Experiences of Hospital Discharge in East

Sussex: Survey Findings - August 2021

What we did...

Between February and April 2021, Healthwatch ran a web-based survey to gather experiences of anyone living in East Sussex who had been discharged [as an inpatient] from hospital between December 2020 and the end of April 2021.

Our goal was to understand how hospital discharge was functioning during the third national 'COVID-19' lockdown.

We focused our questions on capturing feedback on four themes:

- 1. Positive aspects of the experience and those people felt could be improved?
- 2. Whether people received all the information and support they needed?
- 3. If people had any outstanding concerns?
- 4. Anything people still needed help or support with?

This report provides a brief summary of the key themes identified in the responses to the survey.

Whilst offered in hard-copy and online, responses were overwhelmingly electronic, and we acknowledge these limitations and its potential impact on the inclusivity of the responses.

Who did we hear from?

36 people completed our survey.

We heard from 11 people discharged in December 2020, 7 each in January, February and March and 4 in April 2021.

Respondents were across all age groups, including 2 people aged 18 or younger (5.6%), 18 people between 19 and 64 (50.0%) and 15 people aged 65 and older (41.7%). One person didn't want to disclose their age (2.8%).

Nearly three quarter of respondents answered on their own behalf (72.2%), with the remainder (27.8%) being made by people on behalf of those they care for.

The hospitals that people had most commonly been discharged from were the Conquest Hospital [Hastings] (14 - 38.9%) and Eastbourne District General Hospital (12 - 33.3%). Other respondents were discharged from hospitals in Kent, West Sussex and Brighton and Hove.





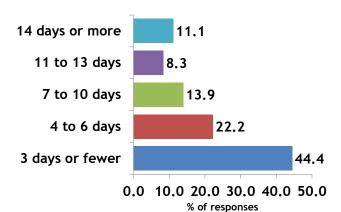


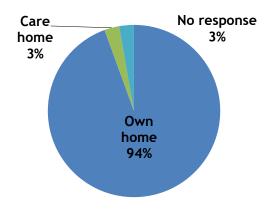
What you told us

Duration in hospital

The most common length of hospital stay was 3 days or fewer (16 - 44.4%).

Four out of five of those responding (29 - 80.5%) had spent ten days or fewer in hospital.





Location of discharge

The overwhelming majority of people were discharged from hospital into their own home (34 - 94%).

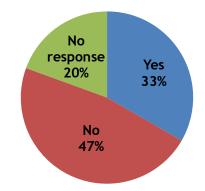
One person (3%) was discharged into a care home and one other did not specify their discharge location (3%).

Information received in hospital

We asked people whether they were given sufficient information about their health condition and treatment whilst in hospital.

Nearly half of the survey respondents (17 - 47%) felt that their expectations were <u>not</u> met concerning the information they received.

Responses included:



"Too disoriented on discharge to fully understand what was going on..."
"Lack of communication not only to patient but family, Hospice and nursing home."
"Dementia patient did not understand what was happening to her."
"I would have liked to know what sort of mesh had been used for my operation. I was so drugged up on painkillers immediately afterwards when the surgeon returned to see me, that I forgot to ask and it doesn't say on the discharge letter."

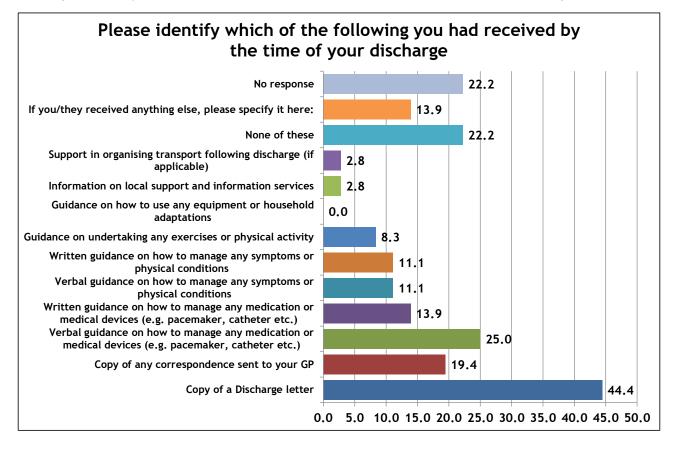
Information provided at point of discharge

We acknowledge that the types of information people receive may vary based on the reasons for their hospital stay, but we were interested in the information offered to them by the time of their discharge.

Two-fifths of respondents (16 - 44.4%) received a copy of their hospital discharge letter, and a fifth (7 - 19.4%) received copies of the correspondence sent to their GP. Concerningly 8 respondents (22.2%) indicated that they received neither of these documents or any other information.

Responses suggest that a greater proportion of respondents received *verbal* guidance on how to manage any medication or medical devices, compared to *written* guidance. Lack of written information could result in patients misunderstanding or forgetting important points about their self-care, recovery process and increase the likelihood of requiring support following discharge.

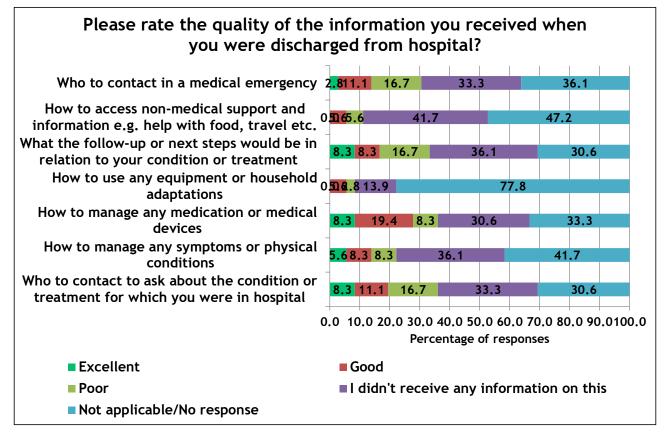
It is noticeable that only one respondent identified that they received any information on local support and information services. This could indicate a missed opportunity to inform patients about community & voluntary sector services. Timely contact with these could potentially reduce non-clinical self-referrals to GPs and other health professionals.



Quality of information at point of discharge

We asked patients to rate the quality of the information they received when discharged from hospital.

The graph below provides a breakdown of the proportion of responses and ratings against different types of information. This identifies where information was received, and whether it was viewed as Excellent, Good or Poor.



Where information was received, that most frequently rated as Excellent and Good concerned the management of medication or medical devices, who to contact about next steps for their condition or treatment and how to use any equipment or household adaptations.

However, in a high proportion of cases, patients were discharged without receiving certain information. For example, two-fifths (15 - 41.7%) did not receive any information on how to access non-medical support and information, such as assistance with obtaining food, travel and other day-to-day necessities. This may be an important consideration in a period of lockdown, where support from traditional support mechanisms such as friends and family may be less accessible.

Just over a third of respondents 36.1% (13) did not receive any information on how to manage symptoms or physical conditions, and a third of (12 - 33.3%) did not get any details of who to contact in a medical emergency. Similarly, 5 people (13.9%) needing equipment or household adaptions did not receive information on how to use it.



What information may have been valuable at the point of discharge?

Our survey asked what information people felt would have been valuable but was not provided at the point of discharge.

We received a range of responses and examples are provided below:

"I would usually have received some "How those looking after me could physio and a chart showing me what I support and care for me when I was could/couldn't do during recovery but most vulnerable." this time I didn't. I was only told 'no heavy lifting'." *"Family not given opportunity to talk"* "My hospital notes pre-admission clearly stated that the hospital face to face with anyone due to no visitors but when a patient has arranges the District Nurses visits, dementia they will not remember any but the discharge nurse flatly refused information given." to do this and I had to do it myself 2 days later." "What effective medication I could "Pamphlets or booklets on how to manage buy OTC [Over The Counter] once the own care after a stroke or heart attack. Who to contact when a stroke happens again (diff. prescribed medication was finished to 1st time) Who to contact i.e. Stroke or would I need to go back to GP?

Who, when and where surgical dressings would be changed."

Association (unless hospital arrange this) A booklet to inform and reassure the patient that all will be well."

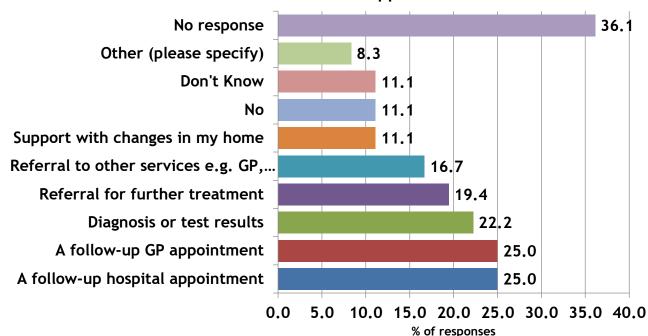
The responses indicate that patients expected that they would:

- receive clear details of what they can and cannot do after discharge, ideally in a written format that they can refer to or show others (carers) when required
- have their support needs clarified, both for themselves and their carers, and have information provided to them about how this could be accessed
- have follow-up services and post-discharge support organised on their behalf
- receive clear details on how their symptoms should be managed after they are discharged
- have greater guidance on self-care and self-medication in the period after discharge

Unmet patient expectations

A key objective of this survey was to explore whether discharged patients had any expectations around follow-up services or forms of support, but which had not happened. The graph below identifies how frequently respondents identified that expectations had been set, but not met.

After you were discharged from hospital, were there any particular services or types of support you were expecting, but which have not happened?



More than a fifth of respondents indicated that their expectations had not been met in relation to receiving a follow-up hospital appointment (9 - 25.0%), follow-up GP appointment (9 - 25.0%) or a diagnosis or test results (8 - 22.2%).

Less commonly identified issues included referrals for further treatment (7 - 19.4%), referrals to other services (6 - 16.7%) and support with changes in the home (4 - 11.1%).

One respondent commented:

"The surgeon told me that he would ring me with a virtual appointment at 4 weeks. I have not had this, and have tried ringing the hospital appointments people 3 times, but they have been unable to give me an appointment. I had a list of questions that I wanted to ask, but couldn't. I couldn't get an appointment with my GP either, until this morning, when I was diagnosed with Diverticulitis."



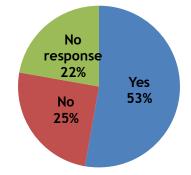
Suitability for discharge

In order to explore whether patients felt that they were being discharged ahead of time, at the right moment or with a delay, we asked patients 'Did you feel ready to leave hospital at the point you were discharged?'

Half of those responding (19 - 53%) indicated that they were ready to leave hospital at the point they were discharged.

However, a quarter (9 - 25%) did not.

Did you feel ready to leave hospital at the point you were discharged?



Some respondents offered reasons why they had not felt ready at the point they were discharged:



As indicated above, different factors played a role in determining whether patients felt that their hospital discharge came too soon. These included:

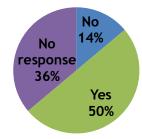
- not feeling physically ready, due to ongoing pain, illness or disorientation
- the timing of their discharge, which may have made it challenging to travel and/or seek support from family, friends and carers
- Concerns over the support available within the discharge environment



Ongoing needs

In order to better understand the situation of discharged patients, respondents were asked whether they had any ongoing concerns about their health, care or wellbeing?

Half of those responding (18 - 50%) identified that they had an ongoing need and 5 (14%) indicated no further concerns, often with positive reflections provided. Do you still have any aspects of your health, care or well-being that you are concerned about?



Those with concerns were asked to identify and explain what these were and what impact they had. These covered a variety of themes including:

- Ongoing physical symptoms, including pain and discomfort
- Conflicting information and advice from health professionals, leading to anxiety over the appropriateness of the course of treatment being received
- A lack of contact with health services and care, including follow-up support and appointments; creating concern about the level of assistance being provided
- Limited clarity on future treatment and symptom management

Examples of the comments provided are included below:

"My GP has put me on one [HRT] that I'm unsure is that same as my gynae consultant wanted, but when I called his secretary, she said I'd already been discharged so I should speak to my GP."

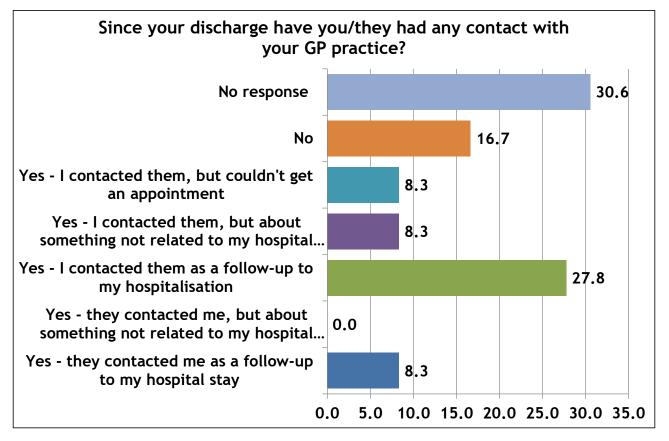
"Still suffering the same symptoms but no follow up." "Continuous abdominal discomfort and griping abdominal pain."

"I am receiving excellent attention for my conditions by the GP and consultants."

Contact with GPs

Linkages with GPs form an important part of the discharge process, often representing the first port-of-call for patient follow-up after their discharge, but also as a support mechanism should any issues arise. Obtaining timely access is important in either case.

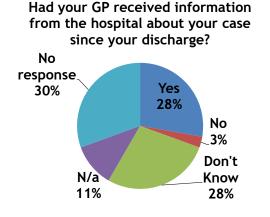
Approximately half the respondents (19 - 52.8%) had contact with their GP after their discharge, with 84% of these interactions being initiated by patients and 16% by GPs. 8.3% (3) of respondents highlighted making contact but being unable to make an appointment.



We asked survey participants if they had contact with their GP since their discharge, and if so, whether they had received information from the hospital about their case.

A quarter of respondents, 28% (10) indicated that their GP had received information about their discharge. However, the same proportion did not know.

Reassuringly, only a small proportion (3%) indicated that they knew for certain that the GP had not received their discharge information. However, this may still have implications for the individuals concerned.



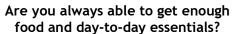
Access to day-to-day essentials post-discharge

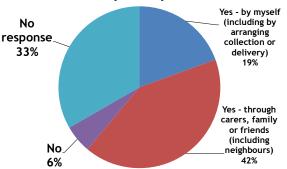
Discharge from hospital during COVID-19 lockdown periods may be different to normal circumstances, and this may affect people's ability to obtain day-to-day essentials and the support they may be able to receive from family, carers and friends.

A majority (22 - 61%) of the respondents we heard from indicated they were able to get enough food and day-to-day essentials after discharge.

Two-fifths obtained these with the support of others (42%), and the remainder were able to access them on their own (19%).

These figures highlight the dependence of discharged patients on others, and the





value of providing discharge information in a form that may be shared with family, carers and friends to enable them to support the patient effectively.

Two respondents (6%) highlighted that they were not always able to get the day-to-day essentials that they require.

Unfortunately, no detail was offered on their circumstances or the significance of their needs. However, this does illustrate the importance of providing appropriate contact information to discharged patients so that they can seek assistance, especially in relation to non-medical or health issues.

During the COVID-19 pandemic, <u>Community Hubs</u> have been used as the primary mechanism for offering support to those unable to access it themselves, lacking assistance from family or friends, or simply unclear on how or where to seek assistance.

Providing information on Community Hubs and clarifying their role with patients before they are discharged would provide a useful safety net to help ensure that everyone has a pathway through which they can access day-to-day essentials and signposting should the need arise.

Comments on the 'whole' hospital discharge experience

A range of reflective comments were received on people's overall experience, and some examples are provided below:

"The hospital were lovely during my stay. I couldn't fault them. My only concerns have been since I was discharged, I felt very abandoned."

"All staff were very efficient and caring."

"Dementia patients should be allowed to have some visits from family as they are totally bewildered by their stay and feel like family have abandoned them."

"My respect form was just handed to me as I left: on reading it at home it was very inaccurate stating I was not married (I am) was of no mental capacity...I am. Subsequent telephone conversation with my GP has corrected these inaccuracies." "As the only BAME patient on the ward I felt isolated and alone. Made to feel my ailment was less important and occupying space that a COVID patient could use. Felt helpless and neglected because of the perceived blame placed upon me, making me question myself and become insular and depressed."

"I was very happy and sent a letter of appreciation to the CEO."

"My doctor's surgery nurse informed me of the need to have injections because my Spleen had been removed. She [the nurse] has been unable to obtain one of them [the medication] in the 10 weeks since my discharge."

that he would be sent home so soon."

"He [the patient] was told he was coming home that day and rang me...The hospital just assumed he would tell me but he often doesn't hear properly/take info in. He says that no-one told him [before]

"The ward seemed to be chaotic first thing in the morning, there did not seem to be a sister in charge and I had difficulty getting a nurse to discharge me."

"Felt very alone and isolated."

Conclusions and recommendations

Although limited in scale, this survey has identified that whilst hospital discharge is a positive experience for some, how it is undertaken can vary and this can impact on how the differing needs of patients are met, both during discharge and in the period after leaving hospital. A quarter of respondents did not feel ready to leave hospital when they were discharged.

A wide range of factors were identified as affecting a patient's experience, but driving influences were the information patients received before being discharged (and the expectations these created), how information was communicated to them and how they were able to use it after they were discharged to understand any follow-up, guide their behaviour or seek out additional support.

We heard that some people did not feel that they received adequate information about their health condition or treatment whilst in hospital, and this combined with limited detail at or after discharge left them unclear as to what had and would happen to them.

This impacted on their understanding and management of their condition, as well as their desire and ability to access appropriate health and community support.

We recommend that:

- all patients should receive a hard copy of their discharge letter and this should include details of a patient's treatment, post-discharge requirements and any next steps. This should be written in plain English and in a form that patients and carers can understand and refer back to.
- written guidance on medication (including self-medicating), pain management and appropriate self-care advice (do's and don'ts) should be given to patients, so that they and their carers are clear on the actions they need to take to minimise the risk of negative outcomes.
- hospital discharge is undertaken in a dedicated transaction, with the same core set of information provided to all patients. This should include as minimum, clear guidance as to who the first port-of-call should be for any issues that arise linked to their hospitalisation.
- patients are provided with the details of the community and voluntary sector support available, and that this should be more comprehensive than a list of contact information, ideally itemising the types of support offered and eligibility for them.

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