

# **“It’s difficult to know what to ask”**

**Communicating information throughout the hospital  
discharge journey**

**January 2018**



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healthwatch  
Surrey

### Background

Discharge from hospital is a key area of conversation in the National Health Service (NHS) for a number of reasons including<sup>1</sup> :

- The potential for longer than necessary stays in hospital to have a negative impact on people’s health and wellbeing;
- The risk of readmission into hospital if a person is discharged before being ready or without appropriate support;
- The number of beds unavailable to people who need to be admitted into hospital as a result of delayed discharge.

The Healthwatch England report ‘Safely Home’<sup>2</sup> and the October 2017 update ‘What happens when people leave hospital and other care settings?’<sup>1</sup> identify a number of issues in people’s experiences of hospital discharge. These include people not feeling fully involved in decisions about their care, not having enough information available, and feeling that their overall needs were not appropriately considered prior to being discharged. The reports also highlight the value of gaining qualitative feedback in order to improve future experiences of leaving hospital for others.

### Introduction

In light of the national discussion about hospital discharge, understanding people’s experiences of hospital discharge continues to be a priority area for Healthwatch Surrey.

We often hear from people who have had a negative experience of leaving hospital, and many of the issues highlighted by Healthwatch England nationally are reflected in the experiences we hear from people locally.

A common theme in what we hear at a local level is a need for improved information and communication throughout the discharge process, with a large number of these comments coming from, or relating to, people aged 65 or over. National guidance highlights communication as an essential factor in successful discharge, particularly for people who require additional care or support<sup>3</sup>, warranting further exploration of this topic at a local level.

Between September and December 2017, Healthwatch Surrey undertook a specific project, speaking to local people aged 65+ (including their family/friends) about their experiences of leaving hospital. We were particularly keen to hear about the information people need to help make the transition out of hospital as smooth as possible, and how this can best be communicated. In total we spoke to 59 people in depth about their expectations, needs and experiences throughout the process of leaving hospital.



1 ‘What happens when people leave hospital and other care settings’ Healthwatch England, 2017

2 ‘Safely Home - What happens when people leave hospital and care settings?’ Healthwatch England, 2015

3 ‘Moving between hospital and home, including care homes’ NICE/SCIE, September 2017

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### Information and communication in hospital

We asked people about their experiences of communication in hospital relating to plans for their discharge and follow-up care, and asked people what methods of communication were most helpful.

Many people told us that it would be useful to have information available to them before being formally discharged from hospital so that they could ask questions and get clear answers. It was clear that a mix of face-to-face and written information was valued; written information was helpful for remembering detail, while face-to-face explanations were experienced as reassuring and a good opportunity to ask questions or seek clarification.

#### Comments prior to discharge

“I like them to talk to me but then there is so much to remember that it is good to have it written down too so I can take it all in – you’re fed so much information that I think it’s good to have a note of it.”

“You like to know exactly what’s being done, you don’t like to be kept in the dark.”

“I need time to ask questions – to get advice and understand.”

“Talk to me face to face. Give me guidance prior to leaving. People are frightened of the unknown.”

#### Comments following discharge

“It’s difficult to know what to ask because you have so much going on and so many people talking to you – you lose track.”

“They sometimes use unfamiliar terms so I like to get things in writing – you think you’ve taken everything in but then you’re home and you can’t always remember. So it’d be good to have the information before leaving so that you can ask questions and clarify things. Then you leave feeling reassured.”

### Information and communication in hospital (continued)

Some people told us that it was important to make information available to someone they trusted as well as to themselves, particularly if their ability to understand information and ask questions themselves had been temporarily affected by ill-health.

#### Comments prior to discharge

“I like to be told, and for my family to be involved.”

#### Comments following discharge

“Where there are appointees with power of attorney, staff need to fully communicate with the person as well as the patient, depending on the mental capacity of the patient at the time.”

“An overview of what exactly happened could have been given to a relative so someone understood - doctors come round during non-visiting hours to review medical care...in my view as the person being treated I am not focused or able to take in what the doctor is saying to me about my health, my condition, my treatment and prognosis. This made me feel excluded from my own care. As I got well, I wanted to know more but family members could not tell me what had been done to me as the doctors and nurses never explained to them and they were not invited to be present when ‘rounds’ were done.”

One gentleman told us about how technology was helping him to ensure that his wife was involved in receiving up-to-date information about his care and plans for leaving hospital:

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**“I’ve been given top class information about looking after myself when I leave. The doctor comes every day and I have an iPad, which I can talk to my wife on. When the doctor comes to speak to me I turn the iPad on and my wife can listen too.”**

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### Do people feel comfortable asking questions

We also asked people whether they had chance to ask questions about leaving hospital and the follow-up support they would need. Many people told us that they felt comfortable and confident asking questions and said that getting answers to their questions was reassuring for them.

#### Comments prior to discharge

“I can ask questions but I know there are many others who can’t.”

“I feel confident to ask and get clear answers. That’s not the same for everyone.”

#### Comments following discharge

“It worked because I knew what was happening and that care was in place so I felt safe to go home.”

“There was a daily update provided by the discharge team to the appointee (with power of attorney) and follow-up care was agreed – good communication.”



Information and communication in hospital (continued)

However, this was not the case for everyone. Individuals commented that they felt there was no time to ask questions and others suggested that the answers they were given were not clear or that explanations contained jargon that they did not understand. Some people commented that communication of information did not take account of their medical state or factor in the involvement of their family.

**Comments prior to discharge**

“It’s hard to keep track of jargon - they don’t tell you what it all means!”

**Comments following discharge**

“I felt I was being a nuisance.”

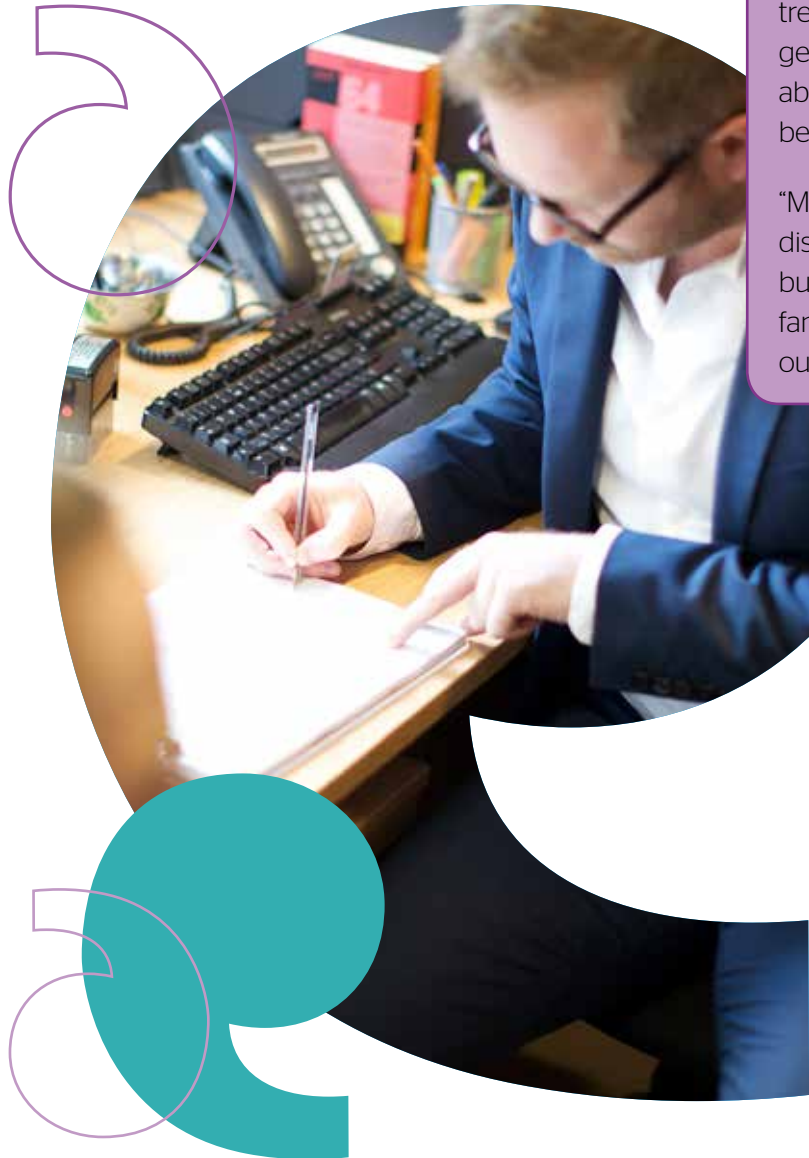
“I didn’t feel comfortable asking because there was no time and my hearing is impaired.”

“The ward nurses were very good but the doctors were too abrupt and short of time.”

“When my daughter arrived, I had no medication. No staff member spoke to her and she tried to find someone to help her understand what she needed to do, what medicine I needed to take and what follow ups - but there was no one available.”

“I had been in difficulties needing additional treatment, was heavily medicated and trying to get well so I barely knew my own name let alone able to understand medical jargon about what had been done to me.”

“My mother’s condition was not checked prior to discharge - i.e. physio had assessed previous week but in that time her condition deteriorated. We (the family) were not informed about how to care for our mother at home or what to expect.”





## What do people want to know?

We also asked people about the information they felt it was important to have prior to being discharged, and identified a number of themes in people’s answers.

### What is wrong with my health?

Some of the people we spoke to said they were unsure why they were in hospital, and suggested that more information about their current state of health would be welcome. People also told us that information about what would happen next with their health was important to them, particularly so that they could be prepared for any changes.

#### Comments prior to discharge

“I don’t know much about why I ended up here. That would be so helpful to know. I just ended up in hospital, so I’d like to know why in case it happens again.”

“I’d like to know more clearly what’s wrong and what will happen next with my health, so I know what to expect.”

“What exactly is wrong? And will it get worse? If so, how?”

### What about my mobility?

A number of people expressed concern about their ability to move around independently after their hospital stay and commented that they would like more information and support to help them get back to being more mobile.

#### Comments prior to discharge

“I don’t know if I’ll need mobility support but I haven’t been walking since I’ve been here. No one has come to tell me if I need to be doing anything or what I can do to get ready.”

“They should talk more about physiotherapy. I’ve had a little walk around but I don’t know what the plan is beyond that – is there anything I can do to help myself?”

#### Comments following discharge

“They only do a bit of physio – they are reluctant – you have to fight for it.”

Within this, people also commented on a need to know the risks involved with going about their day to day life on their return home.

#### Comments prior to discharge

“There are two sides. The medical and then everything else. They know the medical stuff. But what are my risks in day to day life? I like being outside and gardening – what are the risks?”

“How careful have I got to be? What can I do and not do?”



What do people want to know? (continued)

#### How do I get home?

Getting home was a key issue for many people we spoke to. Individuals who were expecting to get a lift from a friend or family member often expressed that it was important to give that person enough notice to prepare.

#### Comments prior to discharge

“I’m ready and waiting for discharge but it depends if my wife can come and get me or not – and get a parking space close enough!”

“I’d need a good hour to prepare to leave and get my things together and let my husband know what’s going on.”

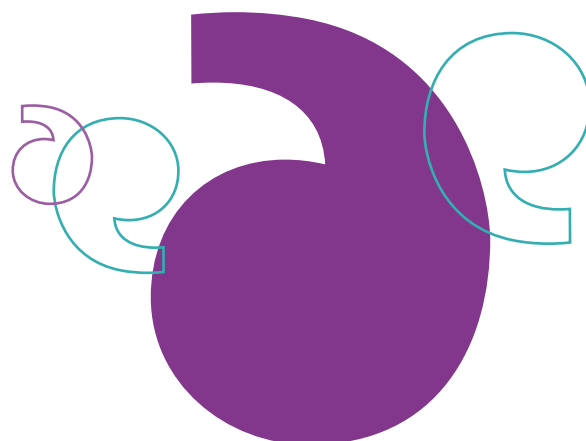
Although a number of people were satisfied with the arrangements made for transport by the hospital, we also heard of cases where arrangements for getting home were not suitable.

#### Comments following discharge

“Told I would be discharged, arranged for daughter to collect me, daughter took time off work, then told I couldn’t go because doctor needed to sign discharge papers and none were available.”

“I had two heart attacks and got the bus home to my sister’s as we had no money for a cab.”

**One lady told us that she was discharged from hospital and taken home by ambulance but that no one had contacted friends or family – when the ambulance took her home there was no one in, and she didn’t have a key. “Luckily they were able to get hold of my neighbour who had a key”.**



“It was a horrific experience. No one asked me, I had had surgery and no one even checked I was mobile and able to get about. My daughter herself had to go find a wheelchair as I couldn’t walk and wheel me out of the hospital.”

“I was given no time to prepare for discharge although I had been asking for the information (calling frequently) for four and a half hours beforehand!”

#### What’s going to happen about my food?

Many people spoke about the practical things that needed to be done when they got home to make sure that they would be safe and well, and expressed concern that these things had not been considered. Some were worried about having food in the house and being able to cook proper meals.

#### Comments prior to discharge

“I need two or three days’ notice so that I can organise food for back home.”

“What’s going to happen about my food? I can’t cook anymore.”

“Normally my partner does all the cooking, she’s the food provider, but we live apart so it’s a question of whether I need something like meals on wheels or something, but that’s all a bit unknown at the moment.”

#### Comments following discharge

“There was very little food in the house and I couldn’t contact anyone to go shopping for me.”



What do people want to know? (continued)

### **What about my medication?**

Where medication was required, people commented that detailed and timely information relating to taking and collecting the medication was important.

#### **Comments prior to discharge**

“They need to be clear about how to take my medication.”

“It’s the medication that’s important to know about and when it will be ready.”

However, people commented that there were often issues getting their medication at the time of being discharged and highlighted that it was important for information about medication to be passed onto family or a trusted person. This theme is consistent with findings from the Hospital Discharge Survey 2017 (local Healthwatch working together), where waits for medication were identified as the top reason for delayed discharge.

#### **Comments following discharge**

“There is always a hold up with medication and my husband ends up having to come back the following day.”

“She was prescribed new medication but that information was not explained to her family.”

“I got told suddenly that I was going home so I got my daughter to come with transport. Then she had to sit and wait for medication. It was midnight before we got the medication sorted.”

### **What else do I need at home?**

Concerns about practicalities also extended to the support people would need at home to continue living as independently as possible. Types of support ranged from mobility aids to care at home, and people often commented that it was important for them to know in advance about the support they would get with doing everyday tasks.

#### **Comments prior to discharge**

“They should know about the support I will need when I get home. Things like how I will get to the toilet on my own? In hospital I have a commode but where do I get one of those? Will I have one at home? That’s hard. And I’ll need something for the bath. I can get my legs over but I might need more help getting out.”

“Who will help me do the laundry or get to M&S? How do I change the sheets? People don’t think about the day to day stuff, you take all these things for granted.”

“It’s a big responsibility going home because I can’t do the maintenance - I’m an old man and I live alone. I’m worried I won’t be able to cope.”

The majority of people said that they did expect to be involved in decisions about their follow-up care and support. In many cases, people did feel involved in plans for after their discharge from hospital, however there were instances where people would have liked more information.

“They’ve talked about getting live in carers for me but they haven’t talked about my space - where will they stay?!”

#### **Comments following discharge**

“There was just a lack of understanding of how the patient lives and the anxiety of moving out of medical care in hospital.”



What do people want to know? (continued)

### Going to residential care/community hospital

Many of the people we spoke to expected to be discharged to their own homes, however for those waiting to be discharged to a care home or community hospital, there were concerns over how to prepare for this. We heard from people that not knowing where they were going next caused them to worry, and there were suggestions that having answers to the small, practical questions would be helpful.

#### Comments prior to discharge

“I’m very apprehensive, I haven’t seen a picture of what it looks like.”

“I would like to have someone to talk to about the home, it’s important to go somewhere where I know the area. It would stop me worrying.”

“What can I expect from the home? The nursing home will know when to take me to the GP. But will I have the same GP when I go in? I’ve been there since 1953!”

“I’m going to a care home but I don’t know which one yet – it will be a strange place...can I take my own furniture and bits and bobs? Will someone know what to pack for me?”

#### Comments following discharge

“Discharged to a community hospital. It would have been very useful to have practical details of what was required at community hospital by way of clothes, aids etc.”



## Summary

People’s experiences of hospital discharge are particularly important in understanding how the process can be improved for others in future. National guidelines highlight the importance of good communication and access to information throughout the hospital discharge journey. In undertaking the present piece of work, Healthwatch Surrey heard first hand from local people about the value of clear communication and information provision when leaving hospital. People highlighted that having information available and communicated in a way that was easy to understand and process was reassuring, whilst lack of information and unclear communication led to experiences of worry.

The information people highlighted as being particularly important included transport arrangements, having food available at home, knowing about the support available following discharge, and having information about where they were going next if this was not familiar to them.

Based on the comments of the people involved, Healthwatch Surrey have produced the following recommendations for consideration.

## Recommendations

1. Hospital staff should ensure that people are supported to ask key questions about the process of leaving hospital, taking into account people’s confidence, ability, and the time required to process information in preparation for leaving hospital (e.g. flexible use of written/verbal communication, jargon-free language);
2. Hospital discharge teams should ensure that processes are in place to identify and record a trusted contact for each patient and that, where consent is provided, the contact is informed of plans for (and changes to) discharge and follow-up care in a timely manner;
3. All patients, and/or their trusted contact, should be involved in planning transport arrangements for leaving hospital to ensure that safe and timely transport is available at the point of discharge;
4. Social care teams and providers of on-going care should work together to consider how transfers to other care settings can be communicated to patients so that they feel reassured about their change in living circumstances. (for example, supply brochures with pictures, arrange a telephone call);
5. Hospital discharge teams should consider how patients (and/or their trusted contact) can be put in touch with services offering practical, short-term home support prior to them being discharged (e.g. Red Cross, Age Concern);
6. Hospital discharge teams and social care teams should explore how technology (e.g. iPads, teleconferencing) can be used to:
  - i) Involve trusted contacts, identified by the patient, in conversations about leaving hospital;
  - ii) Allow patients to find out more about other care settings prior to transfer out of hospital, to support adjustment to changes in their living circumstances.

## What Next?

People do not always have the confidence, ability, or time to ask questions to help them prepare for leaving hospital. A number of people we spoke to suggested it can be difficult to take in information and said that “it’s difficult to know what to ask”.

Healthwatch Surrey are looking at ways in which older people could be supported and empowered to find out information about leaving hospital and their follow-up care; creation of a checklist/conversation record that can be utilised by patients, next of kin, and hospital staff has the potential to aid communication during an individual’s hospital stay, and this is currently being considered.

This report and its recommendations will be shared with commissioners, service providers and other organisations. Responses will be published on the Healthwatch Surrey website in due course.

## Acknowledgements

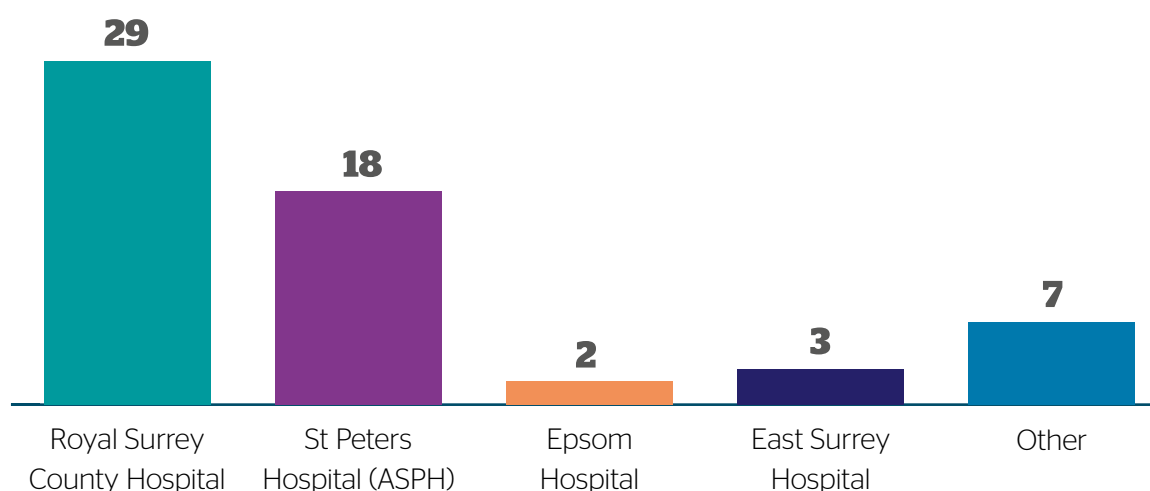
Healthwatch Surrey would like to thank the participating hospitals and all those who contributed their views and experiences. We would also like to thank the Healthwatch Surrey volunteers who supported with this project.

## Appendix 1: Method

### Participants

Between September 2017 and December 2017 we set out to collect feedback from people 65+ (or carers/friends/relatives on their behalf, with consent) who had been discharged from hospital in Surrey within the past 18 months. Feedback was received from 59 people in total (Male = 15, Female = 44; Age 65-103 years), including eight responses from family/friends.

### Recruitment



1. People aged 65+ who were discharged from hospital (or their proxy) in the past 18-months were invited to complete an online survey, promoted via social media in collaboration with local hospitals;
2. Based on methods used by Healthwatch Sutton (2014), Healthwatch Surrey volunteers visited four geriatric wards at the two participating hospitals (St Peter’s Hospital, and Royal Surrey County Hospital) at two time points to speak to patients about leaving hospital. Volunteers also gained consent (including contact details) to follow-up with patients once they were discharged, via telephone, to get a full picture of their experience of leaving hospital.

#### Method (continued)

#### Online Survey

A survey was created using Survey Monkey combining a number of free-text response boxes and multiple-choice questions.

#### Interviews

Initial feedback and expectations about preparing for discharge were gathered by DBS checked Healthwatch Surrey volunteers who visited wards in teams of two or more. A semi-structured interview guide was put together to mirror the online survey structure.

Where patients agreed to be involved in an interview following their discharge, contact details were taken and stored securely, along with an estimated discharge date. 16 people were followed up by telephone after leaving hospital and gave additional comments on their experience.

All participants were offered the opportunity to enter a prize draw for the chance to win one of five £20 Marks and Spencer vouchers.



#### About Healthwatch Surrey

Healthwatch Surrey is an independent local watchdog that gives the people of Surrey a voice to improve, shape and get the best from health and social care services.

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