

# **Hospital Discharge**

"What happens when they come out?"



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# What is Healthwatch Lambeth and what does it do?

The Health and Social Care Act 2012 says that each Local Authority must arrange for an independent organisation called Healthwatch to champion the voices and experiences of the public in health and social care so as to promote better services for all.

#### At Healthwatch Lambeth we:

- Provide information about local health and social care services.
- Help people to find the health and care services they need.
- Get people involved in how these services are monitored, commissioned, and provided.
- Make known the views of local people about their needs and experiences
  of health and care services, so as to influence how services are
  commissioned, provided and scrutinised.
- Report on and recommend how services could or should be improved.
- Make the views and experiences of local people known to Healthwatch England, the national champion of people's voices.
- Make recommendations to Healthwatch England about advising the Care Quality Commission on areas of concern (or go direct to the CQC).
- Are a member of the Lambeth Health and Wellbeing Board.

# **Executive Summary**

Hospital discharge is a common concern for commissioners, NHS trusts and patients, representing one of the most frequently reported-on areas for Healthwatch nationwide.

Lambeth hospitals have faced similar challenges to hospitals in other areas, with increasing pressure to develop systems for discharging patients efficiently and safely. The COVID-19 pandemic beginning in 2020 compounded this urgency.

In 2021, Healthwatch Lambeth was approached by Guy's and St Thomas' Trust (GSTT) and King's College (KCH) hospitals to speak to patients with recent experience of the discharge process. Both hospital trusts had used learning from previous Healthwatch engagement and made changes to the discharge process, with the establishment of three main pathways and the Internal Flow Hubs. The aim of this project was to gain insight into how these changes have impacted on patient experiences and the factors shaping patient perspectives.

Within the context of continued pressure on hospital services and system changes being implemented, these qualitative semi-structured interviews with 18 recent patients and their family members/carers highlight what is important to patients, good practice, and where improvements can be made.

# **Key findings**

Our findings showed patients had mixed experiences in terms of the coordination and communication they received before, during and after their discharge. This was due to a range of factors, including the importance and impact of unpaid carers, their level of familiarity with hospital processes, their capacity to navigate the system, and the strength of their relationship to the health and care system in general. Those who were the most vulnerable, and had the least support, faced the toughest challenges.

### General feelings about discharge

When discussing discharge many participants prioritised their desire to be back at home as soon as possible and spoke about of the hospital's need to 'free up beds'.

Our interviews showed an individual patient's ability to navigate the hospital system, to ask questions, to request relevant information from professionals, and challenge decisions, were all significant factors in their feelings about discharge and affected how prepared they felt to leave.

## Experiences on the day of discharge

Delays and disruption during various stages of the patient's journey have the potential to impact discharge. Delays have a heightened impact on the planned day of discharge, when the final approval of discharge, medication collection and transport arrangements need to be coordinated.

It's unrealistic to expect everything will always go to plan in an acute setting, but our case studies highlight examples of participants who had positive feedback despite experiencing disruption, because of the way hospital staff responded and communicated when delays could not be avoided.

#### What went well

Our findings explore what went well, according to participants, and what happened to make it go well. We found participants placed a high value on quality communication and having positive interactions with staff.

- Close liaison with unpaid carers was often key to securing good outcomes for patients.
- Coordinated discharge happened when different teams within the hospital shared information efficiently.
- Participants also spoke about the importance of feeling they were a priority and collaborating with the hospital teams in decisions affecting their discharge.

#### What happens when they come out?

Mixed feedback was received around issues related to risks associated with discharge, particularly for those who were vulnerable or did not have a strong support network.

Participants largely agreed that while they did not want to remain in hospital longer than necessary, they did not always feel heard by hospital teams when voicing their concerns about getting their needs met once they returned home. This was linked to feedback received about the quality of follow-up and aftercare, reducing the need for further presentations at A&E.

Our recommendations include suggestions made by participants for what could have been done differently and calls for existing good practice to be more consistent. While the feedback relates to inpatients of three hospitals, we hope our findings will contribute to the learning of hospital service providers and stakeholders more broadly.

# Recommendations

# Planning for discharge

#### Communication

- 1. Hospitals should review the early stages of the discharge planning process to ensure patients (and/or carers) have been communicated with and given information (many patients were unable to recall conversations or meetings about discharge).
- 2. Hospitals should consider the communication needs of patients for information in different formats, languages, and those who might require more than one opportunity for a conversation.
- 3. Patients should be provided with leaflets and other forms of written communication to supplement verbal conversations with staff.
- 4. Hospitals should review provision of support at different stages of the inpatient experience for those less able to communicate or advocate for themselves, due to having English as a second language or through social vulnerability.
- 5. Patients should be supported to understand more clearly what needs to happen (tests, investigations, assessments) before they can go home.
- 6. Patients should be given time for consultation and conversations in which questions and discussion of concerns are encouraged. This is particularly important for those who lack support from an unpaid carer.
- 7. Hospitals should provide patients and carers with more advice and guidance around self-managing conditions while on wards, and prior to discharge. This is particularly important for those who find themselves having to wait long periods for treatment such as physiotherapy.
- 8. Hospitals should ensure a variety of communication methods (phone, text, email) are available to patients and/or unpaid carers.

#### **Carers**

- 1. Hospitals should identify and document the strength of the outside support network available to patients as early as possible, so unpaid carers and other family members can be communicated with and kept up to date.
- 2. Hospitals should take into account the nuances of caring arrangements, such as consideration that not all carers are responsible 24/7 or live nearby. The focus should be on having conversations with carers as early as possible without making assumptions about what will be feasible for them to do.

### Multidisciplinary working, coordination, and continuity of care

- 1. Hospitals should ensure robust processes for information sharing when there are multiple teams involved with a patient to ensure continuity of care.
- 2. Hospitals should take steps to ensure effective coordination between teams across the hospital. Efficiency of treatment supports timely discharge, but also has the potential to significantly improve emotional wellbeing of patients.
- 3. Hospitals should review process for ensuring patients are not discharged prematurely. This may include investigating specific instances of hospital readmission and considering the full picture of the decisions involved.
- 4. Hospitals should review all processes, including follow-up, to ensure a consistent, standardised approach is being taken across departments.
- 5. Hospitals should do more work into the specific needs of different social and cultural groups facing barriers in accessing healthcare, and who may be discharged with more complex needs in general.

#### Staff attitudes

- 1. Hospitals should review issues related to staff attitude and responsiveness to patients, acknowledging the pressures on the service.
- 2. Staff practice should include reflection on how patients can be made to feel prioritised, and their voices heard at all stages.

# On the day of discharge

### **Pharmacy**

1. Hospitals should review the pharmacy stage of the discharge process, so patients can be confident their medication will be prepared in time.



#### **Hospital transport**

2. Hospitals should review the process of arranging hospital transport, including information about the service, ease of booking and increased flexibility.



# Aftercare and follow-up

#### **Contact details**

- 1. Hospitals should offer a named contact/number for all patients and carers to use if they have concerns soon after discharge.
- 2. All patients should have alternatives to presenting at A&E if they have serious concerns in the period after discharge, such as being able to speak with the team responsible for them whilst in hospital.

## Follow-up care

- 1. Hospitals should ensure patients admitted through A&E receive the necessary appointments post-discharge and are clear which team is responsible for them.
- 2. Hospitals should conduct a review into the process for discharging to primary and secondary care and adult social care, with particular focus on waiting times and continuity of care.
- 3. Hospitals should work in partnership with other agencies to review the quality of care packages and other interventions put in place to provide support at home, from the perspective of patient experience, including input from unpaid carers.
- 4. Hospitals should provide patients and carers with more advice and guidance around self-managing conditions when they are back at home. This is

particularly important for those who find themselves having to wait long periods for treatment such as physiotherapy.

# Voluntary and community sector support

- 1. Hospitals should provide more information (such as written, easy-read materials) about the holistic support options available to patients, including the charity and voluntary sector.
- 2. Hospitals should develop a consistently proactive approach to signposting, and actively make referrals for patients where this is preferred and consented to.



# Introduction

In 2018, Healthwatch Lambeth partnered with Healthwatch Southwark to build a picture of older people's experiences of health and social care services after leaving hospital.

The Going Home project tracked a group of people for up to twelve weeks after they became medically fit for discharge. Most of these participants were engaged in the Discharge to Assess (D2A) and Step-down pilots and were in extra care schemes for part of this project.

The Going Home project led to further collaboration with hospital trusts and then Clinical Commissioning Groups across both boroughs. It made an effective contribution towards a deeper understanding about the complexities of care that many older patients and their carers face when leaving hospital and the anxieties this can cause.

# **The Going Home Project**

Since the publication of the 2018 report, Guy's and St Thomas' Trust (GSTT) and King's College (KCH) hospitals have made changes to the way hospital discharge is planned.

At the start of the COVID-19 pandemic, the government issued new guidelines to help hospitals free up beds as quickly as possible. In April 2020, GSTT and KCH set up Internal Flow Hubs (IFHs) which were designed to make hospital discharge more efficient, to simplify the process and ensure that all the teams involved with patients were communicating well with each other to ensure people left hospital at the right time and went to the right place.

In 2021, Healthwatch Lambeth was invited by representatives of GSTT and KCH to speak to patients who had recently left hospital to help the hospitals consider the impact of their chosen discharge model on patient experiences and ensure it is meeting their needs.

This report presents our findings about how patients and their carers experienced discharge. Our aim was to gain insight from a patient perspective into how the team that had been responsible for them while in hospital worked to coordinate processes relevant to their discharge, from beginning to end.

# Methodology

Healthwatch Lambeth worked on this project actively engaging service users during March to September 2022. The participants were adults who had been discharged from KCH and GSTT as inpatients. Consent was given by patients to the hospitals to be contacted by Healthwatch Lambeth, and the sample size was drawn from patients who were interested in proceeding with the project after being given more information.

We conducted in-depth qualitative interviews with 18 people asking about their discharge experiences. The discharges took place during the autumn of 2021. Participants were asked to speak about a single, most recent experience of discharge.

Participants were asked to reflect on:

- the earliest contact or communication they received as an inpatient about their discharge,
- the quality of preparation and communication,
- how discharge was organised on the day itself, and
- comments on aftercare and treatment received since leaving hospital.

The aim was to gain insight into how the team responsible for them whilst in hospital worked to coordinate processes relevant to their discharge, from beginning to end.

Demographic information for this project was incomplete as not all participants agreed to provide this information. Of the participants who provided this data, approximately 70% of the group identified as White and 30% as Black British, and 50-50 between male and female. The majority of participants identified as having some form of physical or mental disability. The oldest participant was 89 and the youngest 25.

The interviews were analysed descriptively under broad themes representing the different stages of the discharge process and follow up care. Names cited in case studies have been changed to respect anonymity.

# **Findings**

# General feelings about discharge

Patients, when asked for their memories about their discharge and their feelings towards it, frequently recalled being keen to leave hospital as soon as possible.

The majority expressed feeling confident that the discharge process was working to achieve that outcome efficiently. However, while hospital teams walk the line between discharging too early and risking readmittance, patients and carers experienced a parallel process in being keen to return home but with the reassurance that they had the information and support to be safe in doing so.

In the interviews, some patients did not consider preparation for discharge as a distinct process from completing the treatment itself and having confirmation from the doctor that they could leave.

Few could recall being given leaflets about discharge, the ones that did described them as helpful.

While some felt clear about why the decision to discharge them was taken, other patients could not recall a conversation where the reasons were explained to them. Some participants had memory issues or had been too unwell to recall when and how initial conversations took place. Some indicated that the specific reasons for discharge were not a high priority for them as they were preoccupied with wanting to go home.

For some of the patients interviewed, the process had been less straightforward. One patient spoke about how she had felt uncomfortable as an inpatient due to her interactions with staff, who she perceived to be uncaring and unhelpful. She took the decision to discharge herself. In her interview she stated that she would have welcomed an in-depth conversation about her condition and how she would manage when she got home, but 'they didn't seem to be that interested, so I left.'

Others made similar comments about needing more time to discuss their discharge or having fears about what would happen when they left, they did not feel were addressed.

One patient, who had had multiple stays in hospital, spoke about how she had learned to be proactive in seeking information.

'What I've come to realise is you won't be told unless you ask. So, it was more that I had to do the asking.'

Many of the patients interviewed felt the process of preparing for discharge had been adequate for their needs and had positive comments about professionals who they felt were aligned with their interests.

'It was a speedy exit but a "thankful" speedy exit.'

'I think I just assumed I would be discharged once everything went well. And I was eating well, everything was going good.'

However, overall satisfaction with the service was less likely with people with social or communication needs who required more time to discuss their discharge needs, or who may have felt less empowered to challenge decisions due to language barriers, or additional complex vulnerabilities such as homelessness or chronic illness.

These patients described more negative feelings, including confusion, anger, and a sense of being overlooked or alone. Patients were not clear whether hospital staff should spend more time speaking to them or whether they should recognise when this was needed.

'You have to wait for information, they won't talk to you. I don't know how to say it. They make me upset.'

'I was a "ward discharge." What this means I do not know...I just sat there, and tried not to create any form of fuss until I knew I was going to come home. But I didn't want to create a situation where anybody felt uncomfortable. I just waited (for them to do their job) and kept my mouth shut.'

'They are not really forthcoming, they won't come to you. You have to get their attention.'

Positively, many patients experienced their discharge as a collaborative process between themselves and the hospital and were able to give many examples of good practice.

However, these interviews show that an individual patient's ability to navigate the hospital system, to ask questions, to request relevant information from professionals, and challenge decisions were all significant factors in their feelings about the discharge process.

Several participants qualified their own positive comments by describing themselves as 'pushy' and 'not afraid to speak up,' indicating individual personality traits played a role in the type of service they received.

'I was able to explain and describe everything. And I'm a bit forward so if I wasn't happy at the time I would say. But I feel sorry for older people or people who really don't understand what's going on with them. They just say yes, yes, yes.'

One unpaid carer commented on her father's discharge:

'I was there so I sort of oversaw it, but I don't know how someone on their own would do in that situation.'

Carer interviews highlighted the importance to patients of having people to take on the role of liaising with hospital teams, or who were able to rearrange their work commitments or personal time to allow for short notice discharge plans to be carried out smoothly.

But not all participants had friends or family who were able to support them leaving hospital, whether practically or by communicating with staff, and more work is needed to ensure the needs of these patients are being met.

While these findings are unsurprising given the pressures facing hospital teams, they indicate a lack of flexibility and responsiveness to a patient's needs that would have implications for their overall care.

Some patients had difficulty limiting their feedback to the discharge process, and spoke about A&E, social services, GPs, the attitudes of nursing staff towards them during their stay, suggesting their experiences of discharge in many ways mirrored their experiences of other aspects of the health and care system.

# Timeliness, delays, and quality of coordination

Many of the participants experienced a delay at some stage of the discharge process.

Some of these said they hadn't, but during other parts of the interview talked about how their treatment had been delayed, or surgery being pushed back due to lack of availability of surgeons or consultants.

The way participants answered questions about delays was shaped by the degree to which they understood their stay and their discharge as part of the same process.

One patient described how even though she was frustrated waiting for her surgery, she was satisfied with the way staff communicated with her.

'They did explain things every day. Came along every day. Even when it got put off, they said sorry, we can't do it today, we'll do it tomorrow.'

Another patient had a more negative experience after coming in through A&E.

'I was told I was having a hip replacement and they woke me at 6am, prepped me for surgery and then someone came round saying "they didn't have a hip surgeon." My surgery was likely going to be Monday afternoon, but they would let me know later. And I think there was a bit of a lack of communication there because nobody came back to talk to me about that.'

During her stay, she contracted a viral infection and was transferred to another ward for treatment, delaying her discharge by almost a week. While she was clear about the reasons for this, she felt the length of her stay was in part due to poor communication about the transfer itself.

'I know that one of the nurses was getting frustrated that the orthopaedics team hadn't been to see me because I was on a different ward.'

A lack of coordination was mentioned in other interviews, and this would impact on hospital discharge even though the participants did not necessarily state that.

'There might be ten teams for one person. The communication between all of them is zero and all are meant to be communicating, especially when they have an inpatient. The diabetes team did not come to see me, even though my sugars were skyrocketing.'

Several participants said they would have benefited from more time in hospital but felt unable to voice this or did not consider it worth doing so.

In some cases, they reflected on having mixed feelings, believing in hindsight they should have stayed in for longer, but also recalled being keen to leave.

'Discharge is either very dragged out or very abrupt, and sometimes things get missed because of being rushed. It almost feels, as soon as you are ready to go, it's "ok, bye."'

'It was rushed...I was not fully fit. I was not.'

'(The hospital) do what they want to do, and you only find out what's happening when you get back home.'

# **Experiences on the day of discharge**

All participants were asked to comment on how the day of discharge was managed, with regards to timing, communication, and transport where relevant, as well as liaison with unpaid carers.

There were many positive comments about the efficiency of the hospital teams and where the feedback was more mixed, some participants expressed a reluctance to be critical towards the NHS, indicating they saw and understood their experiences within the framework of the pressures on the health and care system. They spoke of wanting to be fair to staff and were aware of the pressures they were under. However, logistical complications were frequently an issue on the day of discharge.

#### Coordination

For some participants, the delay was an issue for them because they had been told to expect discharge to take place roughly at a certain time, or to ask family members to come at a specific time, only to wait for much longer. The delay could be several hours or another night in hospital.

Some patients and carers were able to cope with the inconvenience relatively easily, but for others it posed more of a challenge and led to feelings of helplessness and frustration.

'It's not clear enough, I think if they can give you more notice of when you're going to be discharged it (would be) a good thing. Because there's no time to set proper preparations in order.'

Some participants spoke of an atmosphere that was generally chaotic, with difficulties getting staff attention and trying to chase them for updates, in which the reasons for delay were unclear.

In such situations, participants said because they were being discharged, and were therefore 'well,' they were not a high priority for staff and felt like they had 'more important' issues to deal with.

More than one participant indicated they felt discouraged from even attempting to seek information or assistance at this stage.

'I find it very difficult to talk to them because they do have a lot to do on the wards. Knowing you're being discharged...you're not on a priority list or anything like that.'

Others understood that they were waiting for a specific process before discharge could take place, such as the ward having to wait for test results, for discharge papers, for a doctor to be available to make a final decision.

#### Medication

Several participants mentioned having to wait for the hospital pharmacy to prepare medication, and delays caused by it not being ready after the discharge had been signed off.

'Why isn't it done the night before? You're waiting hours for medication. You're holding a bed, it just doesn't make sense. You're not allowed to collect it; you're waiting for a nurse to go down and collect it. It's not just that, you're waiting for loads of things. There must be a better system than that.'

In one case a patient experienced a pharmacy-related delay only to eventually be discharged empty-handed (apart from the medication she came in with) and was told to expect her local chemist to courier the next prescription's worth over later in the week.

'To me that's just laziness...if the pharmacist wasn't going to do any medication prep, I could have gone home the night before.'

# Travel and hospital transport

Negative experiences of physically getting home included:

- Discharge taking place at times when unpaid carers were unavailable to collect their loved ones,
- · Hospital transport being late or mistakenly cancelled, and
- Not being aware that hospital transport was an option ahead of the day of discharge, and then having to wait even longer as a result of not having booked earlier.

Several participants said they had made alternative arrangements at their own expense or wished they had done so.

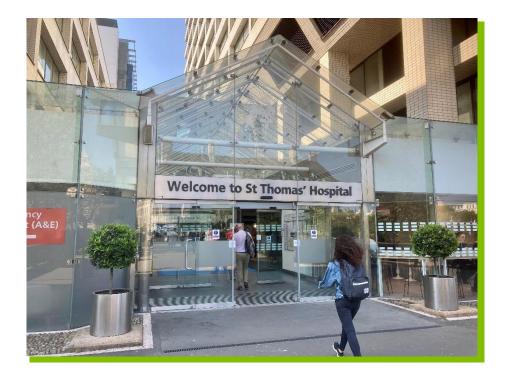
'It looked like there were a lot of people waiting for hospital transport...My son also works at the hospital as a porter and he said I would be in for a 3-4 hour wait in general. And I felt ok enough to be able to walk out on my own...I got a black cab from London Bridge to Canada Water.'

One participant, an unpaid carer who was familiar with the discharge process, spoke about how she had learned to navigate the system and make sure her father's discharge happened on time.

'What we learned and have done since is request hospital transport. It's a waste of resources if we can (collect him) but when it's hospital transport, the hospital make sure the (discharge papers) are ready because they're the ones who've booked for patients to be collected.'

Delays experienced by some participants related to a more general issue around timing, in which patients might feel either they are waiting for unacceptable periods or are being rushed out of hospital.

In such cases, the source of frustration came from a sense of being 'at the mercy' of the hospital's timeline, and processes that were difficult to understand.



# What went well (and what happened to make it go well)

Some participants were able to share positive experiences of timing related to discharge. In these cases, participants described a sense of shared priorities with the hospital, feeling their preferences and views were being heard and respected, and the hospital was working to the timeline that suited the patient.

#### Case study: Debbie

Debbie met with an Occupational Therapist (OT) on a Friday morning in hospital. A doctor had already informed her she was medically ready for discharge, but she needed to complete a physiotherapy assessment and have some aids and adaptations installed in her home. Debbie was told her discharge was unlikely to happen before Monday as a result.

Spending the weekend in hospital would involve being transferred from a private room back to the ward, something she wanted to avoid having spent time on a ward where she had contracted viral gastroenteritis earlier in her stay.

'They were talking about me going back (on the ward) and I was petrified that I would spend the weekend there. I have an 8-year-old child...I was desperate to go home at this point because I'd been in there quite some time.'

That afternoon she was pleasantly surprised to be told to let her husband know a community equipment services team would be visiting her home before the end of the day.

'The OT said she thought it was unlikely the people who come and do the seat risers or do anything before Monday. But as it was, they obviously had a gap or must be local to me...they were able to come around straightaway. They came right after the OT had contacted them.'

The physiotherapy team completed their part of the process on the same day, making it possible for Debbie to be signed off and discharged on Saturday, two days earlier than she had expected.

'The physios came round after lunch, said 'we can wait until tomorrow,' I said no, let's just get it on with it so I can get signed off. They took me through the stair assessment and that was fine.

'Everyone was on the ball, the OT did everything she could to get things moving. I was seen by the junior doctor on Saturday morning and I had the pharmacists come round. They sorted me out, made sure I was ok. My husband was driving up from Portsmouth and they timed it so everything would be ready for him to pick me up. It was so slick, done very very well.'

### Case study: Michael and Carol

Michael, whose wife Carol had been treated following a fall and kept under observation for a fortnight, spoke about the quality of preparation for her discharge and communication with him as a carer.

'The discharge team made it clear that it was their role to do everything that was necessary. It was individuals making it very clear what they were there for...it was a personal service, they were very pleasant, they knew the case and made it easy to get information to them and ask some questions.'

Michael was asked by the discharge team to take photos on his smartphone of the rearranged bedroom and email them over so the physiotherapists could assess Carol's environment. This helped to give him confidence that they were considering her access needs carefully and she would be able to manage during the few weeks that she would be unable to use the stairs at home.

As part of the preparation for discharge, a care package was discussed. Michael expressed doubts about whether it would be needed as he was anticipating being her full-time carer, but the discharge team advised him to accept the care package before deciding whether it was needed.

'They made it clear they wouldn't be able to discharge her until they were confident that everything was in place when she got home...they said if you don't ask for (the care package) straight away you got to go back to social services and ask for the care and somebody's got to make an assessment. So, they were helpful in terms of that.'

The discharge had been complicated by a COVID outbreak, making visits impossible.

However, Michael was able to share a variety of examples of best practice in terms of person-centred care and quality communication that allowed the discharge to take place smoothly.

'On one occasion I went (to the hospital) on the off chance COVID restrictions had been lifted. I called the discharge team for an update and she said, "Wait there, I'll come down and see you." She didn't have to do that. I was quite impressed with that.'

'When I did get through (to the ward) there was no issue about someone taking a mobile phone to her. That was particularly important when I couldn't come.'

'Rather than get tied up in complicated explanations I was able to send (emails) to a named person.'

'I was kept informed all the time, I had numbers I could phone, an email address... I felt they had the thing in hand. I didn't feel that I was one of thirty people all receiving attention. If I tried phoning them, or sent a text, they knew what I was talking about. It was never a 'current thing,' they were familiar with the detail and the background.'

For these patients, there was a sense that staff were frequently and willingly communicating with them, their needs and preferences were addressed, and an open discussion was ongoing between all involved.

They had confidence the hospital teams were working to achieve the outcome that was best for them as patients and carers, and felt themselves to be active participants in the process.

It was significant they were able to reflect on their discharge in detail as a process that started well before the day they went home. They were therefore able to comment on the ways in which staff communicated across departments and with themselves as unpaid carers, so when the day of discharge arrived, it was experienced as one part of a broader experience of care and treatment.

In discussing specific cases, it is important to give an accurate picture of the situation. Though discharge was described in positive terms by these two participants, this did not mean everything went smoothly.

Issues included having to complete a stair assessment in a dirty stairwell (the patient asked to go ahead rather than wait and risk further delays), spending an extra night in hospital because the pharmacy did not have the medication ready in time, feelings of helplessness and frustration combined with uncertainty, difficulty getting through to wards and getting the attention of staff.

COVID outbreaks added an unplanned element to the discharge process, necessitating new restrictions and barriers to contact and communication.

Other participants who discussed their discharge in more mixed or negative terms faced similar issues. There are a variety of reasons for this, including lack of or less reliable support from unpaid carers, conditions affecting memory, not having English as a first language, other barriers related to speech and communication, factors such as poverty and social vulnerability, all of which require further investigation.

However, by exploring 'what went well' in specific detail, these interviews gathered information about what the hospital did so some patients could speak positively about their experiences, with crucial insight into the value of patient-centred care and good quality communication.

Many participants said they were mindful of the pressures faced by hospitals, had adapted from past hospital experiences to tolerate delays and uncertainty, and they did not expect, or wish, to be aware of every detail. It would be unrealistic to expect everything should go to plan for everyone.

We compared the data from interviews and found participant's feelings about discharge were strongly influenced by factors such as being kept informed, feeling their views, needs and preferences were taken into account, and being treated with respect by staff.

It wasn't always the absence of delays and other complications that led to positive feedback, but the response of the hospital and the way they communicated with the patient and carers.

### What made it go well: Summary

- Having a clear named point of contact within the discharge team.
- Having a variety of methods of contact available during preparation (phone, text, and email) so carers could speak to the discharge team using the one that suited them best.
- Continuity of care enabled by robust information sharing and internal communication.
- Working closely with unpaid carers to support the process.
- Patients and carers having a clear understanding of which tests and assessments needed to happen before discharge could take place.
- Tests, assessments, and other processes taking place efficiently and in a coordinated manner.
- Patients feeling the hospital was making them a priority despite other pressures.
- Patients feeling their voices were heard and they were active partners in the process, rather than passively accepting the hospital's decisions.

# 'What happens when they come out?'

### Risk, safety, and anxiety during discharge

Many service users were discharged from hospital with ongoing concerns about their health, perhaps with some aspects of their overall condition worsened, or with different support requirements once they got home.

In these situations, they spoke about their experiences of communicating these concerns to hospital staff, the anxiety of premature discharge, and lack of confidence in discharge decisions prior to going home.

All participants expressed awareness of the priority for hospital staff to ensure people were not occupying a bed longer than necessary, and indicated this was clear to them whether expressly communicated or not.

Some participants perceived the hospital as prioritising discharge efficiency over patient wellbeing, or said they experienced further health complications after leaving due to the speed of the discharge process.

Patients spoke about issues with nursing staff during their stay, including having to wait long periods for personal care, being told on wards to perform tasks for themselves they could not do, or being spoken to in a rude or disrespectful manner.

For some patients these poor experiences contributed to their not feeling safe and comfortable with their discharge plan, with a perception they were being rushed through the system.

Participants were also asked about the services they were referred to after leaving hospital, and the quality of care and treatment they received. The answers varied widely in detail depending on the amount of aftercare that was required, whether or not they had any ongoing conditions, or were readmitted to hospital.

While many participants were satisfied with their discharge and had no serious issues or health concerns at the time of interview, other accounts highlight the poor outcomes experienced by some patients after discharge, what could have been done differently, and a patient/carer perspective on how similar situations could be avoided in future.

## Case study: Linda and Geoff

Linda spoke about her father, Geoff, who had been admitted to hospital following a stroke and brain bleed.

She described the discharge team taking the time to meet with her and discuss the assessments he had done in preparation for discharge, but she still had concerns about him returning to his accommodation on his own.

'The OT did meet me on the ward and assured me they'd done all the tests and he was fine to be discharged, they had no worries about him coping at home on his own. I said, "it's all very well in a hospital environment but are you sure he's going to be able to do this on his own?" He was about to go back to his flat with no support. There was no consideration given to the fact that I might be his carer but I live in Kent and I work...I wasn't on his doorstep.'

Though Linda was given the opportunity to speak to the discharge team, and she described the quality of overall care and treatment in very positive terms, she felt the hospital team were focusing on the need to reassure her of Geoff's safety and protecting themselves in their decision, rather than genuinely listening to her concerns.

Geoff had been an inpatient for eight days, but within 48 hours of discharge was readmitted to hospital.

'He (Geoff) was very weak, quite unstable. He came out Tuesday, I stayed with him Tuesday night. I thought, let him get on and see if he could do everything he normally does, to see if he could cope but he was really struggling. On Thursday morning he said "I can't cope. I can't live on my own like this, I need some help."

Though Linda was able to get her father to his GP, who responded quickly to the situation and made a social services referral, his blood pressure was now raised again.

'The hospital put him (Geoff) on a 6 week rehabilitation programme. The physio came up on Thursday afternoon to assess him, work out what he was going to be doing on this programme. She took his blood pressure immediately and said "I can't carry on with it, his blood pressure's far too high, personally I think you need to call an ambulance. I can't believe he's been discharged without any help." She was really good, she waited with us for the ambulance. She told me I could raise this as an issue with PALS because he should never have been discharged without any support. And after that, I did.'

Geoff was in hospital for another 48 hours before his blood pressure went down again and he was medically fit for discharge.

However, the plan did not include any additional support at home and Linda described feeling desperate and frustrated.

'At this point I had his (Geoff) keys and point blank refused to give them over until something was done. It makes me sound like the worst daughter on earth but I said no, you're not discharging him until a care package is in place. They did put it in place quite quickly the day after that. Three times a day care visits, and someone to do his housework, and he came out on Saturday.'

Other participants raised fears and anxieties about discharge during their interviews, with similar feelings of frustration and the sense they were not being heard when speaking with the discharge team.

In some cases a significant factor in their concerns was the uncertainty over how they would communicate with health and care professionals after they went home, and what would happen if the hospital team was no longer responsible.

While some felt they had been prematurely discharged, more participants indicated a lack of confidence any issues they had immediately upon returning home, or sudden deterioration in their condition, would be managed well.

There was inconsistency in whether participants were able to contact the hospital team caring for them after discharge.

Many said they did not know who they could contact when they needed support or information soon after leaving hospital.

'I had no contact number for who I should call if he came home and things weren't quite right.'

'You're told if you have any problems or you're worried about anything to go through A&E again, which I don't think many people are prepared to do once they've been through it. You can always call A&E. But they don't know your case. It's nothing to do with the nurses and it's not a slight on them. They haven't got the time to chase up your name or look into what you were in for. They're just talking generally, so it would be a generic answer they would give.'

While many participants said they had had no further issues since leaving hospital, those that had further complications or went on to be readmitted said they would have welcomed the ability to communicate more easily with the team that had been looking after them in hospital immediately after discharge.

# Discharge aftercare and follow-up

Participants were asked about the care and treatment they had received after leaving hospital and for any comments about the services they'd engaged with.

Participants gained insight on a wide range of teams across the two hospitals, as they spoke about being referred to specialist clinics for the same issue that brought them into hospital, and receiving a service from physiotherapy teams, district nurses (now Neighbourhood Nurses), Reablement and other adult social care teams, as well as their GP.

Participants reported the following experiences:

- Having to repeat the details of their condition and situation to multiple therapists belonging to a large team at a fracture clinic, with limited continuity of care.
- Having the feeling that staff were 'going through a checklist' and only offering general advice and information not specific to the patient's situation.
- A general lack of adequate communication about appointments, cancellations and other changes affecting treatment. Some participants said they knew to wait for a letter regarding follow-up but not who they could talk to if they had further questions before receiving this, other than their GP.
- Positive experiences of the quality of care and kindness from district nurses and social care teams.
- A participant was told a surgeon had completed a physiotherapy referral, but nothing arrived. She eventually had to go back to her GP and ask them to make the referral, which fortunately they agreed to.
- Other participants reported long delays in physiotherapy treatment commencing, with further concerns about their mobility they felt were not being addressed.
- When physiotherapy commenced, some patients spoke about feeling rushed through the service, and judgements about their level of mobility being made too quickly.
- Participants spoke about aids and adaptations not being suitable for them and facing delays in waiting for adjustments to be made.
- Lack of consistency amongst staff wearing PPE when on home visits.
- The feedback received about social care services included issues with lack of specific time for visits to take place (leading to difficulties with planning and limited independence, choice, and control), lateness in care packages commencing, and lack of clarity over the purpose of the service.
- One participant spoke positively about all services engaged in her father's follow-up and the quality of communication between them. 'I can't fault the aftercare he's had.'

Debbie, on being discharged, had arranged private physiotherapy, but was confused after receiving no follow-up information from the Trauma and Orthopaedics team at the hospital. She was encouraged to chase them by her physiotherapist.

'Because I had gone in through A&E and (the physiotherapist) had experience of other people going through that route...as my discharge papers were signed by someone I hadn't met, I'd been missed. I'd kind of fallen through a hole...It took some time to make sure I got through to the right department, right people...I learned that I wasn't down for any kind of follow up whatsoever. I was told "well, we don't always follow up with people after they've had a hip replacement." But I pointed out that as I spent 9 days in hospital being told I was far too young for such an injury and was normally quite fit and active and healthy I needed to make sure I got back to that. I wanted an appointment and an x ray. Since I got that first appointment, they've been fantastic. I saw the consultant that actually did my surgery, people remembered me. In that respect, very consistent care.'

Olu had been street homeless prior to his admission, and at the time of interview was living in supported accommodation through a referral completed by the hospital. He said he received some level of social care support after discharge but was frustrated when it ended and felt that his needs hadn't been met. Overall, he was feeling a lack of support and disinterest from professionals in keeping him informed, and ensuring he had a strong understanding of his care and treatment, compounded by the stress and vulnerability created by his homelessness.

'The care they gave me was withdrawn, you know, and I have no other help...one of the social workers came and told me they don't want to make it a long project, it's going back to social services, for a decision. They withdrew it. The services, they make me waiting 30 minutes and they're gone. They don't give me enough time. I have reduced mobility, after my sickness I couldn't walk, I haven't walked since December. Since leaving the hospital, I've not been stable, I'm still here, struggling with life. And I don't know where I go from here.'

While it is clear that many patients experience high-quality follow-up and aftercare, this is not consistent across all the routes patients may take in and out of hospital, with patients who had had A&E admissions specifically mentioned.

There were varying levels of clarity amongst participants regarding what kind of follow-up they could expect, and eligibility for different services and interventions post-discharge was not always explained.

Some participants said they didn't remember being given any because they hadn't needed it, while others felt there was more they could have received, or expressed a general lack of clarity about where they would go to find more information about what's available in the community.

'When you're in hospital you don't know what support there is. I only recently found out about the Dimbleby Centre, the cancer centre that offer massages and therapies...Not sure the staff knew either, to be fair.'

'They don't push. Unless I was asking questions, they wouldn't push.'

Some participants also spoke about how it would have been useful to have more time prior to discharge to discuss techniques for self-management of their conditions and to receive more detailed information on medication side effects and the nature of their condition.

This was particularly the case for participants who later experienced long waits for treatment or had difficulties accessing their local GP, and the interviews indicated varying levels of confidence that their needs would be met in the medium-to-long term.

'There's not enough emphasis on trying to help yourself a bit more. They send you home, (tell you to) sit down as much as possible, elevate your leg. They should maybe add: "but try and lift your leg." They don't (try to) pass that knowledge on to the patient. They don't talk about what to do if you're sedentary, exercises while you're sitting down, trying to be a bit more active, to try and prevent blood clots.'

Participants reported a mixed experience of being discharged back to their GPs. While many said they would talk to their GP if they had any questions, others said they did not know who they would contact.

Some felt their GP knew them and their condition well, and received good quality aftercare from them, while others reported issues with a lack of communication and little or no follow-up. It was unclear what the reasons for this were, but some patients said they perceived the issue to be administrative failings and other service pressures.

'(Since leaving hospital) I had three messages from my GP, all saying "very sorry to hear you've had a stroke." I was trying to arrange a private consultation for my shoulder and the GP had lost my referral letters, they had absolutely no clue what was going on. I'm sure they're overworked, too many patients, too much admin but it would have been nice to have heard from the GP, knowing they've got a new stroke patient, to ask me if I need any assistance...I don't have a clue who is supposed to be doing my cholesterol tests, blood pressure tests. They should be checking for warning signs of another stroke...Something is horribly broken there.'

While participants expected hospital teams to focus on acute care, these interviews indicated they would have benefited from more extensive preventative care throughout the system.

In general, participants spoke of the quality of care, both in and out of hospital in broadly positive terms. Many were able to describe specific professionals and practitioners and recall their skill and compassion.

However, access stood out as a distinct issue even for some patients who had positive experiences, indicating outcomes may be determined by patients negotiating, navigating, and requesting services, a dynamic in which some patients will inevitably be disadvantaged.

Patient need and eligibility alone, unfortunately, does not consistently ensure appropriate care and treatment is put into place.



# Discussion and Conclusions

This report discusses patient outcomes in a broader sense, referring not only to clinical outcomes and incidence of readmissions, but to feelings of safety, confidence, and general wellbeing.

Whether unpaid carers are having their needs for information and support met are also considered as closely linked to patient wellbeing. Hospital stays are frequently a time of stress and uncertainty for patients, and waiting for discharge can heighten feelings of being out of control. In such a situation, it is understandable that disruption and complication at a practical level (relating to on-the-day timing, medication, and transport) can have emotional, as well as physical health consequences.

While the logistical arrangements did not always run as expected, this alone was not necessarily the basis for negative feedback from patients. What was important to patients was understanding the reason for the disruption, that hospital teams responded to resolve it, and that this effort was clear to patients.

In accordance with the principles of person-centred care, it is important to recognise that a 'good discharge' for patients is not necessarily one in which everything goes to plan. The negative impact of any disruption can, in some cases, be mitigated by high quality, appropriate and respectful communication with staff, and robust care and support elsewhere.

While the interviews were designed to cover a broad range of issues related to hospital discharge, there was variation in the level of detail in which patients were able to speak about their experiences. This was particularly true when it came to what they recalled of the earlier stages of discharge planning, and what they understood of the reasons behind decisions regarding their discharge, as well as explanations received for any disruption.

There are a number of potential reasons for this, such as patients inferring more than was explicitly explained to them with regards to their care, lack of awareness of the distinct stages of discharge planning, or knowledge of what to expect based on having multiple previous experiences of hospital treatment as an inpatient.

This emphasises the significance of having experience, knowledge and understanding, as well as the skills to self-advocate. Again, the support of an unpaid carer with the capacity to advocate for a patient's needs was also highlighted in multiple interviews as being key to securing better outcomes.

Discharge is affected by many factors not within the control of the hospital, such as the involvement or not of an unpaid carer. However, given the impacts on discharge and subsequent health outcomes, it is important for hospitals to consider what patients are able to access in terms of support networks and other resources at all stages of discharge planning.

This is particularly critical in considering the role health inequalities play in quality of care and treatment for patients, in which patients from different groups face barriers to access and varying outcomes.

It is important hospital teams serving a diverse population in an area with high levels of deprivation take steps to mitigate patient vulnerability and disparity, actively reduce barriers to access, and work in partnership with other areas of the health and care system to ensure they are not replicating inequalities across services.

Hospital inpatients are dealing with a broad range of circumstances, in which systemic inequalities interact with chronic and complex health issues. Where patients come in through A&E, the contact is usually unscheduled and involves people less likely to have regular contact with primary care and community services.

For person-centred care to remain at the heart of hospital discharge processes, the focus should be on ensuring all patient needs are met, in a way that does not require more vulnerable individuals to be (or learn to become) skilled at navigating 'the system.'

A publicly-funded healthcare system has a responsibility to address inequalities, not solely in terms of morbidity and mortality, but in poor experiences and low satisfaction levels in a context of multiple deprivation and disadvantage. Hospital discharge is one process in a complex network of services, in which the desired outcome is deceptively straightforward: ensuring patients leave hospital as safely and efficiently as possible.

However, speaking with patients and carers about their experience and satisfaction reveals a variety of factors at play, including health inequalities, patient perception of the NHS pressures, the impact of bed shortages and the multiple causes of discharge delays in a system that continues to face barriers to coordination, despite the best efforts of skilled and compassionate staff and their leaders. All of these issues would benefit from further investigation. These challenges cannot be met by any one department or team.

However, hospitals in an integrated care system have an opportunity to collaborate with local authorities, primary and secondary care, social care, and the voluntary sector to offer different ways of supporting people through discharge, at home and in community settings.

By working in partnership, hospital discharge processes have the potential to reduce the need for further readmissions and improve the holistic health and wellbeing of the local population.

Healthwatch Lambeth looks forward to working with Guy's and St Thomas' and King's College Hospitals in meeting this challenge and shaping improvements to discharge processes for local people. Thank you to all participants for their time and generosity in sharing their stories with us, and for GSTT and KCH teams in their support of this work.

# **Appendix 1**

# The national picture

Issues surrounding hospital discharge are a common concern for service providers, NHS trusts and patients, representing one of the most frequently reported-on areas for Healthwatch nationwide.<sup>1</sup>

Cuts to NHS and social care budgets over the past decade and the COVID-19 pandemic have challenged hospitals to implement effective, efficient, and safe discharge processes, ensuring the best possible use of resources and optimising patient health, recovery, and wellbeing.

Reducing high bed occupancy is key to achieving this, as a lack of availability of beds impacts the flow of people coming in and out of hospital, operational performance, waiting times and the risk of increased infection rates.

England's hospital beds have halved over the last 30 years<sup>2</sup> with more available for day cases than overnights. The UK's bed occupancy had started to level off prior to the COVID-19 pandemic, at which point it dropped, and demand for beds shifted to critical care departments. The relaxation of COVID-19 restrictions and rising demand for hospital care has exacerbated the pressure of long waiting lists for the NHS, with bed shortages projected to continue into the next decade as services struggle to meet the needs presented by rising levels of chronic illness and a rapidly ageing population. <sup>3</sup>

In this context, hospital policies have shifted to a focus on providing support for patients to spend no longer in hospital than is necessary, and complete more of their recovery at home or in community settings.

The COVID-19 pandemic increased the urgency of addressing the issue of delayed discharge, in which a patient is medically fit to leave hospital but cannot do so, for non-medical reasons related to safety or a lack of clear decision by the multidisciplinary team. Over the winter of 2021-22, despite an edict for hospitals to work with local partners to halve delayed discharges by January 2022, the situation worsened.<sup>4</sup>

Guidance effective April 2022<sup>5</sup> emphasised the use of the 'discharge to assess' model for commissioning bodies and local authorities. This model is designed for services to work together to help people leave hospital sooner, with longer-term needs assessments completed in non-hospital settings.

Additional funding was also available for recovery and support services, rehabilitation, and care for up to six weeks after discharge. This funding came with an expectation that hospitals adopt and review 'eligibility to reside' criteria for all inpatients.

However, while hospitals commit to reducing high bed occupancy, they are balancing the equally important need to avoid the risks associated with premature discharge.

In one 2015 study, nearly a quarter of people who had been readmitted to hospital within three months reported that they had not felt ready to go home at the time of their discharge.<sup>6</sup>

Hospital patients, staff, and unpaid carers, speaking with multiple Healthwatch researchers across England, have raised concerns about discharge taking place before it is safe.

A key underlying cause in cases of unsafe discharge is a lack of appropriate support in place after patients have left hospital, or delays related to poor coordination across services.<sup>7</sup>

The 2016 Ombudsman report highlighted the need for greater integration and joined up working between health and social care services.

The recurring issue of poor integration across other areas (such as communication between acute and community service providers, or between hospital teams and GPs) indicate systemic and structural barriers to discharge planning.

Ultimately the human cost of inefficient, ineffective, and unsafe discharge is avoidable trauma and suffering for patients and their carers, undermining the provision of treatment and care across the system, and contributing to a deterioration of health and wellbeing outcomes.

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- 4. Chart of the week: What's happening to hospital discharges? | The Nuffield Trust
- 5. <u>Hospital Discharge and Community Support Guidance</u> (publishing.service.gov.uk)
- 6. <u>Premature discharge: is going home early really a Christmas gift? | The King's Fund (kingsfund.org.uk)</u>
- 7. <u>A report of investigations into unsafe discharge from hospital.pdf</u> (ombudsman.org.uk)

# **Appendix 2**

# **Strengths and Limitations**

#### The strengths of the project were:

- The collaboration between GSTT and KCH helped to provide a broad picture of discharge across the borough, so the learning can be shared across hospitals.
- The interviews gathered insight based on a wide range of respondent's experiences, including those from seldom heard groups.
- The respondents were demographically and socially diverse.
- The interviews were conducted in a manner that was suitable for the respondents in terms of timing, accessibility, and flexibility.
- The interviews include the views of unpaid carers.
- The interviews placed priority on hearing the voice of the patient, working flexibly and creatively with participants who had memory loss, communication issues or had limited previous experience with community research.
- The interviews were in-depth and designed with scope for respondents to speak at length about what was relevant for them in their personal circumstances.

## The limitations of the project were:

- This project was not designed to target any demographic during recruitment, which limited our ability to compare experiences of different groups based on age, ethnic background, disability, sexuality and gender identity.
- Participants varied greatly in terms of their level of experience with the health system, with some having had multiple hospital stays and others only one. This was related to their history of chronic illness and presence of multiple long-term conditions. More investigation would be needed to avoid a 'one size fits all' perspective on hospital discharge and healthcare generally, but working within the framework of person-centred care mitigates this risk.
- The design of the interview guide, which asked participants to focus on a single recent experience, was at times confusing for those who had a more varied experience to draw on.
- The interviews provide rich insight into the experiences of seldom heard groups, and those living with some level of social or economic vulnerability. However, we did not have enough data to analyse their experiences and the related structural inequalities impacting on their health outcomes in depth.

- There were delays in the recruitment of participants due to Healthwatch Lambeth requiring support from the hospitals, and the relevant professionals were occupied with service delivery pressures.
- Some patients struggled to recall some aspects of their hospital experience, in part due to recruitment delays and in part due to memory loss, and
- For some participants, we had to rely heavily on interviews with unpaid carers and received limited input from the service user. In some cases, this was down to issues of mental capacity, and for others it was due to personal choice. While these interviews provided valuable insight, the carers had a different perspective and experience of hospital discharge which requires more focused investigation.

# **Appendix 3**

# Interview guide

Begin interview with brief discussion about the patient and circumstances surrounding their stay in hospital.

#### **Before leaving hospital**

- 1. Can you tell me a bit about being prepared to leave the hospital?
  - What information was given to you (if any) about what would happen?
  - Were you clear on which health and social care team was looking after you while you were in hospital?
  - What can you say about the communication you received about your discharge? (e.g., Given a leaflet, attended a meeting, informed via carer or family member)
  - Did you feel involved in the plan for your discharge? (e.g., Were you asked for your input, did you share your views, did you feel listened to)
  - Did they explain to you why you were being discharged?
  - Were your family/carers involved with helping you get back home? Do you think they were informed and prepared for your discharge?
  - Did you understand what would happen next? (Egg any assessments or referrals for support after leaving hospital)
  - Did you know who to contact if you had any questions or concerns?

### When you were leaving hospital

- 2. How well do you think your discharged was managed when it was time to leave?
  - What was the timing like? Were there any delays, or did timing feel rushed?
  - How easy or difficult was it to communicate with staff on/close to the day?
  - Did you require travel arrangements in place to leave hospital? Were these arrangements adequate and made clear to you?
  - Did you need to take any medicines home with you? If yes, how easy was it to get them?
  - If needed, was the appropriate care in place for the same day of your discharge? What was the communication around this like?

3. Was there anything that affected your discharge? If so, in what way? (Egg coronavirus, staff shortages)

### After being discharged from hospital

- 4. How have things been since leaving hospital?
  - Did you need further care or treatment after leaving hospital? Tell me more about this.
  - Did you understand what the care or treatment was for?
  - Did you feel you were involved in discussions on your care and treatment that was organised?
  - What was the process to ensure the care and treatment was in place?
  - Can you tell me if you needed to be referred or assessed for further care or treatment?
  - How did that work?
  - How well do you think it was managed?
  - Were you able to communicate with the team that was looking after you? How easy or difficult was it to do so?
  - Do you have any comments on the quality of care and treatment you have received?
  - Were you offered support from any other services in the community after leaving hospital? Do you have any comments on the waiting time and/or quality of support you have received?
- 5. Overall, what went well with the way you left hospital?
  - Did you feel safe when you left? Tell me about that.
  - What do you think led to you feeling the way you did?
  - Do you feel you needed support, care, or treatment after leaving hospital that you did not receive?
- 6. What didn't go so well when you left hospital?
- 7. Can you suggest any improvements so patients in the future have a better experience of discharge?
- 8. Do you have anything else you would like to comment on?

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