Do people feel involved in decisions about patient discharge in Birmingham?

January 2025

healthwatch
Birmingham

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Executive Summary

Background

Hospital discharge is often the final stage of acute medical care, as individuals move from an acute setting to an environment best suited to any ongoing health and care needs. A discharge assessment determines whether an individual needs more care when they leave hospital. If the assessment shows an individual needs little or no additional care this is considered a simple discharge and often the individual is discharged home. A complex discharge means the individual either requires short term care, rehabilitation or reablement[1].

NHS guidance[2] on hospital discharge outlines how health and social care systems should support safe and timely discharge of people who no longer need to stay in hospital. The guidance is structured around three themes (the care journey, roles and responsibilities, and specific needs) and underpinned by 14 principles. A key principle relevant to this study is the involvement of patients, families and carers in discharge planning. A recent amendment to the guidance and the Health and Social Care Act 2022 (Section 74[2]) makes clear that NHS bodies and local authorities must ensure that, where appropriate, patients, unpaid carers, and family members are involved in discharge decisions. Therefore, patients should be asked who they wish to be involved or informed in discussions and decisions about their hospital discharge. Patient involvement should be a genuine and meaningful engagement with patients and their families/carers throughout the entire discharge planning process.[3]

Involving patients, family and carers in the discharge process enables them to make informed decisions and choices that deliver personalised care and maximise their independence. It prepares people for leaving hospital by ensuring their home situation is taken into account, they have the necessary information for self-care, understand any medication they need to take and know who to contact with concerns.[4]

Objectives

We aimed to understand how patients and families are involved in the discharge process from hospitals in Birmingham and how well their needs are considered in the discharge process. We also explored the positive and negative aspects of their involvement in the discharge process and what changes can be made to improve the experience.

Methodology

We developed a questionnaire which was shared with service users through stakeholders, social media and on posters in hospital discharge lounges. To ensure that we were reaching people who might not see the questionnaire on social media, we visited six hospitals[5] and spoke to patients who were being discharged. We also spoke to people at two retirement villages.[6] The views of 248 people are included in this report. We also interviewed six people who completed a questionnaire and wanted to discuss their experiences further.

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1 https://www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance

2 Hospital discharge and community support guidance - GOV.UK (www.gov.uk)

3 Exploring the principles of best practice discharge to ensure patient involvement | Nursing Times

4 Patient discharge from hospital - Care Quality Commission (cqc.org.uk)

5 We visited discharge lounges and waiting rooms for the following hospitals: Royal Orthopaedic, Women' s Hospital, Children's hospital, Queen Elizabeth, Heartlands, Good Hope, City Hospital and BMEC.

6 New Oscott and Longbridge villages.

Summary of findings

This study indicates that the involvement of patients and families/carers can improve patients' hospital discharge. It is important that healthcare professionals actively invite patients and families/carers to participate in discharge decisions and are willing to accommodate patients' needs and preferences, including the important role that families and carers play in ensuring a successful discharge home. This study's respondents noted the importance of assessing the capacity of families and carers, to provide ongoing care, for successful discharge planning.

A well-planned discharge, that has the involvement of patients and families/carers, can reduce the risk of poor outcomes and readmissions. Involving patients and their families/carers in decisions can decrease stress and anxiety. Healthcare professionals need to consult with patients and understand their needs post-discharge, especially what they think they will need and whether they have any help at home. Patients and families/carers who were given information about their treatments during their stay, symptoms to look out for post discharge, how to manage their condition and any new medications, felt more prepared for discharge.

Our study shows involvement sometimes wasn't prioritised and that patients, their families and carers weren't always consulted in discharge planning. The experiences shared show that communication ranged from healthcare professionals giving one-way instructions, to real shared decision-making where patients and their families/carers' needs and preferences were considered. A lack of involvement meant that most participants felt unprepared for discharge and the aftercare provided did not meet their needs. Discharge was often short notice, rushed and poorly planned with patients and their families/carers feeling this was driven by a shortage of beds.

This study also highlights the importance of starting discharge planning early so that discharge does not feel rushed and patients and families/carers are educated to self-care or care for the patient post discharge. People should be involved throughout their hospital stay not just on the day of discharge. Some participants suggested having someone who maintains communication with various stakeholders involved in discharge to facilitate this.

Patients' and their families/carers' suggestions to improve involvement in the discharge process match those outlined in Jones *et al* (2023)[1] IDEAL discharge strategy.[2] This has involvement at its core and describes what the patient and their family need to know before leaving the hospital.

- **I**nclude the patient and family as full partners in the discharge planning process
- **D**iscuss with the patient and family five key areas to prevent problems at home:
    - Describe what life at home will be like
    - Review medications
    - Highlight warning signs and problems
    - Explain test results
    - Make follow-up appointments
- **E**ducate the patient and family in plain language about the patient's condition, the discharge process and next steps at every opportunity throughout the hospital stay
- **A**ssess how well doctors and nurses explain the diagnosis, condition and next steps in the patient's care to the patient and family and use teach back.[3]
- **L**isten to and honour the patient and family's goals, preferences, observations, and concerns.

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[1] Patient Perspectives of the Hospital Discharge Process: A Qualitative Study - PMC (nih.gov)

[2] Strategy 4: Care Transitions from Hospital to Home: IDEAL Discharge Planning | Agency for Healthcare Research and Quality (ahrq.gov)

[3] https://www.nice.org.uk/guidance/ng197/chapter/Recommendations

Key areas for improvement

Explain the complexities of the discharge process

Develop step-by-step summaries of the discharge process so patients and their families/carers understand the numerous steps that need to take place before they are discharged before or after admission. Ensure that this is provided in a clear, simple and visual format (e.g. flowcharts or short videos). Patients and their families will understand what is happening and improve their overall experience.

Communication and information given at time of discharge

Review and improve the readiness and accuracy of discharge letters so that it provides information that ensures people feel ready to leave hospital and self-care when they arrive home. This should focus on ensuring that patients and their families/carers have information about the following:

- diagnoses
- abnormal physical findings
- important test results
- discharge medications with rationale for new or changed medications
- follow-up arrangements made
- counselling provided to the patient and family
- tasks to be completed (e.g. appointments that still need to be made and tests that require follow-up)

Provide a discharge liaison role/nurse to give and explain both verbal and written information.

Discharge checklist and involvement

Work with patients and families/carers to develop a discharge checklist to aid decision making during discharge and change the culture among healthcare professionals so that they prioritise consultation and incorporate their needs and preferences of patients and families/carers. A discharge checklist will depend on a patient's condition and the discharge procedure but should always ask:

- Have we been proactive in planning for discharge and involved patients and their families/carers early?
- Have patients and families/carers been full partners in the discharge planning process?
- Have we discussed with patients and families/carers key issues that might prevent problems at home (e.g. home situation, medication changes etc.)?
- Have we listened to their needs and preferences and have these been adequately considered and included in discharge planning?
- Have we ensured that post discharge care and support has been arranged, and will it meet the needs and preferences of patients and their families/carers?

Review and improve internal hospital processes that delay discharge

Hospital processes such as waits for medication and discharge letters can delay discharge. It is important to review such procedures and how they are communicated to patients in order to manage expectations early in the discharge process. Having realistic conversations about issues such as recovery goals and length of stay in hospital is crucial and can also reduce waiting times for discharge letters and medication. In addition, consider using a discharge liaison role/nurse to facilitate medicine discharge.

Next steps

We presented our findings to system partners at BSOL System Quality Group, who agreed actions that the system will take in response. These actions are included in this final report which has been shared on our website as well as with participants and relevant stakeholders.

In six months' time Healthwatch Birmingham will publish a follow-up report with evidence of progress towards the changes health and social care services have committed to.

Acknowledgements

We would like to thank everyone who shared their experiences. We are grateful to NHS BSOL and the following hospitals - Royal Orthopaedic, Heartlands, Good Hope, Queen Elizabeth, Birmingham Women's, Birmingham Children's, City Hospital, BMEC that helped us access service users. We are also grateful to New Oscott and Longbridge retirement villages who allowed access to service users through their events.

Response from BSOL ICB

The report and its findings were shared with Birmingham and Solihull ICB' System Quality Group. A System Quality Group meeting on hospital discharge was arranged and held on the 5th of March 2025. Present at the meeting were:

HK	Chief Nursing Officer, BSol ICB
VW	Associate Director of Nursing – Quality and Safety, BSol ICB
RR	Deputy Chief Medical Officer, BSol ICB
UH	Deputy Director of Nursing & Solihull Community Lead, Solihull
JM	Regional Deputy Director of Nursing and Quality, NHSE
CKN	Research and Policy Manager, Healthwatch Birmingham
CR	Deputy Director of Ops in Midlands, CQC
CI	Associate Director of Nursing, Solihull Hospital
LG	Chief Nurse, BCHC
JU	Head of Operations, Healthwatch Birmingham & Healthwatch Solihull
JB	University Hospital Birmingham (UHB)
LF	Director of Nursing, UHB
PC	Associate Director of Primary Care Commissioning and Performance, BSol ICB
EP	Deputy Head of Quality, MHPC

We presented the findings of the report and our recommendations. A discussion took place where the group assured Healthwatch that they were aware of the issues highlighted in the report and reported that some work is being done in some of the Trusts (e.g., UHB) but that further action is needed. Discussion focused on the following areas:

- Discharge processes and checklists aligning with consultant ward rounds to make sure that everything concerning discharge is put in place prior to discharge.
- The work around discharge processes and checklists should be identified in the Trusts Quality Improvement Group to ensure good system outcomes.
- Challenges around patients received care outside of acute care and the work being done to develop a script to aid discharge discussions with patients.
- A clearer understanding of how the application of the estimated date of discharge is used and explained to patients, families/carers.
- Use the Primary and Secondary care interface group as an opportunity for learning around hospital discharge.
- Communications and model of acute care – consider a comms approach to sharing information and improving public understanding of the discharge process.
- Using criteria led discharge and improve engagement with consultants on this.
- Standardised patient-facing documentation (e.g. an admissions pack) to support understanding of the discharge process.

Below are next steps and agreed actions following the discussion of the findings and recommendations (also see table below):

- Internal work in UHB around the Quality Improvement and the discharge bundle that is in place will also pick up the areas such as ensuring the medics put the expected date of discharge (EDD)
- Audit approach around monitoring the criteria led discharge – work has already been done around criteria led discharge, but further work is required to move that forward.
- Discussions at primary/secondary care interface meeting to consider improvements and to explore digital opportunities to support.
- Clear system governance around who is leading on what.
- Agreed for HK to link with ICB Director of communications and discuss how consistent messages and good practices can be shared with public.
- Agreed for Chief Nursing Officer, BSol ICB to link in with Digital team and discuss what can be done around the better use of digital system that will help with productivity.
- Adult Social Care ASC providers list to be shared with CQC.
- NHSE to share any good practice and the offer of the communities of practise and any opportunities for joined approach.
- Healthwatch to include mental health data & discharge process for people going into palliative care in the future reporting[1].
- Progress update on the agreed steps to be shared in next Hospital discharge focused update

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[1] This report did not collect any data on this aspect of hospital discharge. This may be considered in a future investigation or call out for experiences.

SQG Date	Action Ref	SQG Agenda Item for Action Reference	Action / Decision	Lead
05/03/2025	2.1	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learning	Internal work in UHB around the Quality Improvement and the discharge bundle that is in place will also pick up the areas such as ensuring the medics put the EDD	JB
05/03/2025	2.2	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learning	Audit approach around monitoring the criteria led discharge - work has already been done around criteria led discharge, but further work is required to move forward	HK/LF
05/03/2025	2.3	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learning	Discussions at primary/secondary care interface meeting to consider improvements and to explore digital opportunities to support	RR
05/03/2025	2.4	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learning	Clear system governance around who is leading on what	All
05/03/2025	2.5	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learning	To link with ICB Director of Communications and discuss how consistent messages and good practice can be shared with public.	HK
05/03/2025	2.6	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learnings	To link in with Digital team and discuss what can be done around the better use of digital systems that will help with productivity.	HK
05/03/2025	2.7	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learning	Adult Social Care (ASC) providers list to be shared with CQC	HK
05/03/2025	2.8	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learnings	NHSE to share any good practice and the offer of the communities of practice and any opportunities for joined approach.	JM
05/03/2025	2.9	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learning	Heathwatch to include mental health data & discharge process for people going into palliative care in the future reporting	CKn/ JU
05/03/2025	2.10	Healthwatch Hospital Discharge Report Summary of the report/ Findings/Discussion/Reflections/ Learning	Progress update on the agreed steps to be shared in next hospital discharge focused update	JB/HK/ RR/ LFJB

Introduction

In August 2024 Healthwatch Birmingham identified variation in the feedback we heard about hospital discharge. Some positive experiences related to how well people were involved in the discharge process and information given about next steps, especially medicine.

However, there were several concerns including:

- lack of communication on next steps following discharge
- new medications not prescribed, nor arrangements made on how to access new medications following discharge
- lack of information or explanation about new medications
- poor assessment and support for ongoing needs
- long waits at discharge lounge and pharmacy
- poor communication of discharge arrangements between different departments
- feeling pressured to leave hospital when they didn't feel they had sufficiently recovered.

Background

Hospital discharge is often the final stage of acute medical care, as individuals move from an acute setting to an environment better suited to any ongoing health and care needs. In a complex discharge individuals are either sent to receive ongoing care and support at home, or to a step-down bed including recovery support in the community. Often alongside an assessment of any longer-term care and support needs. In Birmingham, there are Complex Discharge Hubs located at Queen Elizabeth, Good Hope, Solihull and Heartlands hospitals. These are staffed by complex discharge nurses, social workers, therapists, administration and discharge coordinators and homeless support practitioners. Since their introduction, Complex Discharge Hubs have increased the number of people being sent home, meaning less are being admitted to long-term residential care.[1]

The discharge process has four pathways:[2]

- **Pathway 0:** Discharges home or to a usual place of residence with no new or additional health and/or social care needs

- **Pathway 1:** Discharges home or to a usual place of residence with new or additional health and/or social care needs

- **Pathway 2:** Discharges to a community bed-based setting which has dedicated recovery support. New or additional health and/or social care support is required in the short-term to help the person recover in a community bed-based setting before they are ready to either live independently at home or receive longer-term care and support

- **Pathway 3:** Discharges to a new residential or nursing home setting, for people who are considered likely to need long-term residential or nursing home care. Should be used only in exceptional circumstances – no one should be discharged directly to a permanent care home placement for the first time without giving them time to recover in a temporary placement before assessing their long-term needs. If someone needs social care support to aid their discharge and recovery, NHS trusts should inform the relevant local authority as early as possible during the person's hospital stay.

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[1] https://www.birminghamsolihullics.org.uk/news/complex-discharge-hub-success

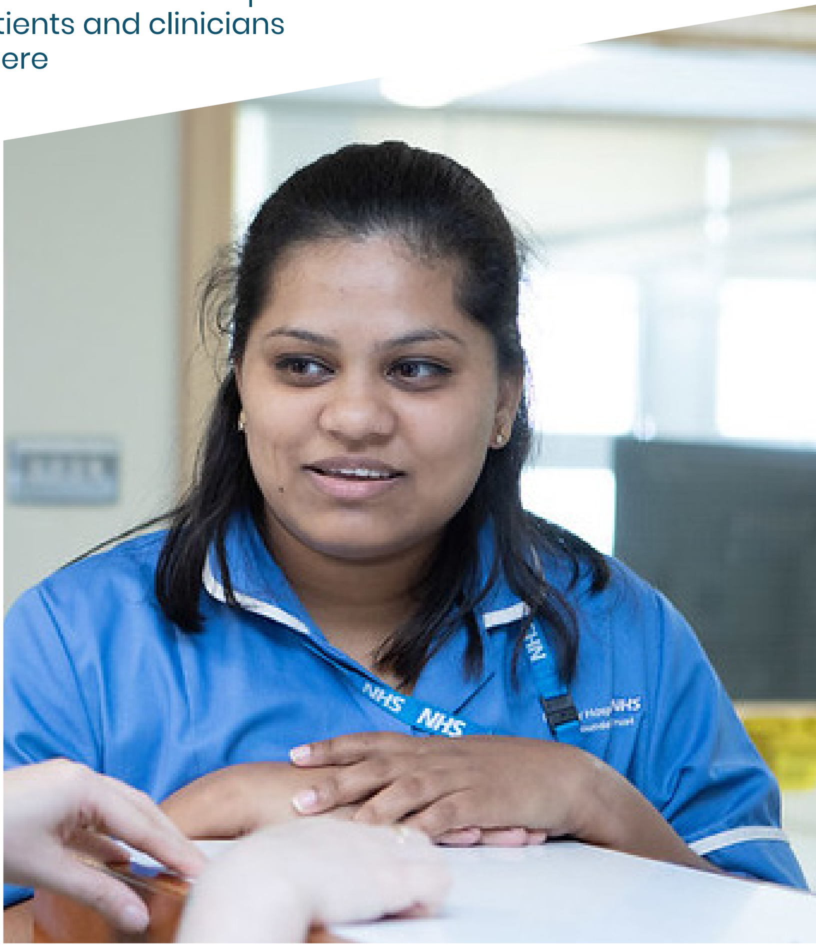
[2] https://www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance

It is best for the individual to be out of a hospital setting after medical treatment has been completed. Reducing the time people spend in hospital lessens the risk of acquiring infections or deconditioning,[1] and people are able to quickly regain or achieve maximum independence and quality of life. However, it is important that individuals have adequate support, and that they are offered choices around what care and support they need following discharge. People should be supported to make fully informed decisions, and the discharge process should be person centred and driven by choice and dignity.[2] This can be done by ensuring that patients and their families/carers are involved in decisions during the discharge process.

Statutory guidance on hospital discharge states that multidisciplinary discharge teams should work with patients and their families to plan the person's discharge, including considering post-discharge needs.[3] NHS England states that patients and their families should be involved in the discharge assessment process. They should also be involved if people need specialised care after leaving hospital. For instance, what support or treatment the patient will get after discharge, who will provide that support, when and how often, how support will be monitored and reviewed, who is co-ordinating the care plan and who to contact when the need arises.[4] There must be genuine and meaningful engagement with patients and their families so they can make informed decisions throughout the discharge process.[5] Involvement should be more than an exchange of information between clinicians and patients. It should be a shared decision-making process with patients and clinicians co-operating to find the best solutions and where the patient's experiences are taken into account.[6]

A recent Care Quality Commission (CQC) report indicates that most people report that they are not routinely involved in decisions about their discharge. According to the report 29% of people said they had little to no involvement in decisions about their discharge (19% said they were 'not very much' involved and 10% said they were 'not at all' involved), compared to 25% in 2022, while 33% of participants said they were involved 'a great deal', a statistically significant decrease of 4 percentage points from 2022.[7]

This study focuses on people's involvement in the hospital discharge process in Birmingham, aiming to understand key issues such as their clinical interactions including decision making and communication/information, collaborative discharge planning and involvement in the discharge process, preparing for self-care and continuity of care.



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[1] Deconditioning is a syndrome of decline in function in frail older people during hospitalisation.

[2] https://www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance

[3] https://www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance

[4] Being discharged from hospital - NHS (www.nhs.uk)

[5] Exploring the principles of best practice discharge to ensure patient involvement | Nursing Times

[6] https://onlinelibrary.wiley.com/doi/epdf/10.1111/scs.12977

[7] Adult inpatient survey 2023 - Care Quality Commission (cqc.org.uk)

Demographics and information about participants

We heard from 248 people who had experienced being discharged from a Birmingham hospital within the last year. Most (60%) told us about experiences that occurred less than three months ago. Eighteen percent occurred between four and six months ago while 19% occurred seven to twelve months ago. Overall, 78% were discharged in the last six months.

The hospitals and trusts in Birmingham that we heard feedback about are shown below.

Table 1: Tell us the name of the hospital you were discharged from

Name of hospital/trust	Response percentage	Response total
Birmingham Children's & Women's Hospital	5%	12
Good Hope Hospital	17%	41
Sandwell & West Birmingham NHS Hospital Trust (City Hospital)	11%	26
Heartlands Hospital	16%	38
Queen Elizabeth Hospital	39%	96
Royal Orthopaedic Hospital	10%	25
Moseley Hall Hospital	2%	4
Spire Little Aston Hospital	0%	1
BSMHFT	0%	1
Ann Marie Howes - Birmingham Community Healthcare	0%	1
Total	**100%**	**245**

Individuals who had direct experience of the discharge process were more likely to complete the survey (70%), than family members or friends (26%) or other (4%). Most (65%) participants were from a white (British/English/Northern Irish/Scottish/Welsh) background; 18% were from a minority background (Arab/Asian/African/Caribbean); 3% from a mixed heritage or multiple ethnic group background; 5% identified as white other and 5% as Irish.

Forty-four percent of the people who shared their experiences have a long-term health condition while 30% told us they have a disability. Five percent told us English was not their first language.

Findings

Where did people go after hospital discharge?

Almost three-fifths (58%) of the participants were discharged straight home with no additional care while 30% were discharged home with minimal care and support. Four percent of the participants were discharged to a care home while 9% went to a rehabilitation unit or a complex discharge hub/care transfer hub. For those who indicated that they were discharged somewhere else (3%), this was to another hospital or to a homelessness unit or House of Multiple Occupancy (HMO).

Following discharge from hospital more (44%) people sought care and support from health and social care (e.g. GP, hospital, social care team) than those (39%) who did not seek care or support. Twenty-six percent visited their GP, 11% went back to the hospital, and 7% saw a social care professional. Those that indicated 'other' (17%) told us they rang 111 or paramedics, went to a hospice for end-of-life care or used private care.

For some, seeing a health or social care professional was pre-arranged as part of the discharge process:

Was told by cardiologist to contact GP next day for appointment to gain repeat prescription for bisoprolol. Doctor had no appointments but I had 2 weeks' medication. Doctors arranged to speak with me 5 days later to add repeat prescription. Doctors were unsure how to advise re ongoing care as I had appointment for ambulatory ecg 2 weeks later.

Other participants contacted healthcare professionals for different reasons after discharge, including:

To get more information

I had to phone the hospital to clarify matters as I had not been told much

My husband became concerned about the pain and swelling in his leg. He rang the number that he was given on discharge and received advice and reassurance.

For further hospital treatment

The day after discharge I had continued to be sick; I was being sick before discharge but still discharged. I was readmitted a week later. I'd been in for surgery for a brain tumour and Id caught covid.

To seek help for social care needs

Seeked help from GP to be able to have district nursing at home and additional equipment. Also seeked adult social care assessment.

Due to a failed discharge

My father was discharged from hospital against our wishes as we did not feel he was fit for discharge, but the hospital disagreed. Upon being discharged and leaving the hospital, my father fell down steps to the car park in the hospital grounds. We took him back to the ward he had just been discharged from and they refused to see him and instead made us go to A and E. He was then in A and E for 32 hours - whilst waiting to be seen, he fell again in the patient toilet and split his nose open. At this point in time, I got quite angry with the staff and informed them he still wasn't well and needed to be readmitted. Thankfully he was admitted again and was in hospital for a further 9 days.

Discharge was a fail. Patient was discharged from ambulatory care too soon, then returned to the QE via ambulance 21 days later with a severe infection, again discharged too early without medication prescribed for them, leading to a re-admittance five days later. After four more days of hospital care and the correct medication, they were discharged.

Case Study 1

I came home and only lasted 6 hours. I had to call 111. The ambulance came and when they checked me everything came out red alert. The ambulance staff told me that the discharge letter said to have gas/oxygen but were surprised that I did not have this on discharge.

I was taken back as a failed discharge. I collapsed in the ambulance so was unresponsive on arrival at the hospital. No assessment was done when I got on the ward - it was done an hour later.

When I was discharged, no discussion or information was given about the content of the discharge letter. No action plan or care plan. They tested my gas levels whilst I was on oxygen, so the results were not accurate. When I questioned this, the staff member told me, 'I am gonna do this again to prove to you that you don't need the oxygen'. We told the Dr, that our father's oxygen levels are okay when sitting down but low when he is moving around.

To arrange own ongoing care

Discharged home on a Saturday, medications had to be sent via taxi home and family collection. No support arranged on discharge. Had to arrange all ourselves including palliative home visit from GP for things that should have been done by hospital.

How involved do patients and families/carers feel?

Levels of involvement in the discharge process varied, ranging from just being given instructions or information to shared decision making. Participants emphasised the importance of an exchange of knowledge and information where their needs are taken into account, that they are enabled to self-care, and patients and families/carers contribute to decisions around hospital discharge.

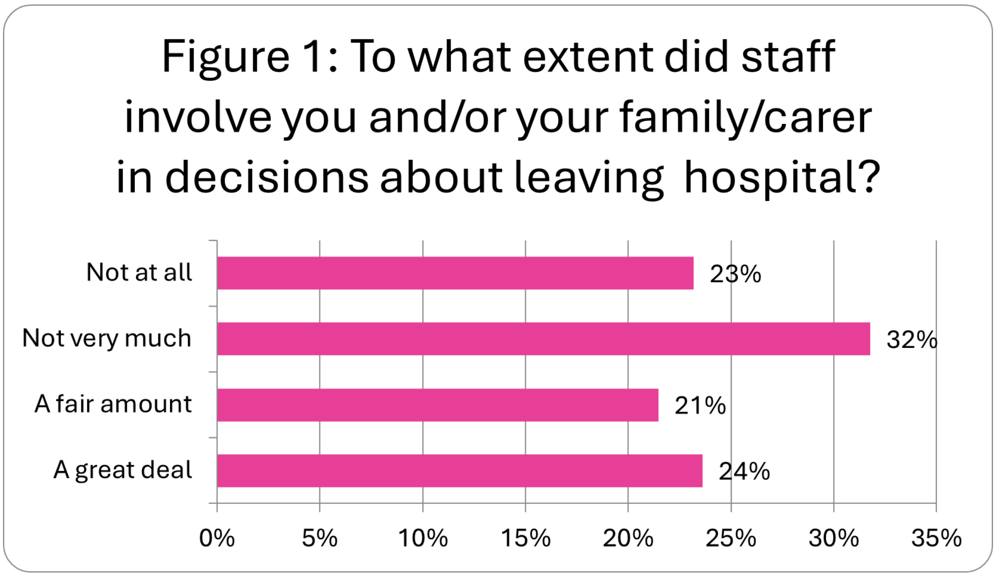
The staff were fantastic, I could not fault them at all. They listened to us as a family when we said she would need physio and further care on discharge from the hospital which is why they referred her on to Moseley Hall. Also, they called me when mom was leaving the hospital and then Moseley Hall called me to tell me that mom had reached the hospital safely.

I had given full permission to the Doctors and Nurses to involve my sister fully in discharge plans and we discussed all together.

I was not involved. Although the consultants visited my ward and saw other patients, I was not seen by a consultant. On the morning of my discharge, I was returning to my bed when a man asked me how I was and had I now done a number 2. I said I had, and he said I could be discharged today. I presume he was a consultant. He was nice and polite.

As a daughter I was trying to make arrangements with very little update on my father's medical status. Given very little advance warning that the hospital wanted to send him home at short notice. No choices just told how things would be on discharge.

Forty-seven percent rated their involvement in the discharge process as poor, 28% as good and 25% as satisfactory. When we asked people about the extent to which staff involved them and their family/carers in decisions about leaving hospital, 55% of participants did not feel involved in comparison to 45% who did. This ranged from those that felt greatly involved to those that did not feel involved at all (see Fig 1).



For a majority of participants, their involvement in the discharge process and planning was limited to healthcare professionals sharing information (38%) or a conversation with a clinician that resulted in an exchange of information (32%). Fifteen percent of participants felt fully involved in the discharge process or felt that their involvement enabled them to make fully informed choices and decisions and felt that their experiences informed decisions made about their hospital discharge (see Appendix Table 1).

When we asked participants whether they felt involved in six key areas, experiences of involvement were split almost evenly between those that agreed and those that disagreed (see Table 2).

Table 2: Do you agree or disagree with the statements below?

Answer Choice	**Strongly agree**	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
I was involved in planning the moment of my hospital discharge or hospital transfer (e.g. when discharge or transfer would happen, medication, any nursing supplies such as equipment)	20%	25%	15%	17%	23%
I was involved in reviewing my ongoing care and progress towards discharge or transfer (e.g. discussing aspects of care needed and updates on discharge or transfer)	18%	25%	13%	18%	26%
I was involved in the organisation of my ongoing care (e.g. what care is needed post discharge, whether I need to go home, into a care home, nursing home, complex discharge hub etc)	18%	23%	17%	20%	21%
I was involved in the hospital transfer conversation of care upon hospital discharge (e.g. discussion around contents of discharge letter, medication overview)	19%	23%	17%	20%	22%
I was listened to regarding the planning of my hospital discharge or transfer	19%	20%	20%	17%	24%
My views and experiences informed the arrangements of my hospital discharge and support that I needed	18%	20%	20%	17%	25%

To understand how discharge will proceed participants wanted to be informed and made aware of what was going on regarding their care. However, some people told us that there was no discussion about the treatment they were having or information concerning a new condition or new treatment. This left many people without an understanding of what to do when they were discharged.

I was in hospital for heart failure for one week. I had absolutely no idea there was anything wrong with my heart, to be told I had heart failure was a shock. There was no real discussion about my heart condition on the ward. The cardiologist nurse that came to see me after they told me I was being discharged gave very little information leaving me with many questions. I was told that I would have a follow up appointment, but this was on the phone not face to face as I needed. Told I would be on two lots of medication but only given one. I am kind of left with many questions. I have no idea if my diet needs to change, what exercise I should do. The nurse just seemed in a hurry and didn't seem to want to have a conversation where I could ask questions. Only spent 5 minutes with me and it was mostly her telling me stuff.

I was told I would be discharged but I was waiting for so long for a liver scan as was waiting for a specialist. In those hours I was sitting around waiting, someone could have come and showed me how to inject myself or use the new drug I had been given. So all that time waiting was a wasted opportunity – we could have used that time usefully to discuss the new drug and talk about contents of the discharge letter. Poor involvement all round, though I can't fault the care.

I did not feel I understood enough about my ongoing medical condition tachycardia going forward e.g. was there anything I should do/not do? Would the tablets cure or alleviate condition? Did I need to return if … happened or simply wait for appointment?

Some felt they had control over when they could be discharged, and that hospital staff handled their discharge in a timely manner and in way that met their needs.

The Dr was so good…they would say this is the best thing for him coz of this. What they are afraid of..was involved in [developing] action plan and treatment plan. It's a busy place and the govt should give them money.

I had major surgery, and I was allowed to decide when I felt ready for discharge.

I was explained everything by the discharge nurse, given dressings and told when to apply them. I was informed if I had any problems relating to my post op care to contact a certain telephone number. I was well informed upon my discharge and was well looked after by all the staff.

However, most people didn't feel in control of when they would be discharged and were just informed 'you are leaving in a few hours' without any consideration of whether discharge was appropriate at the time. Some felt that the discharge was rushed.

There was no involvement from me whatsoever, total shock for me as I still felt ill and I was just told I was being discharged, even though they knew I lived alone.

I was moved around services & finally informed of my imminent discharge with little notice.

There was not any [discussion] - Bed nurse wanted the bed and I was more or less thrown out, no consideration for my disabilities or needs at all.

The discharge was rushed through, no proper information about medication, support and discharge was provided. Discharge process looked very rushed through because they needed bed for somebody else. My father got half of his lung removed and he needs to be fully fit before discharge.

Case Study 2

On the Tuesday early morning to Wednesday, I was spiking a Temperature. On the Wednesday after the Op, discharge was mentioned to which I advised that I wasn't ready till the pain was manageable.

I also mentioned to another team of Professionals that came to see me that the pain wasn't settling, I was still in a lot-of pain and cos I sometimes have a high pain threshold, it didn't mean I could cope! I was still on various pain-Relief on that Wednesday; and had come out-of a Temperature - so it seemed pretty quick that they wanted to discharge me the next day.

When the Ward Sister came on duty, on Thursday she also mentioned about me going home and I also said I wasn't ready; but she said she'll see how my Physio went and what they said. They were happy with everything, so it was agreed for me to be discharged.

When I went to the Discharge Lounge, I was advised that they closed before my Family finished Work; and that they would have to bring me back to the Ward I was discharged from to wait. I got back there only to find that my room was still empty [I thought the room would have had a new Patient in by then!?] and I was given the meal I'd previously ordered and was given a round of Enoxaparin. Which made me feel I was being rushed out.

Some people told us they were being discharged while another patient was waiting at the end of the bed.

I was given nothing. I was just told to go, no warning, doctor came round at 8am and said 3 of us were being discharged and a lady was placed at the bottom of my bed by the porter who was going to be admitted to my bed and he was waiting to take me out, once I had been discharged.

Would have been nice for them to actually tell you and give you time to get dressed at least. And not having people placed at the bottom of the bed they are waiting for when people are still in there, it's embarrassing for both of us and seemed like it was a regular thing they do.

Most people were not involved in decisions on whether ongoing care was needed and for some the ongoing care provided did not meet their needs, wishes or expectations. For some participants the care offered was not needed as they had support at home while others were left without needed support as their home situation had not been considered.

It was a joke. No proper care plan no thought to how the patient was going to cope at home. Been told that it was tough and you need to sit in a chair for hours on end until maybe a care worker might turn up and deal with the mess that this might create. JOKE. Pathetic. The OT was running scared of the physio and wouldn't listen to the patient's requirements because the physio said NO.

Negatively I feel that I have been discarded. I wasn't even asked if there was someone at home/community to support me. I wasn't asked if I knew the impact of my diagnosis. I wasn't informed or referred to a specialist clinic.

Case Study 3

There had been lots of contradictory and vague references to discharge / mainly comments like 'you'll be going home soon and being asked if there was someone at home - but never asking that person if they could cope with looking after the discharged.

Eventually I threw a bit of a fit and said I needed to know what was happening. Then we were given proper information and had proper involvement. Contradictory and confusing pre-discharge process seemed quite normal on the ward.

Participants expressed concern about the information given to them at the time of discharge. They also told us they waited long periods of time for the discharge letter which often didn't have adequate information. As this respondent stated, there could be ***"a bit more detail on the discharge letter regarding the size of the wound and clip/suture information"***. Others indicated that there should be a clear explanation of the discharge letter which did not often happen at point of discharge as this respondent indicated ***"apart from being told that if I got worse, seek medical attention, it would have been better if they had gone over with me, what it said in the discharge letter. That was, that there would be further investigations. I don`t know what these investigations are and they haven`t happened yet. Nothing has been mentioned since. Or because of lack of time was not discussed with patients. provided to them at discharge, especially through the discharge letter".***

Most participants that we met in the discharge lounges of the hospitals we visited were waiting for a discharge letter and medication and had therefore not discussed the contents of the letter with anyone. We observed some patients receiving their discharge letters, but these were not discussed with them. However, we observed nurses asking patients questions around support at home and other issues about their care.

They did not really discuss the discharge letter to let me know if there are changes or something we need to do differently. I need a discussion between me and them.

Just told leaving and wait for prescription. Discharge letter going to GP. No check on transport or any other discussion etc.

Negative consequences of patients not being involved in hospital discharge

Failure to involve patients and families/carers in the discharge process can lead to a discharge that does not take their needs into account and leaves them with a lack of information about their health condition, further treatment, ongoing care or any changes to medication. Patients and families/carers may not understand what is happening and what needs to be done, which can result in stress and anxiety.

I was not involved but sharing my views and experiences from my hospital stay would have been instrumental in deciding the appropriate time for discharge and identifying any required support. Involvement in the discussions about my ongoing care post-discharge was also necessary; but wasn't offered.

Not a lot of involvement. The Dr just tells you, you are being discharged and they strip your bed because you are going. The Dr said to me, how do you feel, I tell him how I feel, if am well or not and then that's it. Then after that discussion, you are left without any further information about what's happening next.

A lack of patient and family/carer involvement is a key contributor to delayed and ineffective discharge.[1] If communication with patients, families and carers is not timely and is unclear, it can lead to feelings of not being supported during discharge as well as misunderstandings about when the patient is going to be discharged and the details of the discharge plan. Uncertainty about being discharged because they were not fully informed about their condition and ongoing care often caused patient's stress.

The discharge was inadequate and there was negligence as canular was also left in hand. They deliberately chose not to listen to the patient and family. We wanted to get the best support for dad so he doesn't have to come back into hospital. The hospital is not his happy place. No one explained what was wrong with him or why he was struggling to breathe.

The physio team did more for me. They asked me more questions about my home and the adaptations I need. The ward manager just told me I was being discharged and sent me to the discharge lounge. They did not tell me anything else. So, while the physio team discussed equipment needs no one discussed the treatment I had had or what I needed to do. I did say that I couldn't be picked up until evening, but they said I couldn't stay on the ward.

During my stay on the ward the diabetic nurse came and said metformin should be taken every morning and night including one dose of insulin. It seems this has changed now but am not sure. Maybe they will clarify this for me here but am a bit in the dark on what's happening.

If patients and their families/carers are not involved in decisions around discharge the patient may feel unprepared to go back home and end up in an environment that does not meet their needs, leaving them unprepared to self-care. This makes readmissions more likely, with one of the main reasons for readmission being that people's needs were not taken into consideration.

The discharge was discussed with the patient, who was off his head in pain medication and unable to make any sensible decisions. It was presented to me as a fait a complis, and he was discharged to my care without my being given any advice or the correct medication.

The hospital couldn't have cared less and just wanted my mom out of there. There was no dignity or compassion whatsoever and they didn't care where she went despite her being seriously ill.

When we discussed my discharge, I told the Dr that carers will be waiting for me at home to put me to bed. The Dr promised that he would get me home between 3 and 5pm – Ambulance didn't come until 11pm. So the carers were sat there for 7hours and have to pay for those 7 hours from direct payments – while I was sat in hospital. When someone is relying on carers to receive you and hoist you – they need to give you an hour or two hours time slot.

Their needs being ignored was one of the main reasons given by participants for their failed discharge and readmission into hospital.

Mother' was a failed discharge (2.5 days). On 2nd admission still not consulted on medical condition / treatments. Again physio / OT were the best at understanding the needs of me as a carer (equipment) not given enough notice on discharge, was basically told a couple of hours beforehand.

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[1] 07-hsc-evidence-reviews-hospital-discharge.pdf (cordisbright.co.uk)

Case Study 4

I tried to discuss his discharge with the doctors at every stage but was given no help or advice.

When he was re-admitted the second time, he was still on antibiotics from the severe infection. I returned to the hospital the next day to find he had not been given his antibiotics or his insulin, which were on the table next to his bed, despite my having given three members of staff the information about his medications. They were not given as they 'had not been prescribed'.

When he was discharged the second time, he did not have one of the medications, a laxative, which had been prescribed. A doctor is going to start an internal enquiry about this because it led to his being admitted for the third time.

When he was discharged the third time, despite my asking for them, he was not given any protein shakes to build up his strength. These arrived at the local pharmacy three weeks later.

Good communication ensures that there is shared expectation early in the discharge process. Having realistic conversations about goals, and length of stay in hospital, is crucial. Early discussions and continuous communication around progress can also reduce waiting times for discharge medications and discharge letter.

If they are saying you are going home tomorrow then they have 24 hours to prepare medications. This should be done during progress discussion. Maybe even have a dedicated middleman to facilitate meds between ward and pharmacy. They are so desperate for beds but then you have to hang around.

I am always keen (like others) to escape the hospital but get frustrated when you are sitting around for hours waiting for medication and discharge letter. There is no point in arranging pick up until I have all that I need!

When you get discharged, you are told that you are getting discharged. I have been waiting for meds and discharge letter for 8 hours. I feel guilty that my husband is hanging around. Its no fun sitting in the discharge lounge.

Early discharge discussions also allow family or carers to prepare. Some patients and families/carers said that discharge was often abrupt and left them very little time to prepare to return home or for their family/carers to make arrangements for their return home.

Until very late in the discharge process it was very confusing and contradictory. There was a considerable amount of home-planning and reorganisation needed for the patient to come home comfortably, and I wasn't really given enough time to plan anything. What I did achieve was mainly due to other patients previous experiences. The medical staff communication between doctors and nurses and between everyone and the patient / carer was appalling - bordering on non-existent.

Whilst waiting for interpreter for patient in front of me in discharge lounge, I could have been seen and discharged, instead of a rush and having notes and paperwork thrown at me because it was 5 o'clock.

Late notice (5.00 pm) and no time to put in place additional care I needed.

I felt pressured and rushed, as if they wanted the bed. There was no concern regarding how I was getting home, I was just left to wait.

Participants also identified issues in communication between hospital staff and external teams (e.g. social care teams). This affected information shared with patients and arrangement of post discharge care, especially for more complex cases.

Communication is important. I could tell that not all staff were on the same page during discharge.

The nurses on the ward didn't know what was going on about the discharge. Only saw them giving out meds but they never really talked to me about discharge. They seemed clueless.

There is complete lack of communication between hospital, Care home and social care. The hospital discharged me early because they needed the bed, and the care home needs 3 days advance notice to prepare and plan everything according to care plan. This lack of communication between hospital discharge team and care home resulted in great stress for me. The discharge team should plan in advance and involve the care home team at right time rather than giving them few hours to prepare. Everyone in the health care system knows that after the care plan has been agreed the care home needs 3 days to prepare and accept the patient.

Case Study 5

Honestly poor discharge process, especially considering there was a discharge coordinator based on the ward - no idea what they are actually paid for.

Too much left to patients and family members to advocate for….. the discharge process could be more efficient and effective for patients and their carers needs and explain what help and support that can be given and arranged or details of how to access in community if not required from hospital.

Complex discharges like this should be communicated to district nurses as well in a timely manner as well as to GP and ensuring palliative care follow up is already arranged prior to going home. Too much onus on patients and family to prompt hospital teams to communicate. Seems once they feel they can't do anything medical for you, you are expected to just get up and leave, like you are taking up valuable space and beds.

Brain metastases were not the patient's fault. They were missed on the initial admission, and we had to go back into hospital within 24 hours of initial discharge and only after we requested the brain scan were the mets found. Everyone in a rush to get patients out of hospital that they forget to actually do the caring whilst they are there.

Improving patient involvement in hospital discharge

Good involvement ensures that patients and families/carers can make informed decisions, and their needs and circumstances inform the discharge plan.[1] It means patients, and families/carers have the knowledge to self-care. Across the responses that we heard, people were clear about what good involvement should look like.

Participants told us good involvement includes:

Patient's and family/carers' preferences being heard and adequately considered, with needs incorporated into discharge planning

It works when people listen and care. We are dealing with humans with issues. We are not robots. Proper planning, schedules, and time scales. Planning for the future. But to do that you have to care which the staff we came across didn't they couldn't care less.

They listened when the Dr tried to discharge me twice. The Nurses told Drs I was not ready.

First time discharge was too soon - no one listened that my father was not yet fit for discharge.

Not being listened to. The staff asked the patient questions when he was not fit to answer them, and these answers over-ruled my concerns about caring for him, and led to his being readmitted twice.

Case Study 6

Proactive planning for discharge by the co-ordinators who by definition should have been co-ordinating. Palliative care patients should be referred for community support on urgent basis for things like access ramps, not on routine council pathways. This should have been arranged and in place prior to discharge but was not.

Ask what needs are, staff to actually look at what the patient needs are and what they are doing for themselves during the admission, and to anticipate what the trajectory will be for recovery or decline and put safety nets in place. We were eligible for CHC but hospital teams never considered this.

Teams to liaise with carers, because ultimately we are the ones looking after the patients from the minute they leave the hospital, we are a help and not hindrance so why hide away from carers?

Patient's social context, including home circumstances, being understood and taken into account

I should have been asked about my own support system once discharged.

Family spoken to so a better understanding of home circumstances could have been established and support should have been put in place before discharge.

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[1] Quality statement 5: Involving carers in discharge planning | Transition between inpatient hospital settings and community or care home settings for adults with social care needs | Quality standards | NICE

Case Study 7

I believe that this person should have been kept in hospital until arrangements had been made for his care at home.

He had had a bad fall which had left him confused and unable to care for himself properly upon discharge.

He was unable to shop for himself and until a friend came to stay with him he was not eating properly.

He had no family to take care of him and the hospital was aware of that.

Clear and consistent communication throughout the discharge process. Patients and families/carers want to understand what happens next, what they need to do and who to contact if needed. Discharge letters must outline this information, but verbal communication is also necessary.

They need to communicate with the patients on a regular basis and should involve the patient and family in all the issues related to discharge process. They informed my family about the discharge only few hours before my discharge and as a result nobody could come to pick me up. Give them at least 24 hrs notice so they can plan.

They need to tell you what's happening i.e. if you are staying longer. E.g. when the Dr visits, they should give you feedback about the treatment options and what's going to happen and what that means for discharge. Would help with anxiety. This was the same for everyone on the ward.

Involving me in the planning of my leaving. Speaking clearly, calmly and not rushed. Explaining about physio. I did not open the envelope for a couple of weeks, then found it contained important physio info, which I hadn't started.

Staff prioritising discharge consultation and including patients in decision making.

During the morning round consultants should spend more time with the patients and try to explain discharge related information themselves rather than leaving it to junior doctors and nurses.

Physio / OT, excellent. Listen to my concerns as the carer, advised / assisted with help and equipment needed. Daily doctors & nursing staff need to be more approachable and communicate better with the carer / family members. Ward receptionist was helpful and informative too.

Am happy with everything. People get upset and anxious is when they don't know…they need to talk to people about what is happening.

My experience was positive - the friendliness and helpfulness of staff. Being able to speak to staff and ask questions. They provided enough information about discharge, what will happen and what to do.

They listened to my concerns and involved me in decisions about me.

Preparing patients to care for themselves post discharge or receiving post discharge care tailored to their needs and preferences.

Proper involvement in the discussions about Hospital discharge should have been ensured, not merely mentioned in passing. I should have been consulted about my feelings post-operation, including pain management, medication review, and mobility confidence. I should've been involved in the discussion around the contents of my Discharge Letter.

I really don't know. perhaps someone taking time to sit and talk to me. And some information as to what you should and shouldn't do after hip replacement to ensure a speedy recovery.

Starting discharge planning early enough so patients do not feel rushed and there is agreement on expectations of care, as well as a clear and updated discharge timeline.

Would be good if it was explained to from the onset everything involved in my surgery to my discharge and was kept informed of checks and X-ray and possible time of discharge.

It could/should have been less rushed, and more consideration taken of my disabilities, I was made to feel insignificant and inconvenient to them. I have had 2 or 3 stays in hospital over the past few years and never have I been treated as I was this particular time.

Case Study 8

A respondents view on how involvement in hospital discharge can be improved

1. Discharge needs to be person centred - is the patient ready, do they know what condition they have and how to manage it?

2. If referred to outpatients, have they contacted outpatients, provided pamphlets on what to expect and given phone numbers of people that can be contacted.

3. The way they discharge as well. On the day he was discharged they told him 'You are leaving - gave him milkshakes and told him he had to leave by 3pm. So, chasing him out really'.

4. Need to follow discharge process and ensure that things like canulars are removed. no discharge process was done to my knowledge. Have a discharge checklist.

5. Have a leaflet that explains to patients and family on the support needed so we can see it. There was no care plan, they just sent him home. He has a mental health condition; they did not consider the impact of this. No help was provided in terms of telling us 'If he drinks this or eat this food it might help with phleghm'.

6. Patient led care - if the patient says he can't breathe, they should check. If they think the patient is using too much oxygen then they should say so and give an explanation.

It's not about new things, it's about doing the things you are supposed to do well. For instance, following the discharge procedure.

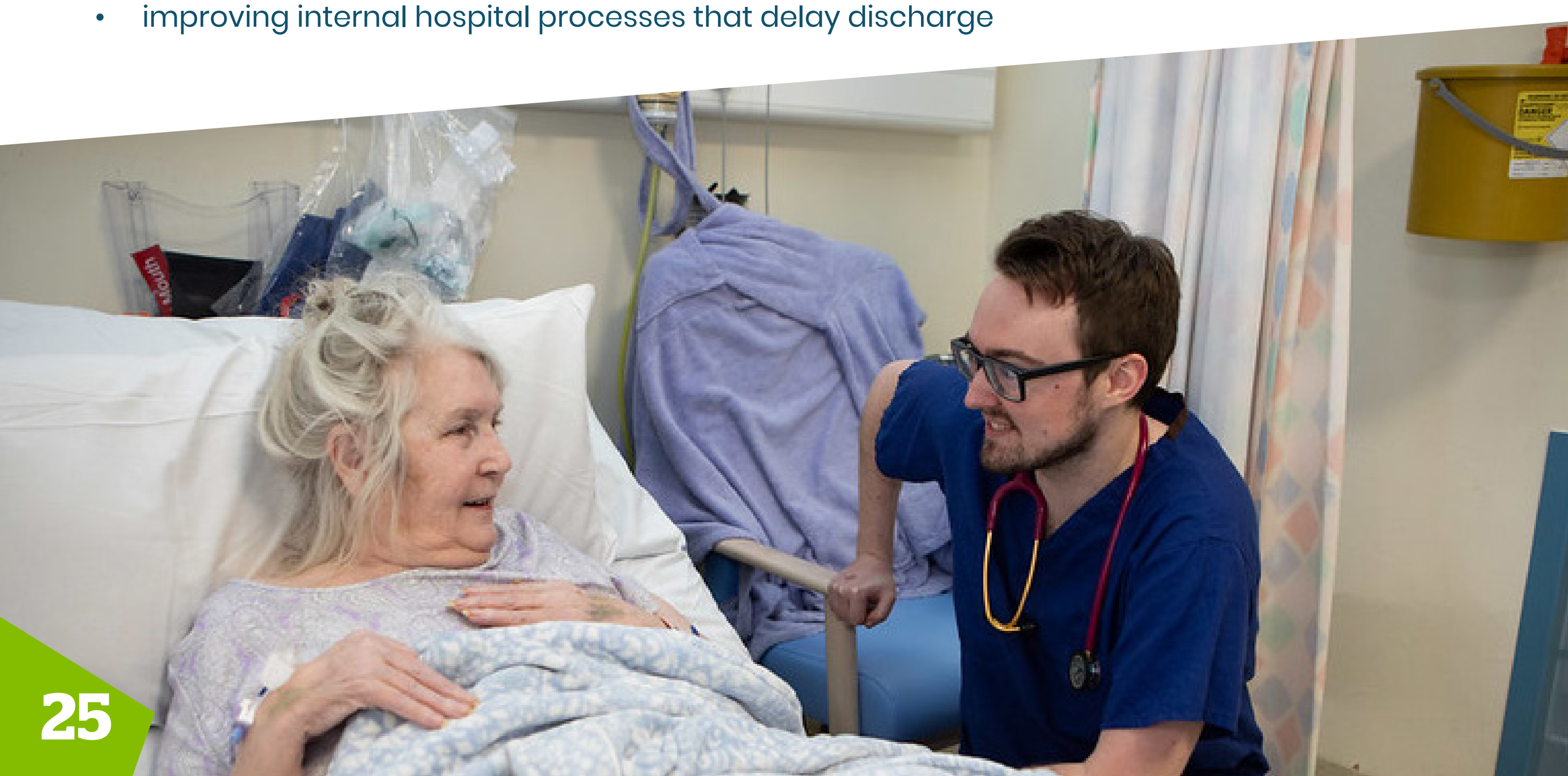
Conclusion

Our findings show that the involvement of patients and families/carers improves hospital discharge and healthcare professionals should actively invite patients and families/carers to participate in discharge planning. There needs to be a willingness to accommodate patients' needs and preferences, including the valuable role that families and carers play in ensuring a successful discharge. and assessing the capacity of families and carers to provide support. Crucially, patients and their families/carers must feel they are being listened to, included in decision making, supported to care for themselves post discharge and receive clear communication around when discharge will happen. Healthcare professionals need to consult with patients and understand their needs post-discharge, especially what they think they will need, and whether they have any help at home. Patients and families/carers who were given information about their treatments during their stay, symptoms to look out for post discharge, how to manage their condition and any new medications felt more prepared for discharge.

Effective patient involvement can also reduce the risk of poor outcomes and readmissions and decreases stress and anxiety. Our study shows involvement wasn't always prioritised and that patients and families/carers weren't always consulted in discharge planning, often being passive recipients of information instead. Experiences of communication ranged from healthcare professionals simply giving instructions to real shared decision-making which considered a patient's needs and preferences. A lack of involvement meant that many participants felt unprepared for discharge and the care provided post discharge did not meet their needs. Discharge was often short notice, rushed and poorly planned with patients and their families/carers feeling this was driven by availability of beds. The patient and their family/carer should be involved throughout their hospital stay, and not just on the day of discharge, and could be facilitated by a healthcare professional whose focus is on maintaining communication with various stakeholders involved in the patient's discharge.

Key areas for improvement:

- better communication
- more information and patient involvement in decision making
- need for a discharge checklist
- improving internal hospital processes that delay discharge



About Healthwatch Birmingham

Local Healthwatch were established in every local authority area across England following the Health and Social Care Act 2012. Our key role is to ensure those who commission, design and deliver health and social care services hear, and take into account, the public voice. Healthwatch Birmingham listens to and gathers public and patient experiences of using local health and social care services such as general practices, pharmacists, hospitals, dentists, opticians, care homes and community-based care. We hear these experiences via our Information and Signposting Line, our online Feedback Centre, and through our community engagement activity led by staff and volunteers. You can read more about the work of Healthwatch Birmingham here: https://healthwatchbirmingham.co.uk/about-us/

How do we select the issues we collect evidence about?

Some of the issues we hear about from patients and the public may require deeper exploration in order to present a comprehensive report to those who commission, design and deliver health and social care services in Birmingham. Members of the public select these issues as part of our Topic Identification and Prioritisation System. By involving members of the public in decisions about our future activities, we ensure we are operating in an open and transparent way. It also ensures that we understand the public's priorities.

Who contributes to our evidence collection?

We explore selected issues with the help of our volunteers, Healthwatch Birmingham board members, patients, members of the public, service users and carers. They share relevant experiences, knowledge, skills and support. Healthwatch Birmingham also talks to key professionals providing or commissioning the service we are investigating. This helps us to form a deeper understanding of the issue from the perspective of these professionals, and encourages them to take prompt action to implement positive changes for patients and the public.

What difference do our reports make?

We follow up our reports to see if our findings have made services better for patients and service users. We hold service providers and/or commissioners to account for changes they stated they would make in response to the report. If Healthwatch Birmingham finds no improvement, we may decide to escalate the issue to Healthwatch England and local regulators. We also monitor the changes to see if people experience sustained improvements.

How to share your feedback about the issues heard in this study

If you are a service user, patient or carer, please do share your experiences with us via our:

- Online Feedback Centre here.
- Information and Signposting line on 0800 652 5278 or by emailing us.

Appendix

Table 1: Overall, how would you rate your experience of being involved in the discharge process

Answer Choice	Response Percent	Response Total
Good	28%	57
Satisfactory	25%	50
Poor	47%	96
	Answered	203
	Skipped	45

Table 2: How would you describe your level of involvement in the discharge process?

Answer Choice	Response Percent	Response Total
I was only given information	38%	89
I had a conversation with the clinicians and there was an exchange of information	32%	75
I worked with the clinician to find the best solutions and my experiences were taken into account in my hospital discharge or transfer	9%	21
I was able to make my own decisions about the hospital discharge or transfer	6%	13
Other (please specify):	15%	35
	Answered	233
	Skipped	15

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