families for enabling us to visit them. We are also grateful for the openness and honesty in offering feedback on their experiences.

Two people have provided invaluable advice throughout the project, and we would like to thank Marlize Phillips, Royal Sussex County Hospital, Rapid Discharge Team and Sharlene Small, Crossroads Care.[108]

We would also like to thank Graham Hawkes (previously CEO for Healthwatch Hillingdon) and Dr Lizzie Ward (Principal Research Fellow, University of Brighton). Both of whom provided advice and learning from related projects.

Lastly and certainly not least, thanks go to our dedicated team of volunteers: Mike Doodson, Jacqueline Goodchild, Nick Goslett, Chris Jennings, Frances McCabe, Sylvia New, Sue Seymour, Lynne Shields, Roger Squier, Alli Willmore. From providing insight to the draft patient questions, carrying out pilot interviews, to interviewing over 80 patients in hospital and ensuring follow-up of 49 of these patients. In addition, Chris Jennings provided additional help with preparing data for analysis that was invaluable.

[107] We visited patients in ten wards and the discharge lounge.
[108] See Crossroads website for further detail.

10. Patients' Stories

"Charlie's story": A positive discharge experience

This patient received good advice and was involved in the decisions made concerning his discharge. This contributed to a good experience despite the difficult context of his condition.

Charlie is in his late 60's. He had a routine bowel screening test which turned out positive and was given a colonoscopy within two weeks. He was told immediately that he had bowel cancer and was followed up with a one and a half hour conversation with a specialist nurse on what would happen next. He was given lots of time for questions and to raise concerns. He was told to bring someone with him and his daughter was also able to support him through the process.

He was operated upon within two weeks. Having received the initial interview, he felt confident about what was happening. He stayed in hospital, which was what he expected. His discharge went well. He had already received plenty of leaflets from the first visit so he only felt he needed a GP letter.

Within two weeks, as he had been told, he was given the results of the surgery. He has visited his GP and is to see the surgeon next week. He feels the whole experience was exemplary and is very optimistic about the future.

"Alan's Story": How lessons can be learned from a poor patient experience

This patient experienced poor quality of care and lack of information at the point of discharge. He also felt that lack of physiotherapy in hospital did not prepare him for going home.

Alan was admitted to A&E and diagnosed with a pelvic fracture, sustained after an accidental fall. After waiting over an hour and a half for an ambulance, and being told he could wait another two hours, he was lifted and brought to hospital in a taxi.

He received "very good treatment" in A&E and in the Acute Assessment Unit (admitted for one day). However, he felt his treatment in Jowers Ward was very poor.

He wanted to be out of hospital as soon as possible, but was concerned that he would not be able to care for his wife who has Alzheimer's until he was physically fit. However, he was provided with no physiotherapy while in hospital and felt this meant his stay in hospital was longer than necessary. The reason given to Alan for not providing physiotherapy was that "I had been moved from one ward to another and missed it."

On the day of discharge, a physiotherapist/occupational therapist visited Alan with a zimmer frame and invited him to walk to the toilet and back. This was the first time he had been out of bed or walked for a week.

At 10am, Alan was advised that he could leave hospital. However, he was left in the ward "blocking a bed" for several hours. Later that same day, he was wheeled to "an exceptionally small, scruffy, poorly furnished room at the front of the Barry Building."

Having sat around for some time with no information, Alan's son asked the receptionist how long it would be before they would be going, only to be told in an "offhand manner", 'Oh, it could be three hours. They are very busy'. The reception staff made it clear that they did not want to be bothered with questions. Alan was finally discharged at 6pm that day.

In addition to his own lack of care, Alan was distressed by the treatment of a lady, also in the waiting room. She was still in her hospital gown, clearly with dementia, and who kept getting out of her seat. She had no one with her to assist with this, despite being "very wobbly clutching her blanket."

The lack of hygiene in the waiting area, the absence of care to both himself and the lady he was waiting with and poor communication contributed to a very poor discharge experience for Alan.

His daughter added 'The reception created unnecessary tension. A smile and friendly manner, a bit of information and some reassurance all would have changed the experience into a positive one.'

"Peter's Story": How lessons can be learned from a poor patient experience

This patient experienced poor communication both prior to and following discharge on two hospital admissions.

First admission to the Royal Sussex
Peter was admitted to hospital and discharged one week later. He had to wait an hour in the discharge lounge to get his medicines as these weren't ready. He described this as a miserable place to be in. His family collected and took him home.

He was not given any information prior to his discharge. However, he was aware that he was being discharged and was ready to go home. He did not receive any calls or visits from anyone once at home. He would have preferred better information prior to discharge and he would have liked a follow-up call.

Readmission to the Royal Sussex
About a week after his first discharge he felt unwell, sick and tired. He therefore attended A&E a couple of days after this.

After spending over 24 hours in A&E, he was readmitted onto a ward.

After eight days, he was discharged from this ward direct to the Sussex Cancer Centre. However, he was given no prior information that this was happening. Overall, he felt the discharge was very poor.

Discharge from the Sussex Cancer Centre
His experience at the Sussex Cancer Centre was brilliant- no complaints at all.

The discharge process was also very good. He remained in his ward until it was time to go. His medicines were handed to him in person whilst still on the ward. He was also given information about what these were and how to take them, together with contact information. However, the numbers provided to him didn't work when he tried them later and he was directed from one person to another and ultimately to 111.

After his discharge he only received one call and this was to check if he was feeling well enough to attend for his scheduled appointment. He didn't hear from or see anyone else.

"Clarissa's story about caring for Ernest": How lessons can be learned from a poor patient experience

This couple experienced communication issues from the hospital, potentially an overlong stay in hospital for Ernest, and did not receive the service provision required at home.

Ernest has dementia and Clarissa, his wife, is his full-time carer.

Clarissa explained how they had care support from Apex four times a day (NHS funded) which gave Clarissa time to do things around the house. They are also paying for regular support from Crossroads for someone to play games with Ernest to 'keep his mind active'. Clarissa also explained that they pay for weekend support from another care company.

Ernest had recently had a stroke and an ambulance was called. The paramedics suggested that he be taken to hospital, not due to the stroke which was resolved, but due to the knee pain he was still experiencing from an operation on his leg he had had earlier this year.

This hospital visit resulted in a nine hour wait in A&E, due to 'no bed being available for Ernest'. Clarissa couldn't understand why they had to wait so long for a scan and x-ray, which in the end just confirmed what she already knew – that the pain was due to Ernest's previous operation.

More frustrating for Clarissa, was the hospital's decision to admit Ernest. His stay was five weeks in total and Clarissa wants to know why he needed to be in so long. She feels strongly that this 'put us back six months' in terms of Ernest's ability to walk and in his confidence in general. Prior to his hospital admission, Ernest's walking was limited but now he requires constant help to move around their bungalow and he no longer enjoys sitting in the conservatory. He also lost a stone of weight while in hospital.

Having been in hospital for this length of time, meant Clarissa had to reinstate the care support that Ernest had received, prior to his admission. Clarissa repeated several times that she had requested a physiotherapist in hospital but has not received this support for Ernest. They were visited by the equipment and adaptation service, Adult Social Care, where the only requirement Clarissa had was for a ramp from the front door down to the drive. They have not received any follow-up on this. They also discussed mental health support to help with Ernest's confidence but again, there has been no follow-up.

"John's daughter's story": A positive discharge story

This patient received excellent service provision by community staff. He also experience smooth discharges from two hospital admissions.

John has poor short memory and therefore our volunteer spoke to his daughter.

John was discharged from the hospital in early October. He was discharged to a care home (as the family were on holiday at the time and unsure when he would be discharged) but subsequently moved in to stay with his daughter. The daughter explained that their experience had been excellent. John had been visited at his daughter's home by occupational therapists, physiotherapists and care link. They had been supplied with all the adaptions equipment John needed. The lady from Carelink was fantastic and helped push along their application to have John moved into sheltered accommodation. The occupational therapists were described as going "above and beyond" their expectations. The only negative was the social worker who was apparently unhelpful.

John was admitted back into hospital three weeks after his first discharge. The occupational therapists had noticed that he wasn't well and his GP advised that he returned to hospital as soon as possible. John had suspected pneumonia and possible norovirus. John stayed in for a week. His second discharge was again very good and the family have no complaints or concerns about the process – quite the opposite in fact. John was offered, but refused a care package at the point of second discharge. The occupational therapists followed this up around a week later to check that he hadn't changed his mind.

The only thing the daughter couldn't advise was what - if any – information John had been given prior to his discharge. But their post discharge experience had been excellent.

“Simon’s Daughter’s Story”: How lessons can be learned from a poor patient experience

This patient received poor communication in hospital regarding his discharge plans, including lack of information about why plans changed. His family were not kept informed either. Post discharge he did not receive the service provision he required.

There was confusion over where my Dad would go once he left hospital. We were told he would go to a rehab place in Hastings (but why so far away) and that he had to wait for a place to become available. So he waited - but was then sent to Haywards Heath hospital. [We were given] no explanation for change of plan. Then the plan changed again to no rehabilitation [provision] but to going [straight] home. He was pleased about going home, but I felt there should be continuing physio. [The hospital staff told us] that wouldn't happen for two weeks.

The Discharge Plan was given to Dad but not discussed with us.

We knew Dad had to have daily injections on his discharge which would be administered by a district nurse. I received a phone call from a district nurse on the day he was discharged, but she had the wrong address - for another patient with the same name as my Dad. She said not to worry, she would sort it out. But I didn't get another phone call to confirm.

It was very worrying because I didn't know if another nurse was coming or not. I had to phone the hospital who gave me the number of the agency, who then confirmed.

[My Dad] had [been given] most of the medication, but not enough paracetamol. [He was] also not [given] enough of the blood thinning injections which are required by the district nurse, so they had to be ordered from his GP. Luckily, he has a neighbour who was able to go and pick them up.

Dad has the mobility aids that he needs. But there is a step from the kitchen into [the] utility room where the fridge is. He hadn't practised [walking between these rooms] before he left hospital. So he had to buy a new fridge for the kitchen.

A physio is now coming once a week. But he is unable to have a shower or wash his hair on his own.

I think more care should have been put in place.

11. Data Tables

Supplementary Analysis:

Table A: Where did patients go after hospital?	No of patients	%
Own home	39	80%
Family home	4	8%
Nursing home/Rest home	4	8%
Home with warden support (on or offsite)	2	4%
Total patients visited at home	49	100%

Note: One patient had rehabilitation first before returning home. Another patient was discharged to a friend's house for a short while, before returning home. Both of these patients were interviewed at home. A third patient received respite before returning to the family home where we interviewed them.

The following tables (B, C and D) are where we have compared two questions to identify any relationship between them.

Table B: How long were patients in hospital for?	*N = No of patients*		
Q28: How long has patient been in hospital (staff question)?	N	%	
0-6 days	29	42%	mean time in hospital
7-20 days	29	42%	**10.7** days
21 days&+	11	16%	
	69	100%	
Table 21 (below) shows Q28 in more detail			
Q34: How much longer is patient likely to stay in hospital (staff question)?	N	%	
			mean time likely to be in hospital from now to discharge
0-6 days	24	41%	
7-20 days	26	44%	**13.8** days
21 days&+	9	15%	
	59	86%	
Q28+Q34 Combined in hospital already plus likely time to discharge*	N	%	
			combined: mean time estimate from admission to discharge
0-6 days	7	12%	
7-20 days	29	49%	**24.6** days
21 days&+	23	39%	
	59	100%	
**Only where both questions were answered*			

Table 21 below shows Q28 in Table B in more detail:

21. How long has the patient been in hospital? (Q28 hospital, not asked in online or home surveys)			
Days	Hospital Interviews	*Total Respondents*	Stranded or Super-stranded?
1	6%	4	Not stranded:
2	6%	4	Total Patients: 29
3	6%	4	42%
4	4%	3	
5	14%	10	
6	6%	4	
7	10%	7	Stranded: Admission above six days
8	3%	2	
9	6%	4	Total Patients: 29
10	6%	4	42%
11	1%	1	
12	3%	2	
14	9%	6	
18	3%	2	
20	1%	1	
21	4%	3	Super-stranded: Admission above 20 days
22	1%	1	
24	1%	1	
25	1%	1	Total Patients: 11
26	1%	1	16%
33	1%	1	
35	1%	1	
40	1%	1	
47	1%	1	
Total Answered	100%	69	

Table C: Did patients receive the support they expected?		Q11 Home Survey: What kind of support have you received?				
		No of patients			*%*	
Q14 Hospital Survey: What kind of support do you expect to receive?	Total	Yes	No		Yes	No
Care Agency	16	13	3		81%	19%
Occupational therapist (adaptation service)	5	3	2		60%	40%
Occupational therapist - Other	2	0	2		0%	100%
District nurse	4	2	2		50%	50%
Physiotherapist	6	4	2		67%	33%
Age UK	0	0	0		-	-
Possability People	0	0	0		-	-
Social Worker	2	0	2		0%	100%
Speech Therapist	3	1	2		33%	67%

Note: The numbers shown are only of those patients that were interviewed at home and comparing their answers, with the answers they gave in hospital.

Table D: Was the patient satisfaction with the discharge arrangements *at home* better as a result of receiving good advice and information *in hospital*?*	**Very Satisfied and Satisfied with the discharge arrangements**	**Unsatisfied and very unsatisfied with the discharge arrangements**
Very Good and Good advice and information (26 patients)	100%	0%
Poor and Very poor advice and information (10 patients)	0%	70%

**A comparison of Q21 Overall, how would you rate how good the advice and information was that you received vs. Q27a considering your overall experience, how satisfied were you with the discharge arrangements made for you? Where both questions were answered*

Survey Questions Asked:

Questions about the hospital experience: Directed to the patient and and/or carer/family member

1. What is the reason you/the patient came to hospital? (Q8 hospital, Q5 online, not asked in home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Respiratory	23%		7%	18		1	19
Fall	18%		20%	14		3	17
Chest Infection	3%		7%	2		1	3
Other infection	5%		0%	4		0	4
Urinary Tract Infection	1%		13%	1		2	3
Other	50%		53%	39		8	47
Total Answered	100%		100%	78		15	93

2. While being in hospital, do you (did you) feel overall that staff (have) treated you/the patient well? (Q10 hospital, Q6 online, not asked at home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes, fully	90%		67%	69		10	79
Yes, partly	9%		27%	7		4	11
No	1%		7%	1		1	2
Total Answered	100%		100%	77		15	92

3. Since being admitted to hospital, has anyone spoken to you/the patient about what might happen when you/they leave hospital /When you were in hospital, did anyone speak to you about what would happen when you left hospital? (Q11 Hospital, Q7 online, not asked at home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes	56%		73%	43		11	54
No	44%		27%	34		4	38
Total Answered	100%		100%	77		15	92

4. Where do you expect (the patient) to be going after hospital?/Where were you told you would go after hospital? (Q13 hospital, Q8 online, not asked at home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Own home	83%		93%	48		14	62
Other residence	9%		7%	5		1	6
Nursing home	3%		0%	2		0	2
Home with warden on site	2%		0%	1		0	1
Care home	2%		0%	1		0	1
Family home	2%		0%	1		0	1
Total Answered	100%		100%	58		15	73

5. What kind of support do you expect (the patient) to receive? /What kind of support were you told you would receive? Select all that apply. (Q14 hospital, Q9 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Social Worker	10%		8%	5		1	6
District Nurse	12%		0%	6		0	6
Care Agency	56%		15%	29		2	31
Occupational therapist (adaptation service)	12%		0%	6		0	6
Occupational therapist - Other	4%		0%	2		0	2
Physiotherapist	15%		23%	8		3	11
Mental Health Nurse	0%		0%	0		0	0
Red Cross	0%		8%	0		1	1
Alzheimers Society	0%		0%	0		0	0
Age UK	0%		8%	0		1	1
Possability People	0%		0%	0		0	0
Other	54%		54%	28		7	35
No of people who answered question				52		13	99

6. When do you expect (the patient) to be leaving? (Q15 hospital, not asked in the online survey or at home)							
				Total Respondents			
Days	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
0	19%			11			11
1	20%			12			12
2	15%			9			9
3	5%			3			3
4	3%			2			2
6	2%			1			1
7	2%			1			1
100	2%			1			1
Don't know	32%			19			19
Total Answered	100%			59			59

7. What advice and information did you/have you (the patient) received? Select all that apply. (Q17 hospital, Q10 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Advice about independent living (including adapting home)	13%		0%	5		0	5
Advice about independent living (Care link)	10%		0%	4		0	4
Advice about social services	10%		0%	4		0	4
Information on district nurses	5%		0%	2		0	2
Other support services e.g. home help, help with shopping etc.	23%		0%	9		0	9
Advice about medication	36%		0%	14		0	14
Advice on diet and liquid intake	3%		0%	1		0	1
Info on social groups and local activities	0%		0%	0		0	0
Telecare (elderly person alarm)	5%		0%	2		0	2
Other	21%		29%	8		2	10
None	15%		71%	6		5	11
No of people who answered question				39		7	46

8. Do you/did you feel involved in the decisions being made regarding plans for your/the patient's care when you/the patient leave hospital? (Q18 hospital, Q11 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes definitely	43%		36%	24		5	29
Yes partly	32%		21%	18		3	21
No	25%		43%	14		6	20
Total Answered	100%		100%	56		14	70

9. If Yes (to 8. above) How? Select all that apply. (Q19 hospital, Q12 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Given options for accommodation	14%		0%	4		0	4
Given options for different care/support	34%		0%	10		0	10
The care/support you had before hospital has been discussed and considered in planning your discharge	41%		60%	12		3	15
You (the patient) has been asked for your opinion	48%		40%	14		2	16
No of people who answered question				29		5	34

10. Were you/the patient helped to understand the options? (Q20 hospital, Q13 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes fully	53%		36%	25		4	29
Yes partly	26%		9%	12		1	13
No	21%		55%	10		6	16
Total Answered	100%		100%	47		11	58

11. If Yes (to 10. above) How? Select all that apply. (Q21 hospital, Q14 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Explanation of types of accommodation	12%		0%	3		0	3
Explanation of types of care/support	65%		0%	17		0	17
Explanation of any changes to your care from before you entered hospital to when you leave	15%		25%	4		1	5
Given the option to clarify anything not understood	27%		100%	7		4	11
Other	12%		0%	3		0	3
No of people who answered question				26		4	30

12. Were you/the patient given the opportunity to talk about any concerns you/they had? (Q22 hospital, Q15 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes	71%		46%	36		6	42
No	20%		38%	10		5	15
Don't know	10%		15%	5		2	7
Total Answered	100%		100%	51		13	64

13. Are/were you confident that the arrangements being made will/would be suitable for you/the patient to live away from hospital? (Q23 hospital, Q16 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes fully	67%		38%	34		5	39
Yes partly	22%		15%	11		2	13
No	12%		46%	6		6	12
Total Answered	100%		100%	51		13	64

14. Were you/the patient provided with any written information on your/their care plan? (Q24 hospital, Q17 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes - Discharge letter with information on medication, care contact details etc.	12%		38%	6		5	11
Yes - Discharge letter without any additional information	0%		0%	0		0	0
Yes - 'Let's get you home' leaflet	4%		0%	2		0	2
Yes - 'Planning your discharge' booklet.	2%		0%	1		0	1
Yes - I have seen my care plan and I am assigned to a social worker	4%		0%	2		0	2
Yes - Other	10%		8%	5		1	6
No	69%		54%	36		7	43
Total Answered	100%		100%	52		13	65

15. Did you/Do you/the patient feel prepared to go home? (Q25 hospital, Q18 online, not asked at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes fully	57%		50%	31		7	38
Yes partly	26%		21%	14		3	17
No	17%		29%	9		4	13
Total Answered	100%		100%	54		14	68

16. Was your/the patient's discharge later than you/the patient were originally told? (not asked in hospital, Q19 online, Q22 in home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes		26%	15%		12	2	14
No		74%	85%		34	11	45
Total Answered		100%	100%		46	13	59

17. By approximately how many days? (not asked in hospital, Q19a online, Q22a in home)							
				Total Respondents			
Days	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
1		27%	50%		3	1	4
2		36%	0%		4	0	4
3		27%	0%		3	0	3
5		0%	50%		0	1	1
35		9%	0%		1	0	1
Total Answered		100%	100%		11	2	13

18. What were the reasons for the delay? Select all that apply. (not asked in hospital, Q20 online, Q23 in home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Medication/prescriptions not ready		9%	50%		1	1	2
Care home place not available		0%	0%		0	0	0
Care home couldn't' accept me on the discharge day		0%	0%		0	0	0
Occupational therapist had not assessed my home for adaptation		0%	0%		0	0	0
My home had been assessed but adaptations had not been made		0%	0%		0	0	0
Patient transport service not available		0%	0%		0	0	0
Care package being put in place		55%	0%		6	0	6
Other		45%	50%		5	1	6
No of people who answered question					11	2	13

19. Overall, how satisfied are/were you with the arrangements being made for leaving hospital? (Q26 hospital, not asked online or at home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Very Satisfied	43%			21			21
Satisfied	29%			14			14
Neither Satisfied nor Unsatisfied	20%			10			10
Unsatisfied	4%			2			2
Very Unsatisfied	4%			2			2
Total Answered	100%			49			49

Questions about the hospital experience: Directed to the staff

20. Is this patient considered "frail" by the hospital? (Q27 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes	60%			42			42
No	40%			28			28
Total Answered	100%			70			70

Table 21 is under supplementary analysis

22. Is this a readmission patient ie discharged and readmitted for related conditions since 1st January 2018 (Q29 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes	26%			18			18
No	74%			52			52
Total Answered	100%			70			70

23. If Yes (to 19. above) How many days ago was the patient in last? (Q30 hospital, not asked in online or home surveys)							
				Total Respondents			
Days	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
1	18%			2			2
7	27%			3			3
10	9%			1			1
21	9%			1			1
28	18%			2			2
60	9%			1			1
62	9%			1			1
Total Answered	100%			11			11

24. If Yes (to 19. above) Where was the patient living before he/she was admitted this time to hospital? (Q31 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Own home	83%			15			15
Nursing home	6%			1			1
Other	11%			2			2
Total Answered	100%			18			18

25. Where is the patient likely to be discharged to once they leave hospital? (Q32 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Own home	80%			55			55
Family home	1%			1			1
Nursing home	6%			4			4
Care home	1%			1			1
Newhaven Rehabilitation	1%			1			1
Cravenvale Rehabilitation	0%			0			0
Knoll House Rehabilitation	0%			0			0
Other temporary home	1%			1			1
Home with warden on site	0%			0			0
Other	9%			6			6
Total Answered	100%			69			69

26. If Q32 rehabilitation - Where is patient likely to go after this? (Q33 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Own home	100%			1			1
Total Answered	100%			1			1

27. How long is patient likely to be in hospital for? (Q34 hospital, not asked in online or home surveys)							
				Total Respondents			
Days	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
0	8%			5			5
1	8%			5			5
2	7%			4			4
3	5%			3			3
4	3%			2			2
5	10%			6			6
7	16%			10			10
8	3%			2			2
9	2%			1			1
10	3%			2			2
11	2%			1			1
12	3%			2			2
14	3%			2			2
16	7%			4			4
17	2%			1			1
18	3%			2			2
22	2%			1			1
23	2%			1			1
25	3%			2			2
27	2%			1			1
36	2%			1			1
100	5%			3			3
Total Answered	100%			61			61

28.Has the patient received information on discharge? (Q35 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes	52%			35			35
No	48%			32			32
Total Answered	100%			67			67

29. If Yes (to 25. above) What kind of information as he/she received? Select all that apply. (Q36 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Discharge letter with info on medication, care contact details etc.	20%			7			7
Discharge letter without any additional information	0%			0			0
'Let's get you home' leaflet	6%			2			2
Planning your discharge' booklet	0%			0			0
Care plan explaining arrangements for after hospital	40%			14			14
Verbal information only	37%			13			13
Other	9%			3			3
No of people who answered question				35			35

30.What condition is the patient in hospital for? (Q37 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Respiratory	27%			19			19
Fall	10%			7			7
Other infection	3%			2			2
UTI	4%			3			3
Other	56%			39			39
Total Answered	100%			70			70

31. Did the patient have a care plan before they entered hospital? (Q38 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes	38%			25			25
No	62%			41			41
Total Answered	100%			66			66

32. What kind of support did they receive? Select all that apply. (Q39 hospital, not asked in online or home surveys)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Social worker	4%			1			1
District nurse	22%			5			5
Care agency	78%			18			18
Occupational therapist (adaptation service)	4%			1			1
Occupational therapist - Other	0%			0			0
Physiotherapist	9%			2			2
Mental health nurse	4%			1			1
Red Cross	0%			0			0
Alzheimers Society	0%			0			0
Age UK	0%			0			0
Possability People	0%			0			0
Other	9%			2			2
No of people who answered question				23			23

Questions about the home experience: Directed to the patient and and/or carer/family member

33. Since I visited you in hospital, have you been readmitted?/Have you been readmitted to hospital this year? (not asked in hospital, Q23 online, Q2 in home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes		17%	7%		8	1	9
No		83%	93%		39	14	53
Total Answered		100%	100%		47	15	62

34. Why were you readmitted? (not asked in hospital, Q25 online, Q4 in home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Respiratory		38%	0%		3	0	3
Urinary Tract infection		0%	0%		0	0	0
Chest infection		0%	0%		0	0	0
Other infection		0%	0%		0	0	0
Fall		13%	0%		1	0	1
Other		50%	100%		4	1	5
Total Answered		100%	100%		8	1	9

35. Where did you go after hospital? (not asked in hospital or at home, Q27 online)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Own home			93%			13	13
Family home			0%			0	0
Nursing home			0%			0	0
Care home			0%			0	0
Newhaven rehabilitation			0%			0	0
Cravenvale rehabilitation			0%			0	0
Knoll House rehabilitation			0%			0	0
Other temporary home			0%			0	0
Home with warden on site			0%			0	0
Other residence			7%			1	1
Total Answered			100%			14	14

36. What issues made the arrangements effective/ineffective? (not asked in hospital, Q28 online, Q7 home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Reasons given for effective arrangements							
Information was provided		37%			17	0	17
Understanding about information provided		22%			10	0	10
Suitable arrangements		37%			17	0	17
Accessing support		39%	25%		18	1	19
Ability to self-manage		28%			13	0	13
Clarity around instructions about medications		13%			6	0	6
Medication provided		35%			16	0	16
Ability to get the medication needed		7%			3	0	3
Explanation of why medication has been presented/changed		9%			4	0	4
Contact with Care link		4%			2	0	2
Appropriate/completed Adaptations		15%			7	0	7
Other-positive		17%			8	0	8
Reasons given for ineffective arrangements							
Lack of information provided		7%			3	0	3
Lack of understanding about information provided		4%			2	0	2
absent arrangements		7%	75%		3	3	6
Unable to access support		7%			3	0	3
Inability to self-manage		9%			4	0	4
Unable to get the medication needed		2%			1	0	1
Incomplete adaptations		2%			1	0	1
Other-negative		13%			6	0	6
Mixed or neutral experience of arrangements							
Other-neutral		7%			3	0	3
Other-mixed		9%			4	0	4
Total Answered			100%		46	4	50

37. Please rate how well arrangements for where you lived went? (not asked in hospital, Q29 online, Q6a home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Very effective		21%	50%		10	6	16
Effective		53%	8%		25	1	26
OK		13%	17%		6	2	8
Ineffective		11%	17%		5	2	7
Very ineffective		2%	8%		1	1	2
Total Answered		100%	100%		47	12	59

38. Did anyone from the healthcare service make contact to find out how you/the patient were getting along following discharge? (not asked in hospital or online, Q8 home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes		76%			34		34
No		24%			11		11
Total Answered		100%			45		45

39. If yes to 38. Who contacted you? Select all that apply. (not asked in hospital or online, Q9 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
District Nurse		30%			10		10
Social worker		9%			3		3
Occupational therapist (supplying mobility and equipment/safety aids)		36%			12		12
Other Occupational therapist		12%			4		4
Care link		9%			3		3
Finance Team		0%			0		0
Care agency		52%			17		17
Other		55%			18		18
Carers/Family members only: Carer's assessment		3%			1		1
Carers/Family members only: Carer's hub		0%			0		0
Carers/Family members only: other Carer's support		3%			1		1
No of people who answered question					33	0	37

40. If no to 38. Would a follow-up call within 30 days after discharge, have helped you/the patient? (not asked in hospital or online, Q10 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes a lot		18%			2		2
Yes somewhat		9%			1		1
No		45%			5		5
Don't know		27%			3		3
Total Answered		100%			11		11

41. What kind of support have you received after leaving hospital? Select all that apply. (not asked in hospital, Q30 online, Q11 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Social worker		11%	9%		5	1	6
District Nurse		36%	0%		16	0	16
Care agency		50%	9%		22	1	23
Occupational therapist (adaptation service)		25%	0%		11	0	11
Occupational therapist (other)		14%	0%		6	0	6
Physiotherapist		25%	18%		11	2	13
Mental health nurse		0%	0%		0	0	0
Red cross		0%	0%		0	0	0
Alzheimers society		0%	0%		0	0	0
Age UK		2%	9%		1	1	2
Possability people		2%	0%		1	0	1
Other		43%	64%		19	7	26
No of people who answered question					44	11	55

42. Were there any serious problems with the arrangements made? (not asked in hospital, Q31tomatch online, Q12 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes		22%	33%		10	2	12
No		78%	67%		36	4	40
Total Answered		100%	100%		46	6	52

43. If Q42 is yes, what were the problems with the arrangements made? Select all that apply (not asked in hospital or online, Q13 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Understanding about information provided		20%			2		2
Appropriate arrangements		40%			4		4
Accessing support		40%			4		4
Ability to self-manage		30%			3		3
Clarity around instructions about medications		0%			0		0
Suitable medication provided		10%			1		1
Getting the medication needed		20%			2		2
Contact with Care link		0%			0		0
Suitable/completed adaptations to home		0%			0		0
Not knowing who to contact		20%			2		2
Other		80%			8		8
No of people who answered question					10		10

44. Did you know who to contact should a problem arise? (not asked in hospital or at home, Q32 online)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes			73%			8	8
No			27%			3	3
Total Answered			100%			11	11

45. Overall, how would you rate how well the arrangements for support are? (not asked in hospital, Q33 online, Q14 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Very Good		27%	40%		12	4	16
Good		56%	10%		25	1	26
OK		2%	10%		1	1	2
Poor		4%	40%		2	4	6
Very Poor		11%	0%		5	0	5
Total Answered		100%	100%		45	10	55

46. Were you/the patient involved in the decisions about leaving hospital? (not asked in hospital or online, Q15 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes fully		44%			20		20
Yes partly		27%			12		12
No		29%			13		13
Total Answered		100%			45		45

47. How? Select all that apply (not asked in hospital or online, Q16 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Given options for accommodation		4%			1		1
Given options for different care/support		25%			7		7
The care/support you had before hospital was discussed and considered in planning discharge;		64%			18		18
Patient was asked for their opinion		54%			15		15
No of people who answered question					28		28

48. Were you/the patient provided with any written information on your/their care plan? (not asked in hospital or online, Q17 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes - Discharge letter with information on medication, care contact details etc.		53%			24		24
Yes - Discharge letter without any additional information.		16%			7		7
Yes - “Let’s get you home” leaflet, “Planning your discharge” booklet.		2%			1		1
Yes - (I am assigned to a social worker) and have seen my care plan.		11%			5		5
Yes - Other		11%			5		5
No		22%			10		10
No of people who answered question					45		45

49. Would you/the patient have felt more prepared if you/the patient had received something written? (not asked in hospital or online, Q18 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes		50%			5		5
No		30%			3		3
Don't know		20%			2		2
Total Answered		100%			10		10

50. Were you able to access enough food and drink, and any support you/they needed to be able to eat well? (not asked in hospital, Q35 online, Q20 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes		98%	63%		45	5	50
No		2%	38%		1	3	4
Total Answered		100%	100%		46	8	54

51. Overall, how would you/the patient rate how good the advice and information was that you received? (not asked in hospital, Q36 online, Q21 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Very Good		19%	36%		8	4	12
Good		42%	27%		18	3	21
OK		14%	9%		6	1	7
Poor		21%	27%		9	3	12
Very Poor		5%	0%		2	0	2
Total Answered		100%	100%		43	11	54

52. On reflection, do you feel you were/the patient was fully prepared for going home? (not asked in hospital, Q18 online, Q25 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes fully		58%	50%		26	7	33
Yes partly		31%	21%		14	3	17
No		11%	29%		5	4	9
Total Answered		100%	100%		45	14	59

53. In what way did you feel prepared/not prepared? Select all that apply (not asked in hospital or online, Q26 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Ways given for feeling prepared							
Information provided		11%			5		5
Understanding about information provided		7%			3		3
Appropriate arrangements		47%			21		21
Accessing support		31%			14		14
Ability to self-manage		16%			7		7
Clarity around instructions about medications		16%			7		7
Suitable medication provided		29%			13		13
Getting the medication needed		18%			8		8
Contact with Care link		4%			2		2
Suitable/completed adaptations (to home)		9%			4		4
Other-positive		7%			3		3
Ways given for not feeling prepared							
Lack of information provided		7%			3		3
Lack of understanding about information provided		7%			3		3
Inappropriate/absent arrangements		4%			2		2
Unable to access support		9%			4		4
Inability to self-manage		11%			5		5
I didn't feel ready to leave hospital		4%			2		2
Other-negative		16%			7		7
Neutral comments							
Other-neutral		9%			4		4
No of people who answered question					45		45

54. Considering your overall experience, how satisfied were you/the patient with the discharge arrangements made for you/them? (not asked in hospital, Q37 online, Q27 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Very satisfied		27%	38%		12	5	17
Satisfied		48%	15%		21	2	23
Neither unsatisfied nor satisfied		9%	15%		4	2	6
Unsatisfied		11%	15%		5	2	7
Very unsatisfied		5%	15%		2	2	4
Total Answered		100%	100%		44	13	57

55. If you/the patient were readmitted, do you feel the arrangements made this time around were better than the first time? (not asked in hospital or online, Q29 home)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Better		0%			0		0
Same		50%			4		4
Worse		50%			4		4
Total Answered		100%			8		8

56. Patient only: I have been feeling optimistic about the future. (not asked in hospital or online, Q30 home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
None of the time		10%			4		4
Rarely		15%			6		6
Some of the time		30%			12		12
Often		40%			16		16
All of the time		5%			2		2
Total Answered		100%			40		40

57. Patient only: I have been dealing with problems well. (not asked in hospital or online, Q31 home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
None of the time		3%			1		1
Rarely		10%			4		4
Some of the time		33%			13		13
Often		38%			15		15
All of the time		18%			7		7
Total Answered		100%			40		40

58. Patient only: I have been feeling good about myself. (not asked in hospital or online, Q32 home)

				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
None of the time		3%			1		1
Rarely		10%			4		4
Some of the time		38%			15		15
Often		38%			15		15
All of the time		10%			4		4
Total Answered		100%			39		39

Demographic questions

The following questions were not asked of the home survey patients as they had already been asked these questions in hospital

				Total Respondents			
Age Group	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
65-70	18%		25%	13		3	16
71-80	39%		42%	28		5	33
81-90	30%		25%	21		3	24
91+	13%		8%	9		1	10
Total Answered	100%		100%	71		12	83

				Total Respondents			
Gender	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Female	64%		67%	49		10	59
Male	36%		33%	27		5	32
Total Answered	100%		100%	76		15	91

Sexuality	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Heterosexual	100%		93%	57		13	70
Gay	0%		7%	0		1	1
Lesbian	0%		0%	0		0	0
Bisexual	0%		0%	0		0	0
Total Answered	100%		100%	57		14	71

				Total Respondents			
Ethnic Origin	Interviews			Interviews			
Only the ethnic origins that were responded to, are recorded here	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
White British	96%		93%	70		14	84
White Irish	1%		0%	1		0	1
White - Other	1%		7%	1		1	2
Mixed White & Asian	1%		0%	1		0	1
Total Answered	100%		100%	73		15	88

				Total Respondents			
Disability	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Yes	50%		43%	31		6	37
No	50%		57%	31		8	39
Total Answered	100%		100%	62		14	76

If yes to disability, **Type of Impairment.** Select all that apply. (Q46 Hospital, Q43 Online)							
				Total Respondents			
	Hospital Interviews	Home Interviews	Online Survey	Hospital Interviews	Home Interviews	Online Survey	Total respondents
Physical Impairment	67%		83%	20		5	25
Sensory Impairment	3%		33%	1		2	3
Learning Disability	0%		0%	0		0	0
Long Standing Illness	23%		17%	7		1	8
Mental Health condition	7%		17%	2		1	3
Other	17%		33%	5		2	7
No of people who answered question				30		6	36