



Sussex
NHS Commissioners

healthwatch
In Sussex

ROAR Programme - Third Project

Understanding patient and family/friend carer experience of rapid COVID-19 hospital discharge



July 2021



Content

Sussex Health and Care Partnership’s Discharge Mission Statement

Through positive and collaborative leadership, we will work together as a health system to ensure patients are discharged when they are ready, regardless of the time or day of the week, by focussing on mutual trust between providers and basing success on outcomes achieved for individuals, not on individual organisational indicators.

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What we set out to achieve

The engagement is part of a wider funded programme of collaborative engagement work, between Sussex NHS Commissioners and local Healthwatch in Sussex, known as the ROAR programme. This is the third project in the ROAR programme (for 2020/2021) and is part of a phased engagement plan looking at hospital discharge. Please note that this engagement was originally planned for last quarter of 2020, but due to system pressures related to the second wave of COVID, it was agreed to delay the project.

Over the past year, COVID has meant changes to the way patients are discharged from our hospitals; together, the Sussex NHS Commissioners' Public Involvement team and Healthwatch in Sussex **wanted to better understand patient and informal carer (family and friend) experience of the more rapid discharge from hospital, and the impact this has on the patient's future care at home.** (See Appendix A for the scope of this work).

Ultimately, this work will help inform more effective discharge planning and process and post discharge support for patients, and for their families and informal carers when a stay in a Sussex hospital is needed.

This work needs to influence hospitals' discharge processes and adult social care (where applicable), through leaders, to their staff. This is to ensure hospital teams and individual patients and their carers/families follow a jointly-planned and well-communicated process for leaving hospital, rather than experiencing an isolated event at the end of the patient's stay. It is important to link the processes in hospital to the reality of post-discharge care at home.

The insight gathered through this engagement builds on an earlier insight review, and is intended as a **pilot/proof of concept** to inform the potential for further steps (subject to funding and system appetite).

As discharge planning is a journey, this engagement explored patient experience of early communication through to their preparedness for post-hospital care, either at home or in a different setting. Engagement was carried out through a semi-structured post-discharge telephone interview with 45 people (who were either patients or their family/friend carers). The questions (see Appendix B) were co-designed and included feedback from residents and community ambassadors.

We were mindful of the need to listen for indications of health inequalities; however, the difficulty in identifying a substantial group of patients, compounded by the limited mechanisms for engagement owing to the need for social distancing, has meant that understanding demographics in relation to health inequalities has not been a focus of this phase of the research. The Sussex NHS Commissioners' Public Involvement team plan to explore with inclusion engagement funded partners, how future engagement could be more inclusive. This will be explored in the Phase 4 plans.

Each of the three local Healthwatch carried out 15 semi-structured telephone interviews (therefore a total of 45 experiences) with people (or their family carers) who had stayed in one of the following hospitals during April 2021:

Bexhill Hospital

Conquest Hospital

Eastbourne Hospital

Princess Royal Hospital

Royal Sussex Hospital

Rye Hospital

Current lived experience understanding and insight

What is known:

- Phase 1 - Sussex Health and Care Partnership Discharge Support - Patient and Public Feedback Review (August 2020) details insight to inform the reporting of this project.
- Healthwatch Brighton and Hove and Healthwatch East Sussex have gathered evidence through their wellbeing check services, and this will be reviewed and themes/trends from these included in the reporting of this project.
- Sussex NHS Commissioners should have access to information for West Sussex from the teams providing follow-up checks, which should be reviewed and any themes/trends from these included in the reporting of this project.

Recommendations

This report and the recommendations were shared with the hospital Trusts for factual accuracy and comment before being published. As this was a pilot/proof of concept, the work was small scale, aimed at gathering qualitative feedback. There is currently no further funding allocated for Healthwatch to continue exploring this area; further discussion will take place when looking at this report to agree next steps.

1. Where it is necessary for a discharge process to change, as was [necessary in 2020/21](#), it was right to stop issuing the 'Lets Got You Home' leaflets to avoid giving patients misleading information. However, it is important to recognise the need to rapidly develop and issue alternative information (including in alternative formats if required) so people can still benefit from being able to familiarise themselves with written information.
2. Healthwatch in Sussex have made many recommendations over the last seven years to encourage Trusts to ensure that patients and their family/friend carers are involved at all stages of discharge planning and understand that this is a formal process. This sample demonstrates, again, that this is not systematically the norm.

We therefore strongly recommend the Sussex Health and Care Partnership co-designs a standard discharge checklist (with a minimum set of requirements) and an audit process to ensure this is a process requirement. This needs to include:

- Reference to how people can make sure patients and their family/friend carers understand they are taking part in a planning conversation.
 - Not relying on a single conversation, but enable people to reflect and ask questions at different stages of their hospital stay, recognising that whilst discharge planning starts from the first day, not all patients are in a position to understand and recall what is had been said on day 1.
 - Making reaffirming “count down” to leaving hospital everyone’s business (from the consultants to the housekeeping staff).
3. In the Healthwatch England Report¹ (published in October 2020) a short-term recommendation to ‘*provide everyone leaving hospital with a follow-up contact, always assigning a single point of contact*’, remains important today as it did in October 2020. With under half the people not able to remember if they were given details, we recommend more work is carried out to consistently implement this.
 4. We also recommend that family/friend carers are given a point of contact whilst the relative/friend is in hospital.

1

https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20201026%20Peoples%20experiences%20of%20leaving%20hospital%20during%20COVID-19_0.pdf

Themes

Through this engagement, we aimed to identify a baseline of:

- Themes and trends of good practice
- Themes and trends of weakness in the process/pathways (including communication)
- Areas that may put people's safety at risk or increase the likelihood of quick readmission.

We have based themes on the Sussex Health and Care Partnerships (our integrated care system) principles for discharge (see Appendix D for the full list of principles). The detailed findings can be found in Appendix A.

Principle 1: Early discharge planning

Under this principle:

- Patients have an agreed discharge plan, including an estimated date for discharge from when they are admitted.
- Health and social care work with individuals and their families to plan for and deliver the estimated date for discharge.
- Discharges take place on the same day as the decision is made that the patient no longer needs to reside in hospital.

26 people (58% of the 45 interviewed) do not remember having any information about hospital discharge. Of the remainder, 17 people (38% of the 45) found verbal and written information easy, very easy or neutral to understand. A further 2 patients found it difficult to understand the information.

None of the 45 people interviewed remembered having the [Let's Get You Home](#) Leaflet but this would have been due to the use of a different leaflet, due to the changes stemming from pandemic needs. While this is a result of COVID-19 Infection Control measures, the feedback from participants suggest that patients were not given any source of written information to help them understand how discharge planning works.



Apart from 10 interviewees (which correlates to the number of planned admissions) people were very vague about when discharge was first mentioned, how involved they were and what they were told.

This concurs with other studies and implies that more attention still needs to be given to this aspect of care; repeated conversations need to take place and written documentation needs to be explained otherwise it is not remembered.

The focus was on treating infection. No talk of going home until 10 days into stay.

They talked a lot to each other and not always to me, but I didn't mind because they know what they're doing and I just do what I'm told!

Principle 3: Home first discharge to assess

Under this principle:

- Assessments under the Care Act, continuing healthcare and mental capacity take place in people's own homes unless a short period of stepdown reablement is required.
- Decisions about long term care are not made in hospital but after people have accessed reablement/intermediate care services.

The majority of people (42, 93%) felt ready to go home. Only three people reported not feeling ready to be discharged. However, of those that did feel ready, they expressed feeling rushed and unprepared for 'coping' at home, particularly those living alone.

Most people had their medication explained, or were already familiar with it, so were prepared in this way, for leaving hospital. Two people reported experiencing difficulties with medication running out due to receiving less than 7 days worth or because of administration errors.

Some of the commentaries indicate some excellent examples of good practice to support people leaving hospital (see page 15.)

In most cases, people felt they either already had the equipment they needed at home, or this was arranged before leaving hospital/rehab. Notably, four people experienced issues with these arrangements.

Less than one half of interviewees remembered being given details of who, how and when to contact the hospital if they had concerns about the medical condition that led to them being in hospital. In most cases, people were told to contact their GP or to go to A&E if they were concerned.

6 in 10 people felt the care arrangements were as expected after leaving hospital, with most of the comments being positive. Some comments suggested that progress has been made. However, some people reported still being in a lot of pain.

Seven people had experienced a setback, one mentioning that they had fallen at home afterwards. This suggests falls prevention referral should be a consideration for future discharge pathways.

Despite the system suggesting that people receive welfare calls from the hospital (or on behalf of the hospital) only seven people received such a call or a visit from the hospital. It may be, that this is not considered when patients go to a care home/rehab or step-down facility?

We asked how well people had coped after leaving hospital and whether there was anything that would have made this better for them. Two people mentioned that better communication from services about recovery would have been useful.

Principle 7: Engagement and choice

Under this principle:

- People and their family and carers are engaged and supported to go home or to a stepdown facility to enable them to make a considered choice about future care and support needs.
- All staff understand choice and can discuss discharge proactively.
- Voluntary services support people regardless of how they fund their care, ‘Home to Hospital’.

The self-assessment of the system suggests that *‘due to lack of engagement, patients and their family and carers are frequently not involved in planning for discharge early, resulting in limited ability to make informed decisions about the options available.’*



I was told where I was going. Equals not given any choice.

I felt that I needed a more personal ‘one-to-one’ session, as I was not fully receptive to [what they were suggesting].



When asked, 4 out of 10 patients said that staff spoke to them about plans for leaving hospital throughout their stay. However, patient comments told a different story. It was also clear that families felt out of the loop in what was being planned.

Three-quarters of family carers **were told the person was going to be discharged.** **However,** it seems this was often only for the purpose of ensuring the family were available to collect the patient. Also, when practical problems arose, it was suggested that communication broke down.

These findings have been identified previously by Healthwatch in Sussex, and others, as shown in the Phase 1 reporting, the changes in discharge processes necessitated by COVID-19 brings the need for change and improvement into sharper focus. Hospital staff need to be more explicit in their communication, so people are fully aware they are discussing plans for leaving hospital and onward care. We have also recommended that information is shared with patients clearly and in an appropriate (ideally written) format, as well as verbally. Bringing people on the discharge journey is important, which is why we have previously recommended that patients and their informal carers are involved in any conversation about their own discharge and particularly where decisions are made.

Principle 10: Communication and information sharing

Under this principle:

- Discharge plans are agreed by individuals, families, carers, clinicians and other professionals and are consistently adhered to by everyone involved in the person's care
- Information regarding discharge plans is shared with the individual and their families/carers as well as between organisations
- Communication is shared in a timely manner - including changes to a patient's condition.

Those patients who had gone into rehab were generally pleased. One person suggested that although the facilities were good, they were unable to use them as there was not enough staff to supervise.

One half of the people we spoke to said their family carers had been given a point of contact within the hospital. This was to enable the family to stay in touch with how the patient was doing, and where this was the case, people commented positively. Family members of other patients struggled to get any information or updates. Patient comments suggested that many families experienced some form of difficulty getting access to information and/or talking to the patient.

Regarding information provided to patients to help them care for themselves at home, only 15 out of 36 people rated this as extremely helpful or very helpful. A further 13 suggested the information was somewhat helpful. However, in some cases the information was inappropriate, for example, abbreviated terms were used and therefore not understood and/or pages were missing.

“ They gave me a lot of information verbally, but once the decision was made that I could go home I was too busy thinking about the plans and feeling so relieved to be able to leave that a lot of the conversations went a bit over my head to be honest. ”

Important insight

At the end of the interview, we asked people for their final thoughts, and whilst many shared positive comments and gratitude, some of the narrative should be a concern to leadership teams.

- *“My hospital stay was ‘dreadful’, due to being cold and draughts coming through the windows.”*
- *“No TV, phone, books, newspapers so was very bored.”*
- *“Left too long on commode at night.”*



- *“Daughter was shocked to find a DNR form when her mother was discharged. She feels her mothers would not have been in a state to make a reasoned judgment and that the family had not been involved in this conversation. It should not have come without warning.”*
- *“Hygiene issues in ICU. The patient acquired fungal infections, basic washing was not attended to.”*
- *“Person is aware that the hospital experience has left her with anxiety problems, but is recovering and optimistic about their future.”*
- *“Night staff were unable to assist the person because ‘one had back problems and the other an arm injury’.”*

Our learning

Quality of forwarded information: In some cases, the listed phone numbers forwarded to Healthwatch (after consent) were incorrect or not appropriate. Several numbers went straight through to GP surgery switchboards. One contact number was given as the Next of Kin but was the phone number of an estranged relative who was very unhappy at being contacted.

This should raise concern beyond this review. If the information is wrong, people may fall through the gaps of aftercare.

Structuring the conversation: If the work is continued, the questionnaire schedule needs to be reviewed. Items that go together are dotted around rather than bunched, making the interview at times, hard to navigate. A suggestion would be to start the questioning with how the person is so that you get a feel of whether they are fit enough to answer and what their worries are. Afterwards, discharge questions could follow.

General observations from interviews

Disorientation of care journey: Several people found it difficult to know when they had gone into hospital and when discharged and how long they had been in hospital. That appeared to be either because they were quite muddled by their hospital experience (not their mental capacity, for example, dementia), or had been in and out of hospital or had rehab at the end so remembering dates and experiences was difficult. If this data is crucial for future analysis, it might be best to have it from the hospital.

Acuity of poor health: On the whole, participants seemed a very *poorly* group of people. Most were very old, and contrast to the age-group of referrals for wellbeing checks, as experienced by Healthwatch Brighton and Hove.

It seemed that none had had a follow-up call, which leaves a question as to who is monitoring the wellbeing of these people?

Proof of concept: This report demonstrates the importance of having a way of finding out if changes are right for patients as well as for managing the demand and flow of patients in hospital.

Thank you and personal impact

We would like to thank our system partners who have enabled this work to happen. This is particularly at a time when discharge teams have had to work incredibly hard to cope with the demand in the middle of a pandemic.

Similarly, a thank you to the a previous hospital patient and the community ambassador, who tested out and fed back on the questions used for this engagement.

Thank you to the 45 people who took part in our interviews and who spoke with honesty and offered such valuable insight.

To our fantastic interviewing team:

- Duncan Stewart
- Frances McCabe
- Gaye Webb
- Jenni Wright
- Jo Tuck
- Kate Mclachlan
- Pam Lovegrove
- Phil Hale

Our interviewers, as well as gathering insight, have also supported people to:

- Follow-up on second COVID-19 vaccination that was missed due to being in hospital.
- Encourage someone who was experiencing pain to phone and discuss this with their GP.

Context and Methodology

Phase 1 - Desktop research carried out by Sussex NHS Commissioners. The research drew together the available insight and evidence relating to discharge experience during the pandemic. This was reviewed, and compared and contrasted against the findings and recommendations in the Healthwatch England/Red Cross [Report](#) published on 27 October 2020.

Phase 2 - Gathering of patient and family/friend carer experience (this engagement). This is a pilot/proof of concept so activities were planned on a small scale when compared to the volume of Sussex residents discharged from hospital during the pandemic.

Phase 3 - Triangulating insight to summarise recommendations from Phase 1 and 2 and discussion with health and care stakeholders to develop action plans.

Consideration of health inequalities and further insight needed from protected characteristic groups

Mapping of “what good looks like” based on insight, and testing concept with key stakeholders

Phase 4 - To be developed from the learning from other phases. This phase may include an application to NHS Charities to extend this to work within the system in order to identify any necessary developments to improve supportive discharge.

The discharge engagement will inform the decision-making of the Additional Capacity Oversight Group, responsible for the delivery of this part of the Long Term Plan for the Sussex Health and Care Partnership (our Integrated Care System).

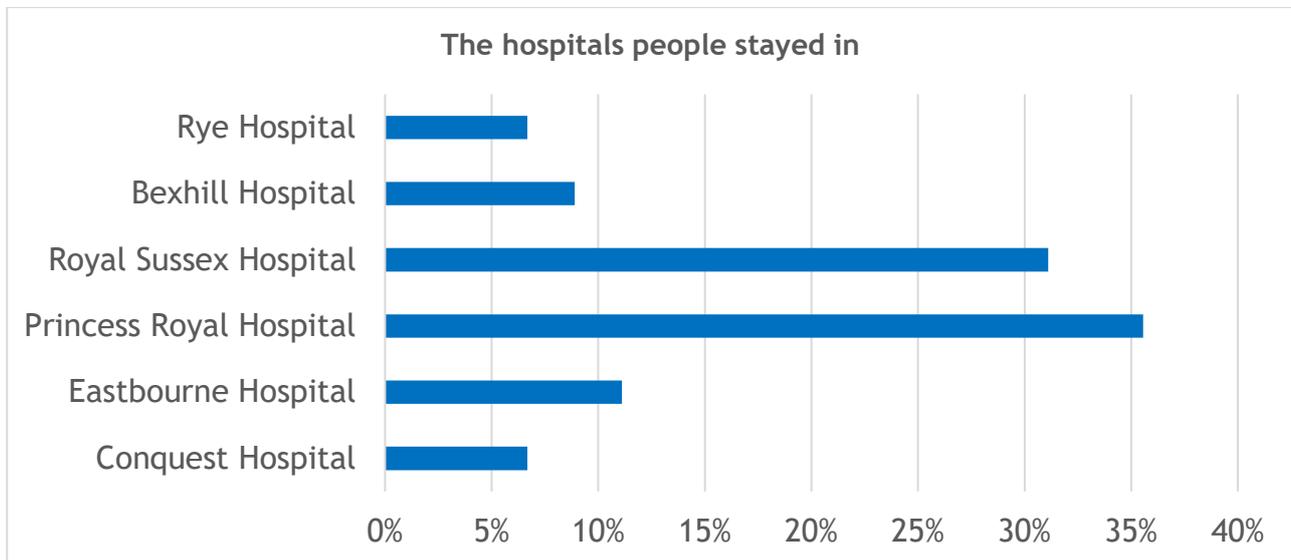
Where possible, this work will also look at improving people’s ability to care for themselves through access to better information and clearer processes.

As discharge planning is a journey, this engagement explored patient experience of early communication through to their preparedness for post-hospital care, either at home or in a different setting. Engagement was carried out through a semi-structured post-discharge telephone interview with 45 people patients. The questions (see Appendix B) were co-designed and included feedback from residents and community ambassadors.

We were mindful of the need to listen for indications of health inequalities; however, the difficulty in identifying a substantial group of patients, compounded by the limited mechanisms for engagement owing to the need for social distancing, has meant that understanding demographics in relation to health inequalities has not been a focus of this phase of the research.

To mitigate the lack of choice and potential exclusion of people who cannot participate in phone conversations, it was originally planned that the Discharge Teams would be asked to promote the completion of a questionnaire to people who do not wish to or cannot participate in a semi-structured telephone interview. However, the pandemic pressures have meant this was not viable within the timeframe of the project.

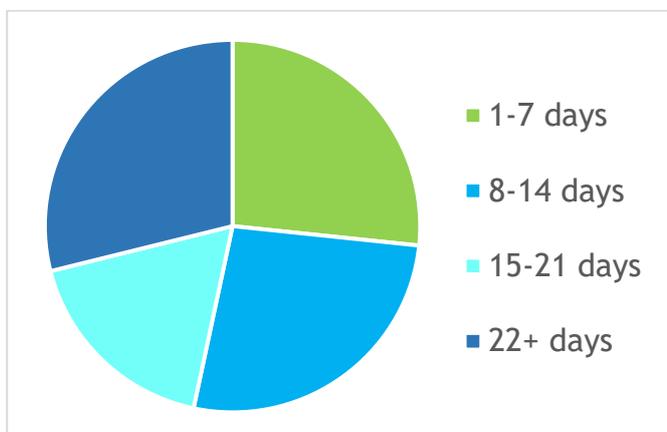
Detailed findings



We asked people when they had left hospital. Most people were able to give details of when, which ranged from the six weeks ago to the end of April. For others, this was not a straightforward question.

“ I cannot remember as [the patient] has been in and out of a number of hospitals recently.
Not sure, I’ve been in and out of hospital four times recently as I’ve been falling. Last time a friend called the paramedics and I was taken to A&E.”

Peoples’ length of stay in hospital(s):



Nearly half of the participants had been in hospital for more than a fortnight, with some in hospital for a longer period of time.

Seven people spoke of being in more than one hospital as a result of their health condition(s).

Less than a quarter had been in hospital for a planned procedure/reason.

Principle 1: Early discharge planning

We asked people what they remembered being discussed about the plan for leaving hospital before they arrived on a ward. One half (51%) said this was not discussed.

There were three examples where the communication could be considered a success.



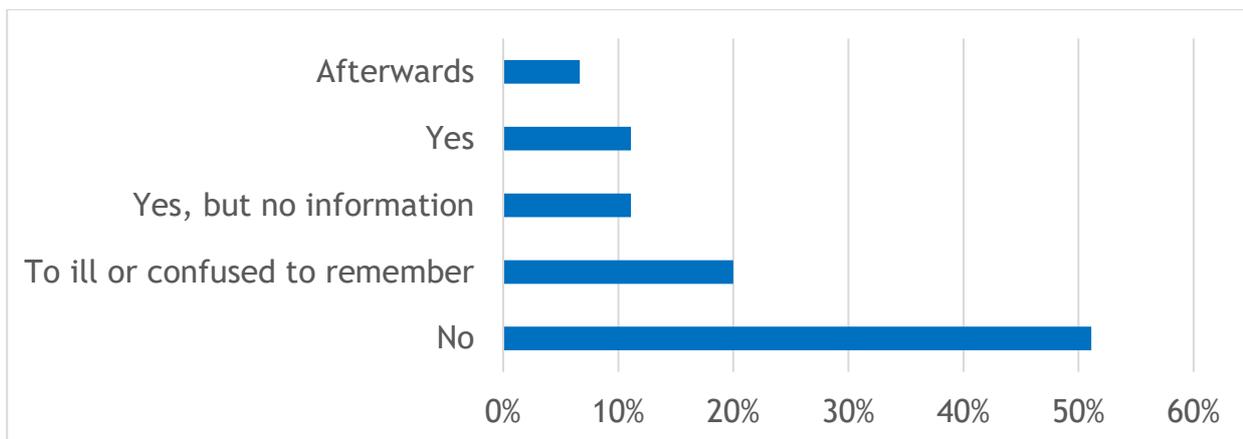
When I was in A&E they said I would be in for about a week but they also said if this or that, then it would be longer.

At the pre-admission appointment I was told to expect to be in hospital for a few days. Don't remember getting any paperwork - although did get a leaflet about the procedure and what to expect afterwards, which was helpful.

I was told at the pre-admission clinic that I would be in hospital for a few days. There were some complications so it was a little longer.



Given that 10 people had referred to having a planned procedure, it is interesting that only 5 remember having written information beforehand.



Nine people (20%) remembered discharge planning discussions happening early in their hospital journey.



Never received the leaflet and discussion around discharge began towards the end of my hospital stay.

Most of the conversation was with my partner, due to memory issues. Conquest phoned her to tell her about the transfer to Bexhill and that it was for rehab.

Spoke to my daughter. No, in fact, was given very little notice of discharge despite phoning each day. Was just told she would be discharged when she was medically fit, then given less than 24 hours notice.

I was in a lot of pain and had a lot of drugs, so was a bit floaty.



Out of 22 (i.e. those people who gave an answer to the question), one half felt the information given to them was easy/very easy to understand. However, 6 felt it was neither easy nor difficult, and 2 found it difficult to understand the information.



No issues with communication but appointment (pre-admission) felt rushed and not much time to ask questions.



Many people commented that there was no discussion/information available.

Principle 3: Home first discharge to assess

Only three people reported not feeling ready to be discharged, but others expressed feeling rushed and unprepared for 'coping' at home, particularly those living alone.



I was rushed out of hospital to make way for COVID patients. I was told I was leaving immediately in the middle of my breakfast..



Nearly 82% (36 people) said they were prescribed medication/medical items to take home, and over one half of these (52%) said the medication was explained to them before leaving hospital. Four people said they received no explanation, out of which one person's comment suggested they did not need any explanation as they knew what the medication was for.

Only 35% (16 people) remembered being asked by the staff if they needed any support with getting their ongoing medication once they had left hospital. Two people reported experiencing difficulties with medication running out due to receiving less than 7 days' worth or because of administration errors.



I had good written information about the medication.

I would really have liked someone from the GP surgery to visit me, as I'm in considerable pain. I did ring the surgery but was told they had not received my discharge papers yet.

Obviously too busy!! The pain has shifted from the side to the front, making me very uncomfortable. They only person to have contacted me since I was home is the man about some physio. I am going to ring the surgery again tomorrow. I did need some additional tablets from the Chemist, and they kindly delivered them to me in person.

Some of my medicines were discontinued in hospital and I was sent out with less than a week's supply. It took 7 days for my GP to return a call about prescriptions, some of which I had run out of.



We asked people how soon after being told they were ready to leave hospital, did they leave the ward/room. The responses varied hugely from immediately to days. Comments suggested delays were due to arranging care packages, additional adaptations or transport.

Some of the commentaries indicate some excellent examples of good practice to support people leaving hospital.



A member of the ward staff went down with me to the entrance to make sure I was OK and got the taxi OK.

I was told I'd be discharged at 2.15pm, so they cooked me some dinner, but the ambulance arrived at noon, so I missed my lunch. However, the hospital made-up some sandwiches for me to take home, so I would not go hungry.

Lots of lovely well wishes and very good care from the nurses on the ward. They taught me how to get out of the chair in a better way and gave me tips about carrying a cup of tea, when I got home and stuff like that



Often the delays in actually leaving came down to the availability of transport. 71% (32 people) were offered transport to leave hospital, with only a couple of people reporting that they were not asked how they would get home.

One person shared that their drug chart did not accompany them to rehab. This caused a delay in receiving analgesics, which left them in pain for some hours.

Most people felt they either already had the equipment they needed at home, or this was arranged before leaving hospital/rehab. Notably, four people experienced issues with these arrangements.



I was provided with a hoist but this was about three weeks' after being discharged. I have only been out of bed once. I am unable to get out of bed without a hoist.

Was provided with a walking stick and rails were installed in my home but I need a walk-in shower.

Someone provided me with two frames and a grab rail. I could do with another rail outside and I think I have the man's number somewhere so I will ring him or ask my surgery when I ring them.

I was supplied with a walking frame that was too big and it took 10 days for the physio to replace it.



Only 42% (18 people) remembered being given details of who, how and when to contact the hospital if they had concerns about the medical condition that led to them being in hospital. Four people could not remember if they had been given this information. In most cases, people were told to contact their GP or to go to A&E if they were concerned.

62% of people (26) said that the care and support from health and care staff in their own home (or the home they stayed in when they left hospital) happened in the way they had expected it to. Most of the comments (28 people) were positive and spoke of progress being made.

We also asked people about how well they had coped after leaving hospital and whether there was anything that would have made this better for them. Two people mentioned that better communication provided in hospital about what to expect at home/from services once at home would have improved their discharge experience. The majority of people said there was not anything else that could have made things better.



Not really, but taking a long time to recover and I think my rehab could have been more active.

I was talked in to having a carer, who insisted on helping to wash me. Would have been better to have asked what was needed, e.g. getting breakfast/making my bed.

It would have been nice to have someone at my home or someone to visit. I live alone and was pretty much left to my own devices. I was physically OK, really, but I was very tired and quite lonely to be truthful, after the hustle and bustle of the ward.



The majority of people (84%, 37) did not get a follow-up telephone call or visit to see how they were after their hospital stay from or on behalf of the hospital. It may be that this is not considered where people go to a care home/rehab or step-down facility?

72% of people (32) felt they were recovering/recovered as they had hoped. Seven people had experienced a setback.

- One person had fallen since and had to go back to hospital.
- One person had acquired a hospital infection, so was readmitted from rehab.
- Another felt the same since being in hospital so did not see the point of the treatment.
- Several people mentioned they were still in pain. Others expressed having difficulties coping with issues arising from their condition.

Principle 7: Engagement and choice

Just over one half of the people responded positively to the question about being involved and included in plans for leaving hospital, but only 4 people felt they were able to influence the plan.

“
The [patient] wanted to return home sooner than the hospital would agree to this, so they felt they did not listen to her.
They were very rushed and so the discharge was very quick. They needed the bed.
I was informed that I was to be discharged to a care home, paid for by the NHS, as a form of convalescence. It was not up for discussion beforehand, but as I was perfectly happy for the hospital to make the decision and do all the arranging, I was not bothered.
I was very anxious about leaving the security of the hospital but accepted the need for the transfer.”

79% (34 of the 43 patients who answered this question) said their family carers were told they was going to be discharged. However, this was usually in order that the carer could collect them. However, when practical problems arise, there was a suggestion by patients that the communication broke down.

“
Discharge was planned for one day and all told this in the morning. But at lunch time all told that no transport could be arranged and so I was not being discharged. However, they later were told an ambulance was available and so I was discharge, but my son was not informed and so was not at home to greet me.”

We asked if the staff on the ward spoke to the person *throughout* their stay, about the hospital's plans for them leaving hospital, when they were ready. 40% of patients (18) said yes to this question, but their subsequent comments told a different story.

There was a stark difference in the comments from “*Staff would talk everyday about plans for going home - making preparations, etc.*” to “*Don't recall any such conversations taking place*”.

“
I (daughter) made a point of seeking information during hospital visits.
I remember one or two chats with the Sister when the doctors did their ward round. But mainly they talked to each other, not to me.
Only towards the last couple of days.”

People recalled being tested for COVID at different times of their hospital stay but many were not given the result. In the case of one person, this created fear about being taken home in a shared ambulance.

Principle 10: Communication and information sharing

One half of the patients said their family carers had been given a point of contact within the hospital, so they could stay in touch about how the patient was doing. Where this was the case then people commented positively. However, comments suggest for other families, they experienced some form of difficulty getting access to information and talking to the patient. This was for a variety of reasons, including:

- The patient changed wards multiple times during their stay
- The phone was often engaged or unanswered for long periods of time
- Family members were told someone would phone back, but they never did.

“

Sometime my [relative] couldn't get through and sometime the person they spoke to didn't know about me or my condition and they were told that someone would call them back - but they never did.

”

Patient feedback indicates a lack of information being provided to patients on advice about caring for themselves after leaving the hospital.

“

Good information regarding pain expectations and advice on lifting and pain management. Otherwise not much information at all.

The discharge letter was full of abbreviations, so was difficult to understand.

Was given a leaflet/guidance for lumbar patients but some of the pages were missing.

I was given simple exercises but thought these were too simple and not really helpful.

I was given medication, but no follow up from anywhere was arranged or received.

”

Scope of the engagement/project

For the purpose of transparency and to manage expectations we have detailed below the scope of this project. We acknowledge that the limitations of this work will mean that there are gaps in the understanding of experiences and it is hoped this will be addressed in Phase 4.

This was a small-scale, qualitative engagement project to identify some broad themes to inform more focused work and future decision-making.

The primary focus was on interviewing individual patients or their informal carers whose hospital stay would have led to the patient being discharged on pathway 1 or 2 (see below).

Discharge to assess model – pathways

Pathway 0

50% of people – simple discharge, no formal input from health or social care needed once home.

Pathway 1

45% of people – support to recover at home; able to return home with support from health and/or social care.

Pathway 2

4% of people – rehabilitation or short-term care in a 24-hour bed-based setting.

Pathway 3

1% of people – require ongoing 24-hour nursing care, often in a bedded setting. Long-term care is likely to be required for these individuals.

<https://www.gov.uk/government/publications/hospital-discharge-service-policy-and-operating-model/hospital-discharge-service-policy-and-operating-model>

For people categorised as experiencing Pathway 0, separate access to individuals will be discussed and included in more detail in Phase 3 and 4.

Locally and nationally, it is understood that currently, it is difficult to gain access to individuals who have been through Pathway 3.

We aimed to avoid contacting people where the discharge was for end of life care, as we felt the timeframe did not allow for sensitive development and refinement of the engagement activities.

The main element of the work was engaging with people through phone interviews, due to the current social distancing requirements. This meant that it potentially excluded those who either cannot use the telephone or who do not have the confidence to use a telephone as a method of communication. Originally it was planned that the hospital Trusts would be asked to offer access to the hard copy/online questionnaire to patients in hospital who could not communicate over the phone or did not wish to have a phone call but may want to share their experience. However, the pandemic situation did not allow for this.

Should a participant have been identified as only able to participate through a translation service, then their involvement would have been managed through the Sussex Health & Care Partnership's engagement team, as they have access to appropriate support (such as SignHealth and interpreting services). However, this was not the case.

As this engagement is the proof of concept/pilot phase of the project, we did not work with Sussex Partnership NHS Foundation Trust (who run the Acute Mental Health Hospitals in Sussex) or Sussex Community NHS Foundation Trust (who run the community hospitals in Sussex). However, this will be considered within Phase 4 of the project.

The short timeframe and small number of interviews being undertaken mean:

- the scope for understanding why people are sometimes quickly readmitted to hospital (known as a failed discharge) is limited
- children's experiences did not form part of this engagement, but young adults who stayed on adult wards will be included if the Trusts provide contact details. This was not the case in the end.

Patients who have stayed in an acute hospital outside of Sussex were not included in this work. Instead, the Sussex Health and Care Partnership's Public Involvement team will be exploring with others what engagement is taking place to understand the discharge experiences of Sussex residents.

Questionnaire

These are the initial ideas for semi-structured questions:

1. Which hospital did you stay in?
2. When did you leave hospital?
3. How long were you in hospital?
4. Was your stay in hospital planned (for a scheduled procedure) or unplanned?

How well did the hospital staff explain the plan for you leaving hospital

Discharge planning starts as soon as patients are admitted.

5. What do you remember being discussed with you about the planning for leaving hospital, before arriving on the ward?
6. Did you understand the information given?
7. Were there any reasons why you may not have been able to take this information in, and if so, what would have helped?
8. Did the staff on the ward continue to speak to you about plans for you leaving hospital?
9. Did you feel included and involved in the plan?
10. Is there anything that would have helped?

How well did the hospital staff communicate with any people that are important to you, for example your family or carers?

11. Having spoken to your family/friends since leaving the hospital, how well did they say they had been involved or kept informed about the plan for you leaving hospital?
12. Were your family/family carers given a point of contact to get in touch with to see how you were while you were in hospital?

Preparedness for post-hospital care

13. Did you feel ready to leave hospital when you were discharged?
14. How soon after you were told you were leaving hospital did you leave the ward/room? Where did you go after that? (discharge lounge?)

15. Did the hospital check with you that you had transport to get you home, and if you didn't, were you offered transport?
16. Were you prescribed any medication to take home with you? Did the hospital explain what it was for and how to take it? Did you have to wait long for it before you were discharged?
17. Did the hospital ask you if you needed any support with getting your ongoing medication once you were home?
18. If you needed any equipment to help with your recovery once you were home, were you provided with the right information and contact details to obtain it?
19. Were your family/family carers told that you were being discharged?
20. Did you have a COVID-19 test while you were in hospital?
21. If you did have a test, if you didn't get the results before leaving hospital, did the hospital explain to you how to self-isolate until you received the results?

For most patients, even those receiving support from others, there is an element of caring for yourself when you are discharged. For example:

- understanding how you keep your wound clean
 - dietary restrictions/recommendations
 - medication - what you can carry on taking and what you need to stop, as well as how to take your medication
 - signs and symptoms to watch out for.
22. Thinking back, do you feel you were given the right information to help you care for yourself? If not, what would have helped?
 23. Were you given details of who and how to contact them if you had concerns about the medical condition that led to you being in hospital?
 24. If you had a package of care or support from health or care staff in your home, or the home you stayed in when you left hospital, did this happen in the way you had expected? If not, what happened?
 25. Thinking about how well you coped when you left hospital, is there anything that would have made this better for you?
 26. Did you get a follow-up telephone call or visit to see how you were after your hospital stay and if yes, was this helpful?
 27. Are you recovering as well as you had hoped from your hospital stay? Have you had any setbacks?
 28. Do you have any final thoughts you would like to share with us about your hospital stay or your discharge?

10 Discharge Principles

These are taken from the Sussex A&E Discharge Board - Discharge Improvement Plan (May 2021).

Principle 1 : Early Discharge Planning

- All patients have an agreed discharge plan, including an estimated date for discharge (EDD) and planned discharge pathway, at the point of admission
- People have a clear understanding of when their treatment is going to happen, what it will achieve and when they will go home
- Health and social care work with individuals and their families to plan for and deliver EDDs
- Discharge planning includes community, social services and voluntary sector as part of an MDT
- All patients go home on the date agreed on or near to admission
- All discharges take place on the same day as the decision is made that the patient no longer needs to reside in hospital

MDT = Multi-Disciplinary Team

Principle 2 : Monitoring and responding to system demand and capacity

- Capacity matches demand and responds in real-time to variations
- A sophisticated understanding of system demand informs decision making at all levels
- Flow across the system is smooth, timely, safe and effective
- Outcome destinations reflect a Home First D2A approach
- Partners use data to examine flow and have a shared understanding of the cause of poor outcomes for patients or reduced capacity in the system

Principle 3 : Multi-disciplinary working

- MDTs are established across all wards
- Daily MDT's meetings take place, attended by adult social care, community, VCSE and mental health
- MDT's operate a Home First D2A approach to discharge, with community teams working to pull individuals out of hospital and assess at home or in a step-down facility
- MDT staff trust each other's' assessments and discharge plans, using a trusted assessment and reablement approach

Principle 4 : Home First Discharge to Assess

- Home First D2A is the destination of choice for all – individuals, families, carers, clinicians and other professionals involved in a person's care.
- Home First D2A is seen as a safe alternative to bedded care
- Assessments under the Care Act, continuing health care and mental capacity take place in people's own home unless a short period of step down reablement is required
- Decisions about long term care are not made in hospital but after people have accessed reablement/intermediate care services.





Principle 5 : Flexible working patterns

- 7 day working ensures assessments and decisions about long term care take place when the individual is ready, regardless of time or day of the week, and in an individual's own home or reablement step-down facility
- Transport, pharmacy, housing etc are in place to support smooth discharges when the individual is ready, regardless of time or day of the week
- Care providers accept new referrals and restarts for packages of care when the individual is ready, regardless of time or day of the week.

Principle 6 : Trusted assessment

Independent care sector assessments

- An assessment is being carried out on behalf of several providers by someone trusted by all providers

Within hospital (acute or community)

- Assessments are carried out in people's own home or in step-down facilities for more than one purpose across several pathways – initial screening ensures it's safe to do so drawing on expert advice if needed

Adult social care

- Eligibility determinations are carried out by a third party when the local authority is unable to do so

Principle 7 : Engagement and choice

- People and their family and carers are engaged and supported to go home or to a step down facility to enable them to make a considered choice about future care and support needs
- All staff understand choice and can discuss discharge proactively
- Voluntary services support people regardless of how they fund their care, home to hospital

Principle 8 : Improved discharge to care homes

- Care homes and systems work in tandem to facilitate discharges 7 days a week, including evenings
- Care homes are supported by a named clinical lead and have access to primary care support
- Care homes report few poor discharges or failed discharges
- People with increased acuity are well managed in care homes due to a strong support network with primary and community care
- Care homes are well supported by access to out of hours/urgent care services, particularly weekends and evenings, to prevent unnecessary admissions





Principle 9 : Housing and related services

- The system uses demand, capacity and impact data to improve support to people of have housing needs or are homeless
- Discharge is timely because staff know a person's housing status on admission and act on their support needs.
- Housing staff are part of discharge support services to deliver joined up services
- Support for home adaptations, equipment, telecare and health is quick and easy to access and is delivery promptly.

Principle 10 : Communication and information sharing

- Discharge plans are agreed by individuals, families, carers, clinicians and other professionals and are consistently adhered to by everyone involved in the person's care
- Information regarding discharge plans is shared with the individual and their families/carers as well as between organisations
- Communication is shared in a timely manner – including changes to a patient's condition

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