Your healthwatch Leeds

Leaving hospital

What people discharged from hospital and their family members had to say

March-May 2022

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Summary

Introduction

Healthwatch Leeds decided to find out about people's experience of hospital discharge following national reports on the subject indicating some of the current challenges (see Background p.7). A lot of work in the planning of health and care services before and during the Covid-19 pandemic has focused on trying to make sure that people don't stay in hospital any longer than they need to. This was partly initiated by the need to free up beds during the pandemic but also because it is recognised that prolonged hospital stays can cause loss of independence and deterioration in a person's health[6].

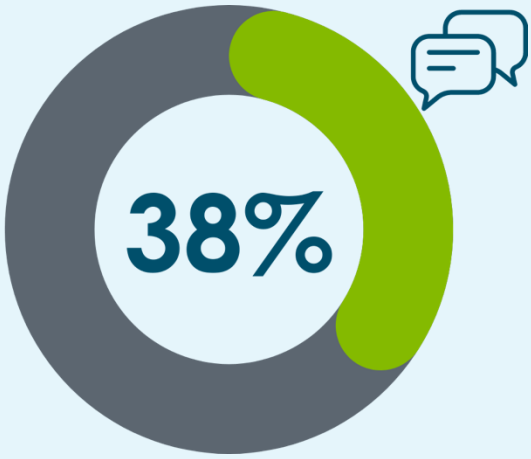
The 'Discharge to Assess' model introduced in 2020 aims to ensure that people are discharged to the right place with the right support at the right time without unnecessary waits for care assessments whilst in hospital. However, we know that this doesn't always happen because of current challenges in the health and care system. It is key that as we move forward, people's experiences both during discharge and after leaving hospital are at the centre of plans to get things right.

Between March and May 2022, we carried out a survey with people who had been recently discharged from hospital or with their family members, to ask about their experiences during and after discharge.

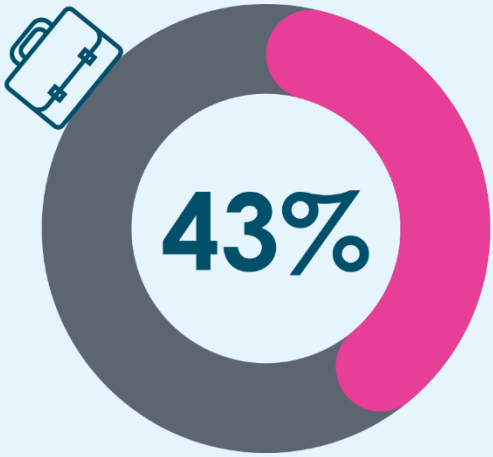
Key Findings

Over 200

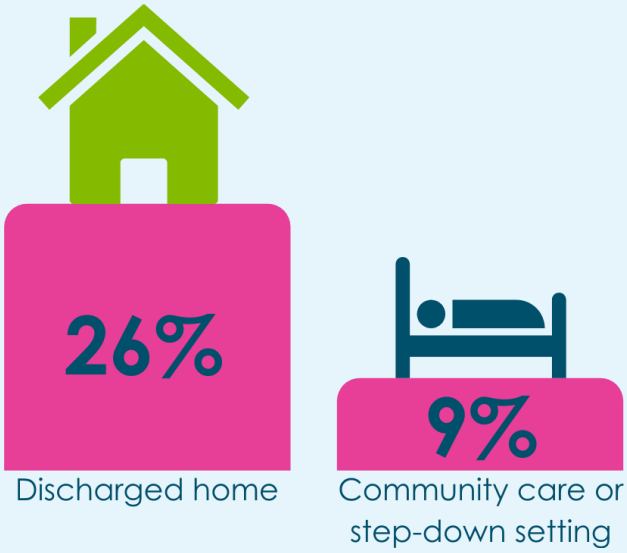
people discharged from hospital and their family members shared their experiences of being discharged from hospital.



of family members said they were dissatisfied with how involved they'd been in conversations about discharge whilst their relative was on the ward. Dissatisfaction was lower amongst people discharged, with 18% expressing dissatisfaction.

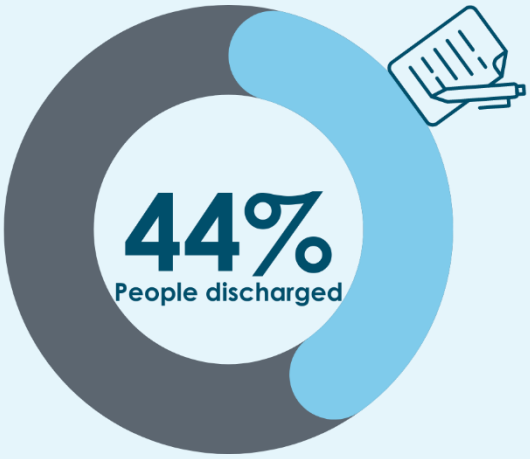


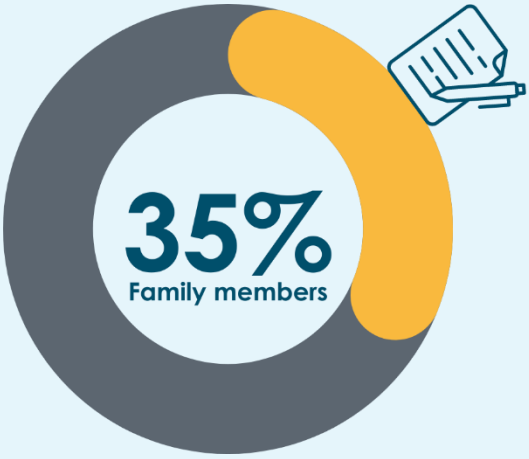
of family members and people discharged (combined) said they didn't feel prepared for discharge, citing having not been informed it was going to happen or that it felt rushed or happened at very short notice.



26% of those discharged home expressed dissatisfaction compared to 9% of those discharged to a community care or step-down setting. The main reasons given for this were poor communication about what was happening regarding discharge and a lack of practical and professional support during and after discharge.

of people discharged said they were asked about any communication needs when they were in hospital, (as per the Accessible Information Standard[8]).





Less than half of people who were discharged home (44%) said that they were given written contact details of who to contact if they needed any further advice following discharge. This figure was lower still for family members (35%).

Only 10% of family members of people discharged home said that they had been told about Carer's Assessments.

Where discharge had worked well, people cited good communication, feeling involved in the process, involvement of their family members where applicable, and good co-ordination and quality of after-care.

Key recommendations

- **Improve involvement of people in conversations about their discharge at all stages of their hospital journey.** A key aspect of this is making sure people have as much advance notice of their discharge as possible. **Under Section 91 of the Health and Care Act[1] which came into force on 1st July 2022, NHS Trusts now have a legal duty to involve all patients likely to need further care and support in discharge planning.**

> **"Tell the patient you are going to discharge them. Patients need to know this, NOT just left to wonder what is happening," person discharged**

- **Family members need to be recognised as an integral part of the discharge journey and should, where appropriate, be involved in discharge conversations from admission until the person gets home.** Many families provide vital support with everything from transport home, hands-on care and emotional support, as well as taking on a co-ordination role. Section 91 of the Health and Care Act (see above) also extends to involving unpaid carers in discharge planning.

"A sit-down conversation is needed with the relatives to explain the plans and what to expect," family member

- **Routinely ask people receiving hospital treatment or care and their family members whether they have any communication needs** and act on these in line with duties outlined in the Accessible Information Standard. **Communication needs aren't always visible.**

- **Improve identification of family carers and refer to Carers Leeds for information and support as required.** Work from the assumption that all family members might have a caring role. Carers should be clearly identified and flagged on the patient's record, with permissions actively sought prior to or during admission.

- **Ensure that everyone leaving hospital is given appropriate follow-up contact details for further support and advice.** This information should also be given to any family or unpaid carers who are supporting the person leaving hospital.

- **All partners involved in hospital discharge should review their discharge information, policies and procedures** to check that they involve both people staying in hospital and their family carers, where appropriate, at key points.

Background

In November 2021, a Transfer of Care Hub was set up in Leeds comprising staff from Leeds Community Healthcare NHS Trust, the Reablement Team (Leeds City Council), Adults and Health and Leeds Teaching Hospitals NHS Trust discharge teams. The hub was put in place as part of the development of the 'Discharge to Assess' (or 'home first') approach to hospital discharge, as outlined in current government guidance on hospital discharge and community support[2]. Its role is to co-ordinate the discharge of all adult patients from Leeds Teaching Hospitals NHS Trust who require:

New or additional health and/or social care support at home

or

Recovery, rehabilitation, assessment, care planning or short-term intensive support in a 24-hour bed-based setting, before returning home. In Leeds, this would either be in a community care or 'step-down' setting.

The Discharge to Assess model places a new responsibility on acute hospital teams to work closely with community health and social care services to ensure people get the support they need after leaving hospital. Where people no longer require an acute hospital bed but may still require care services, they should be provided with up to six weeks' funded support following discharge. This could either be in their own home or in a residential/ward setting. The aim of this is to give people the opportunity to recover and rehabilitate before their longer-term health and care needs and options are assessed and agreed.

Discharge to Assess aims to reduce delayed discharges by ensuring that people don't have to wait unnecessarily for assessments in hospital. It also aims to prevent 'overprescribing' of care that isn't needed and avoid people being discharged permanently into a care home for the first time following a hospital admission. Both outcomes can lead to reduced independence.

Under the Discharge to Assess model, it is estimated that:

- 50% of people will be discharged home with no or minimal support from professionals or the continuation of a care package that was already underway before hospital stay (Pathway 0)

- 45% will be discharged home with new, additional, or restarted support from community health and social care services (Pathway 1)

- 4% of patients would be discharged to a 24-hour bed-based setting for recovery, rehabilitation, assessment, care planning or short-term intensive support before returning home (Pathway 2)

- 1% will be discharged to a care home for the first time (Pathway 3)

This report relates to people's experience of being discharged from an inpatient stay at any of the hospitals that are part of Leeds Teaching Hospitals NHS Trust. It does not cover discharge from mental health inpatient units.

Throughout the report, we have included extracts from the current government guidance on hospital discharge and community support[2] to give an indication of what is advised nationally.

Why we did it

We have been aware of the issues surrounding discharge from hospitals for several years and it has been recognised within both the local and national health and care system as an area of concern. Healthwatch England and British Red Cross[3] and Carers UK[4] have independently produced reports following the introduction of the Discharge to Assess model outlining some of the issues from the perspective of both people using services and unpaid family carers. Key themes from these reports were people not feeling involved and informed in discharge planning and insufficient follow-up support and aftercare.

In the National NHS Adult Inpatient Survey 2020 Benchmark report[5], three out of the five lowest scoring areas for Leeds Teaching Hospitals NHS Trust (all below the national Trust average) related to patients' responses to the following questions:

- Q40. Before you left hospital, did you know what would happen next with your care?

- Q35. To what extent did hospital staff take your family or home situation into account when planning for you to leave hospital?

- Q37. Were you given enough notice about when you were going to leave hospital?

Delayed discharge can cause loss of independence and deterioration in a patient's health[6] and incur unnecessary costs to the NHS and local authority. Conversely, being discharged too soon, or without the necessary support and aftercare can lead to hospital readmissions[7].

At the beginning of the Covid-19 pandemic, there was pressure on the NHS to free up capacity in hospitals to cope with a surge in demand from Covid patients. Two years on, there are ongoing pressures on health and adult social care services. This has been due to increased demand combined with staff shortages. Anecdotally we have heard from health and care, colleagues, that this has meant that not everyone has been able to receive the most appropriate after-care for their situation.

The aim of this piece of work was to hear about how recent changes in the discharge process and Covid pressures have affected people's experiences of being discharged, as well as the support they have received once they left hospital. It is also about hearing about the experiences from the point of view of family and friends who are such an integral part of people's support networks. It is key that these experiences are at the centre of planning as we move forward, as the priority must be to getting it right for people and their families and unpaid carers.

What we did

Working group

In February 2022, a working group was set up comprising organisations who are involved at different stages of the hospital discharge process in Leeds. It also included an 'expert patient' from Leeds Teaching Hospitals NHS Trust. The working group helped us to understand the different pathways that people take when being discharged from hospital, as well as recent changes and challenges. The group helped to design and test the survey as well as work out the most effective ways to get it out to people.

The working group agreed that the focus of the project should be to hear from people who had been discharged from hospital recently (i.e.: in the last two months) and who had been assessed as needing some health and/or social care support. It was also agreed that it was important to hear from unpaid family carers.

Survey

There were two different versions of the survey – one for people who had been discharged home, and one for people who had been discharged to a community care setting, care home or supported living. The survey could either be completed by the person who had been discharged from hospital or their family carer or friend. Some of the main areas covered by the questionnaire were:

- How involved they had felt in the discharge process.
- Whether they felt they had stayed in hospital too long or not long enough.
- What support they had received once discharged and whether they felt it met their needs.
- If an unpaid family carer, whether they had been offered a Carer's Assessment

Between March and May, survey packs were sent out via the following organisations, with the option for people to complete a paper copy of the survey and return it to us in a Freepost envelope, complete it online or call Healthwatch Leeds to complete it over the phone:

1. Leeds Teaching Hospitals NHS Trust Transfer of Care Hub. Everyone who had been discharged during March and April 2022 to their own home and had been assessed as needing some support was sent a survey to complete and return to Healthwatch Leeds in a Freepost envelope.
2. Carers Leeds shared the link to the survey in their newsletter and gave out hard copies to people they knew were caring for someone who had recently been discharged from hospital.
3. Age UK Leeds sent out surveys to everyone who had used their Hospital to Home service and/or Home Support Service between January and April 2022.

Target groups

Within the identified target audience, we also wanted to focus on hearing from people from the following groups who we know may be more likely to experience additional barriers when using health and care services:

- People from culturally diverse communities
- People with a learning disability
- People with a sensory impairment.

We know that for some people from these groups, communication needs may also make it less easy for them to complete a written survey. To encourage people to participate, we produced an easy-to-read visual flyer and offered interpreters, the option to complete the survey over the phone and a £5 voucher as an incentive. These flyers were sent out to over 50 services and community groups who we knew were more likely to work with these groups of people. We asked them to share the flyer with people who may have been discharged from hospital in the last two months.

Enter and View*

During April and May, we carried out a series of Enter and View visits to the following providers of community care where we completed the survey face-to-face with people staying at these facilities. Community care settings are places that provide rehabilitation to people discharged from hospital to help them become as independent as possible before returning home.

- Ward 30, St James' Hospital (Villa Care)
- Ward 31, St James' Hospital (Villa Care)
- Bilberry Ward, Wharfedale Hospital (Villa Care)
- Heather Ward, Wharfedale Hospital (Villa Care)
- Green Lane Intermediate Care Centre (Four Seasons Healthcare)
- Harrogate Lodge (Four Seasons Healthcare)
- East Leeds Recovery Hub (Leeds City Council)
- North-West Leeds Recovery Hub (Leeds City Council)
- South Leeds Recovery Hub (Leeds City Council)

We also did an Enter and View visit to Elmet House, a unit that has 12 'step-down' beds. Step-down beds are for people who are ready to be discharged from hospital but are not ready to return to their former home or level of independence.

As part of each Enter and View visit, we also asked providers to send out survey packs to friends or relatives of everyone who was staying at the care setting.

*'Enter and View' is a statutory right that Healthwatch organisations have whereby trained authorised representatives can visit premises where health and care is provided, to observe the nature and quality of the services.

Videos

In the survey, we asked people if they would be willing to be filmed talking about their experience of hospital discharge. As a result, we were able to film 14 people talking on camera about their experiences, either as someone who had recently been through the process themselves, or as an unpaid family carer supporting someone else. The videos highlight three different aspects of the experience of hospital discharge:

- Episode 1: Information (https://youtu.be/JtXlNXJLhnM)
- Episode 2: Returning home (https://youtu.be/BvlVngivlj8)
- Episode 3: Family carers (https://youtu.be/8Rv8XKtdmuE)
- Episode 4: Kim (https://youtu.be/PCFH_jZoZI8)
- Episode 5: Heather, Nicola and Royston (https://youtu.be/EnrxcwYioZo)

What we found

We received a total of 203 responses to the survey. 161 (79%) were from people who had recently been discharged from hospital and 42 (21%) were from a family member. Over half (59%) of the responses were gathered as part of our 'enter and view' visits to community care and step-down settings. The remainder were from people (or their family members) who had been discharged back to the community.

Involvement of people in discharge planning

What the 'Hospital discharge and community support' guidance[2] says:

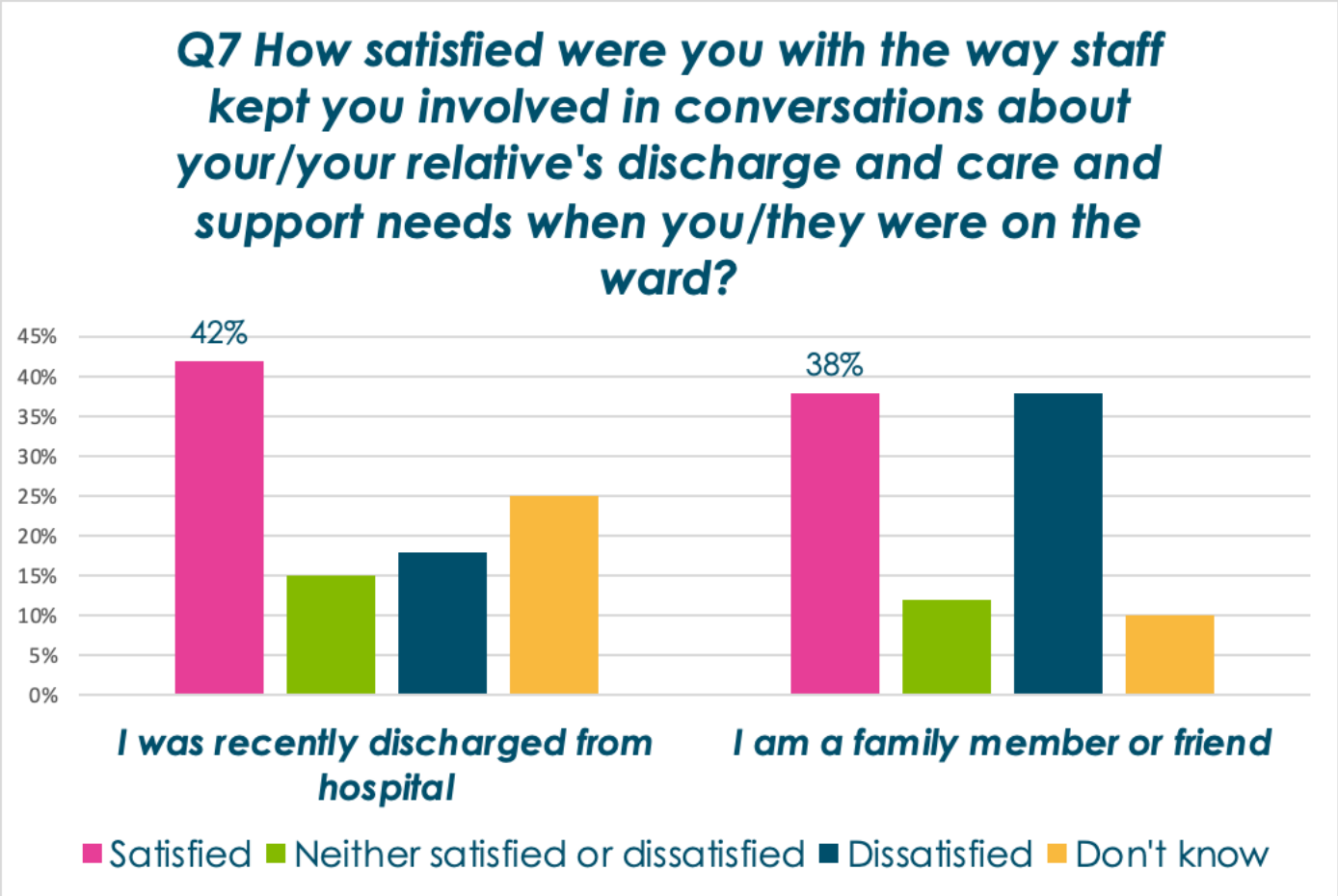
"Where relevant, the decision about when to discharge a person, and any support they might need before an assessment of their long-term needs, should take into account the views and circumstances of any unpaid carers as well as those of the individual."

"Planning for discharge from hospital should begin on admission. Where people are undergoing elective procedures, this planning should start pre-admission, with plans reviewed before discharge. This will enable the person and their family or carers to ask questions, explore choices and receive timely information to make informed choices about the discharge pathway that best meets the person's needs.

From the outset people should be asked who they wish to be involved and/or informed in discussions and decisions about their hospital discharge, and appropriate consent received. This may include a person's family members (including their next of kin), friends or neighbours… Paid care workers and personal assistants may also be included. A person who does not have family or friends to help, or who may find it difficult to understand, communicate or speak up, should be informed of their right to an independent advocate."

When asked about how involved people felt at different points of their hospital journey (on admission, during their stay on the ward and when they got home or to their new care setting), the responses were

broadly similar at each of the different points. There was however a marked difference between responses from people discharged and family members, who were over twice as likely to be dissatisfied with how they'd been kept involved in conversations.



It is worth bearing in mind that 60% of survey respondents who were discharged home said their family and friends were helping to look after them. As such, these unpaid carers should be recognised as an important part of people's support during discharge, and their comparatively high levels of dissatisfaction are viewed as a key indicator that more needs to be done to recognise them as a key partner.

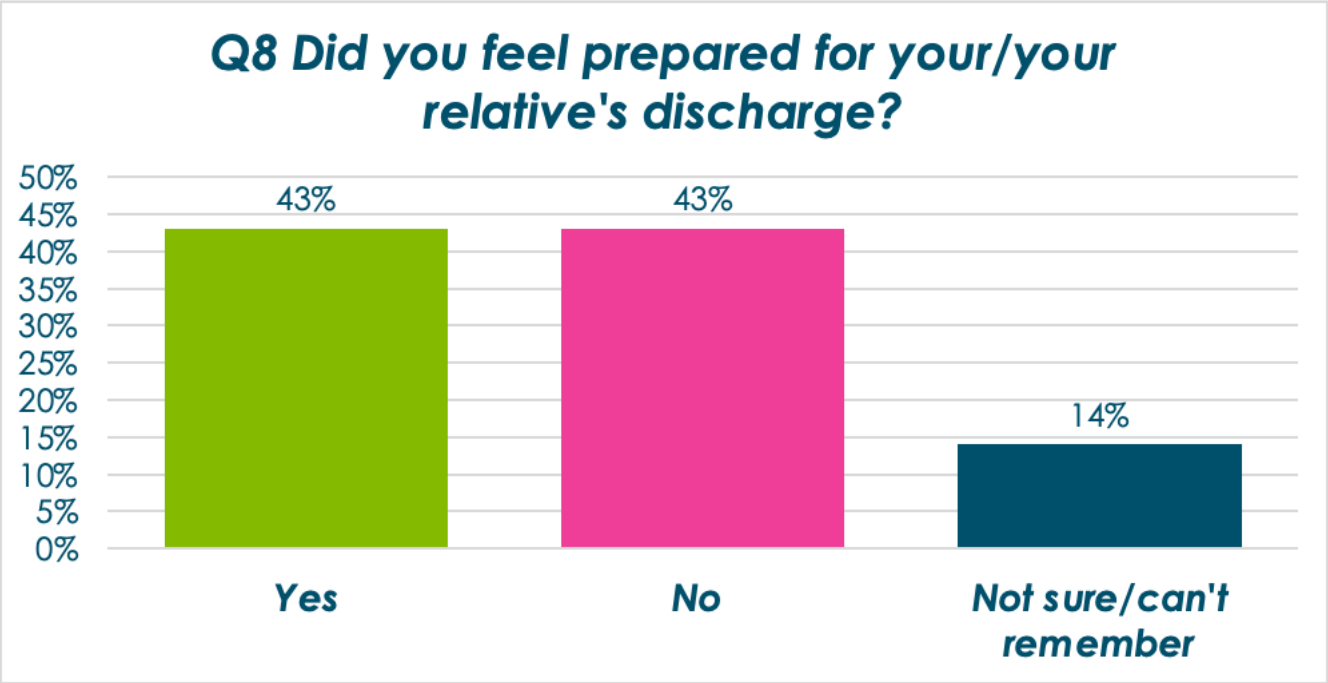
Not only should it be seen as good practice to involve people and their carers in discharge planning, but also be recognised as a legal duty. Since 1st July 2022 when it came into force, Section 91 of the Health and Care Act1 states that "where an adult patient is likely to need care and support after their hospital discharge, patients and carers should be involved in discharge planning".

"I spoke to the desk when I visited and asked if there were any plans to discharge and for them to let me know. The next day my dad was discharged, nobody had let me know and he was just sent home. Without a care plan just with a bag of tablets," family member

"There was no liaison with us regarding our mum's discharge. Nobody contacted us to inform us of how she was recovering. The only information we received was from Mum herself when we called and spoke to her directly on a daily basis," family member

"Was sat waiting for ambulance transfer from 11am until my wife came to visit at 4pm as no one told her I was getting discharged," person discharged

Feeling prepared for discharge



Responses were split equally between those who felt prepared for discharge and those who didn't. Communication and being kept informed about the discharge process was a key theme.

"The transfer was a good experience. The hospital prepared her well and were helpful. She knows she is in the facility as she still isn't ready to go to independent living," family member

Just under half (48%) of the people who said they didn't feel prepared for discharge mentioned not having been told what was going to happen. Over a third (33%) said that they felt that the discharge had felt rushed and very short notice. A number of comments implied that some people had only been told at the point of discharge or only a few hours prior.

“I had been in hospital about two days when a doctor said to me “Would you like to go home?” I said “Yes” but did not think it would be immediately. I was out in the rest room and the sister rang my daughter to make sure she was not at work. I had no cash, only my night attire and no house keys. I felt thrown out. I don’t know how people go on with no family,” person discharged

“In hospital they didn't speak about discharge. I didn't get any warning that I was going to be moved, no-one comes and tells you anything,” person discharged

For some family members, being kept out of the loop meant that they were not able to support their loved ones as effectively as they wanted.

“They did not tell us [my mum] was being transferred from LGI to Chapel Allerton [hospital]. No reason given as to why and when. My mum rang frightened from the ambulance saying, ‘I'm in the back of a van, and I do not know where they are taking me’. I didn't know who to contact or call,” family member

This is something that was highlighted in the Carers UK recent report on hospital discharge[4]:

"A very clear thread from carers' experiences shows that carers have not been involved, consulted, or given the right information in order to care safely and well. If carers are considered to be partners in care, then, like health and care professionals, they need access to relevant information to help them support a person needing care safely." Carers Experiences of hospital discharge report (Carers UK).

Another common reason given by people for not feeling prepared for their discharge was a lack of practical information. The kind of information people wanted included discharge letters, instructions for after-care, and relevant contact details.

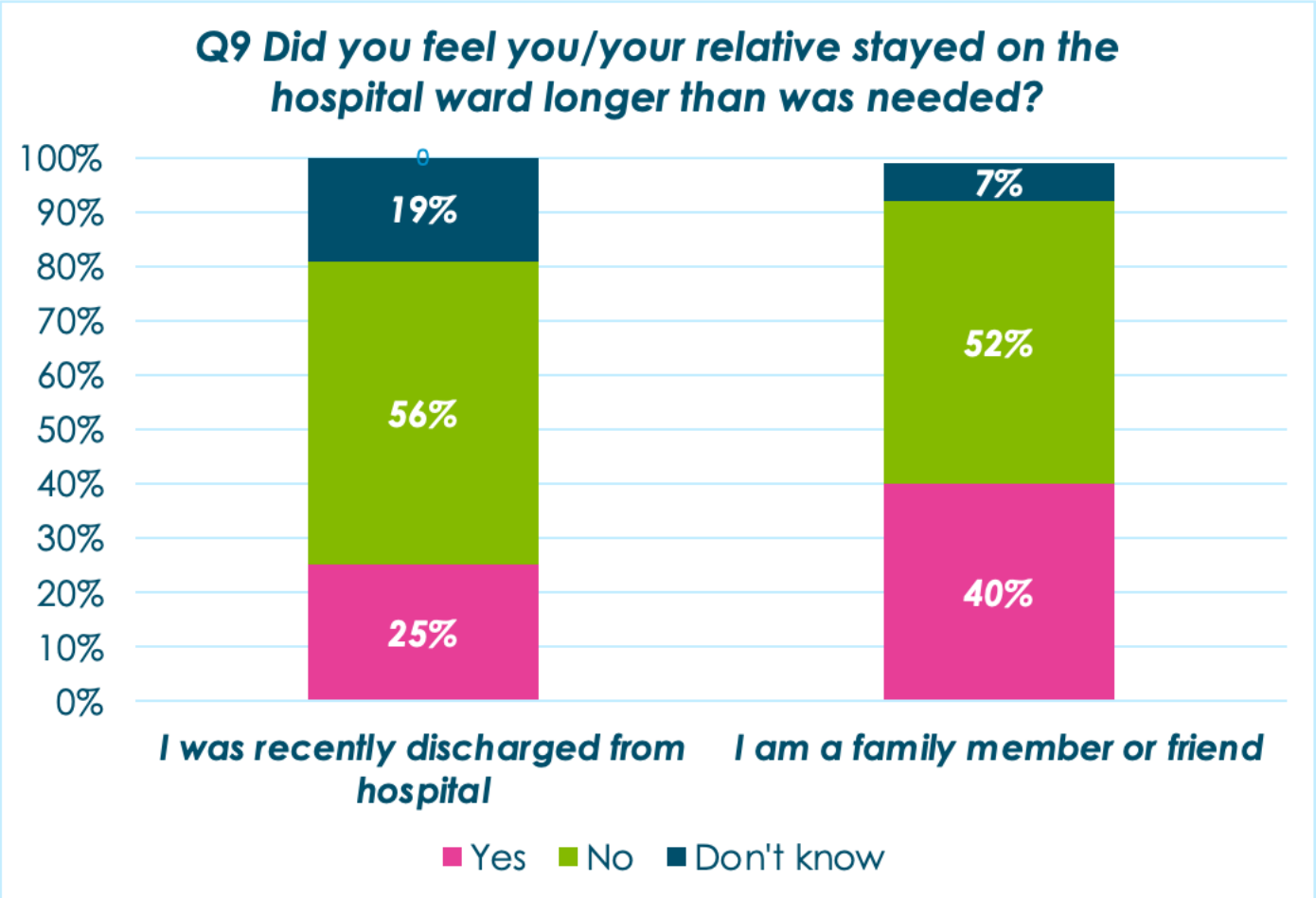
"I was told I could leave but given no opportunity to ask questions or receive an explanation of my condition," person discharged

"It would have been better if I had been given a clear action plan and a list of the necessary contacts to continue my care and recovery at home," person discharged

"No mention of wound care at home, either verbal or written on the discharge note. Sent home with a 40cm+ wound with metal clips in situ. No information was provided about clip removal or dressings," person discharged

Other reasons given for not feeling prepared were:

- Not feeling well enough
- Delayed transport
- Insufficient medical supplies provided
- Lack of care and support arranged at home



Family members were more likely than people discharged to say that they felt their relative had stayed on the hospital ward too long. Both relatives and people discharged gave similar reasons as to why their stay had been extended further than necessary. They were as follows:

- Waiting for a bed in the right care setting or availability of a care or rehabilitation package at home

- Waiting for equipment or adaptations at home
- Delays in treatment
- Delays seeing a social worker
- Deterioration in health whilst in hospital – two people talked about the loss of function due to staying in bed for too long, whilst two people felt it was due to poor care in hospital
- Testing positive for Covid

Some people mentioned that staying in hospital longer than needed could impact on patient's mental and physical health.

"She was kept in hospital for far too long… She had been left in bed so long that hairdressers had to cut lugs out of her hair. She also came back 'padded'… I insisted she came home before she further deteriorated," family member

"I was getting depressed, and I really wanted to start practicing walking again," person discharged

What the 'Hospital discharge and community support' guidance[2] says:

"Health and social care professionals should support and involve the individual to be discharged in a safe and timely way to ensure they are only hospitalised for as long as they require hospital care. Discharging people once they no longer need acute care improves their outcomes and reduces the risk of medical complications…"

Communication preferences and needs

"My mum aged 89 who has dementia/Alzheimer's was treated like she didn't have it and could remember things," family member

The Accessible Information Standard (AIS)[8] places a duty on all providers of health and care services to identify, record and meet the communication needs of people with a disability and/or sensory impairment who use their services. Overall, only 14% of people said that they were asked about communication needs. A high proportion (38%) answered "not applicable", which unfortunately doesn't give an indication as to whether they were asked. When we looked at the data for groups of people who are more likely to have some communication needs, in some cases over half of the respondents said they were not asked about them.

When you/your relative was in hospital, were you/they asked about any communication preferences or needs?

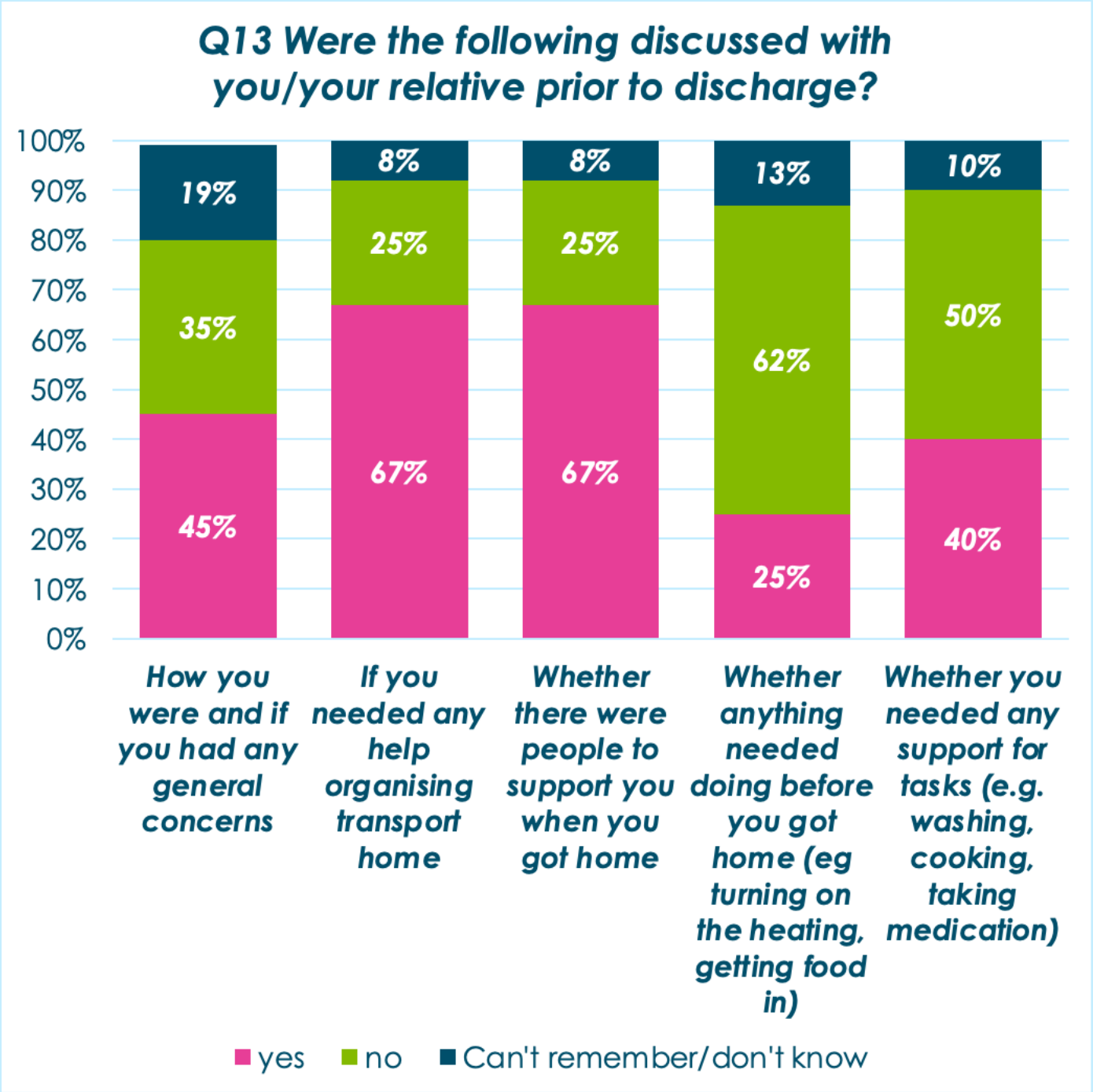
	Total number of responses	Yes	No	Don't know	Not applicable
Blind or visually impaired	20	15%	55%	20%	10%
Deaf of hearing impaired	28	18%	39%	25%	18%
Autistic	2	0%	100%	0%	0%
Learning disability	4	25%	50%	25%	0%
English not their first language	13	31%	38%	0%	31%
All survey respondents	203	14%	38%	9%	38%

People with a learning disability and those for whom English is not their first language were more likely than other groups to be asked about communication needs.

"Being asked about communication needs was an issue as they have a learning disability and appear more capable," support worker

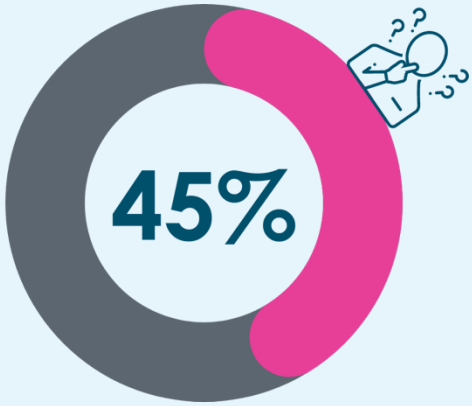
People discharged home

The following questions were only asked of those people (62 responses) and their family members (20 responses) who were discharged to their own home rather than a community care or step-down setting.

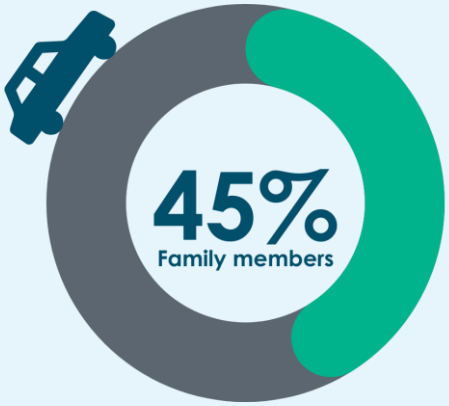


The above chart shows the responses from people who were discharged home. There were some differences between their responses and those of family members.

Of the people who were discharged home:

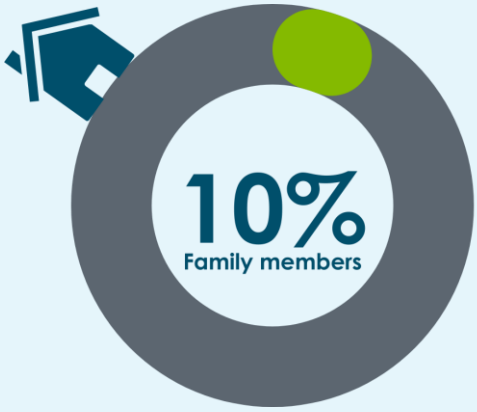


Only 45% said they were asked how they were and whether they had any general concerns about discharge.

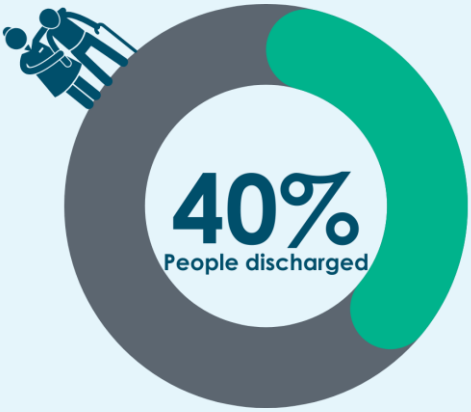


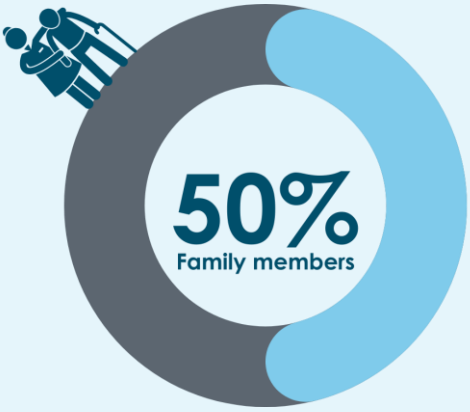
67% said they were asked whether they needed any help with organising transport home. The perception from family members was markedly different, with only 45% saying that transport home was discussed.

Although the majority (67%) said they were asked whether there were people to support them when they got home, 25% said this wasn't discussed with them. Among the 20 family members who responded, the number was higher, with 75% saying this was discussed with them.



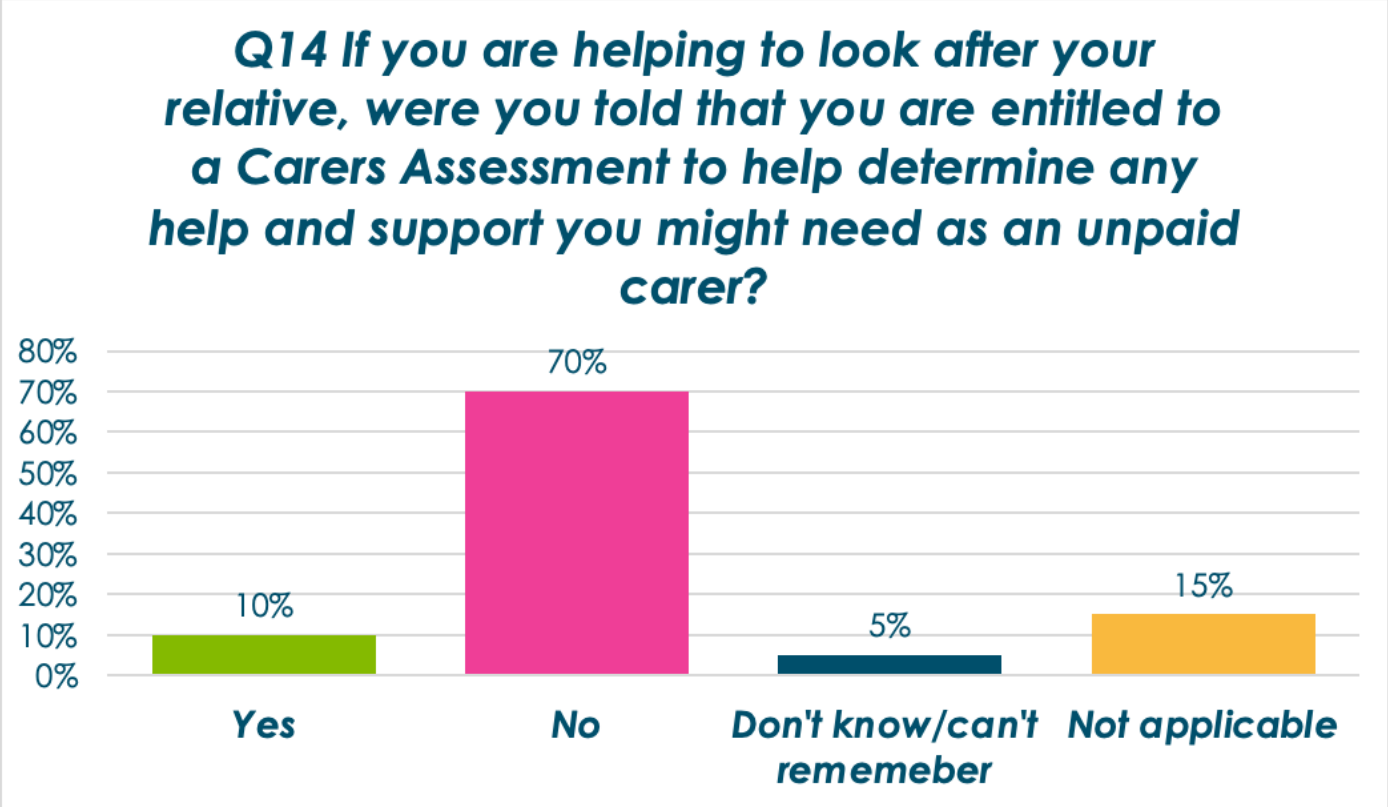
25% said they were asked whether anything needed to be done before they got home (e.g.: turning on the heating, getting food in). Only 10% of family members said that they were involved in discussions about this aspect of discharge.





Only 40% said they were involved in discussions about whether they needed any support at home for tasks (e.g.: washing, getting dressed, cooking, taking medication). The response from family members completing the survey was slightly higher, with 50% saying that they had been involved in discussions about ongoing support required at home. It may be that the numbers for this were low because some respondents had already been assessed as not requiring this kind of support.

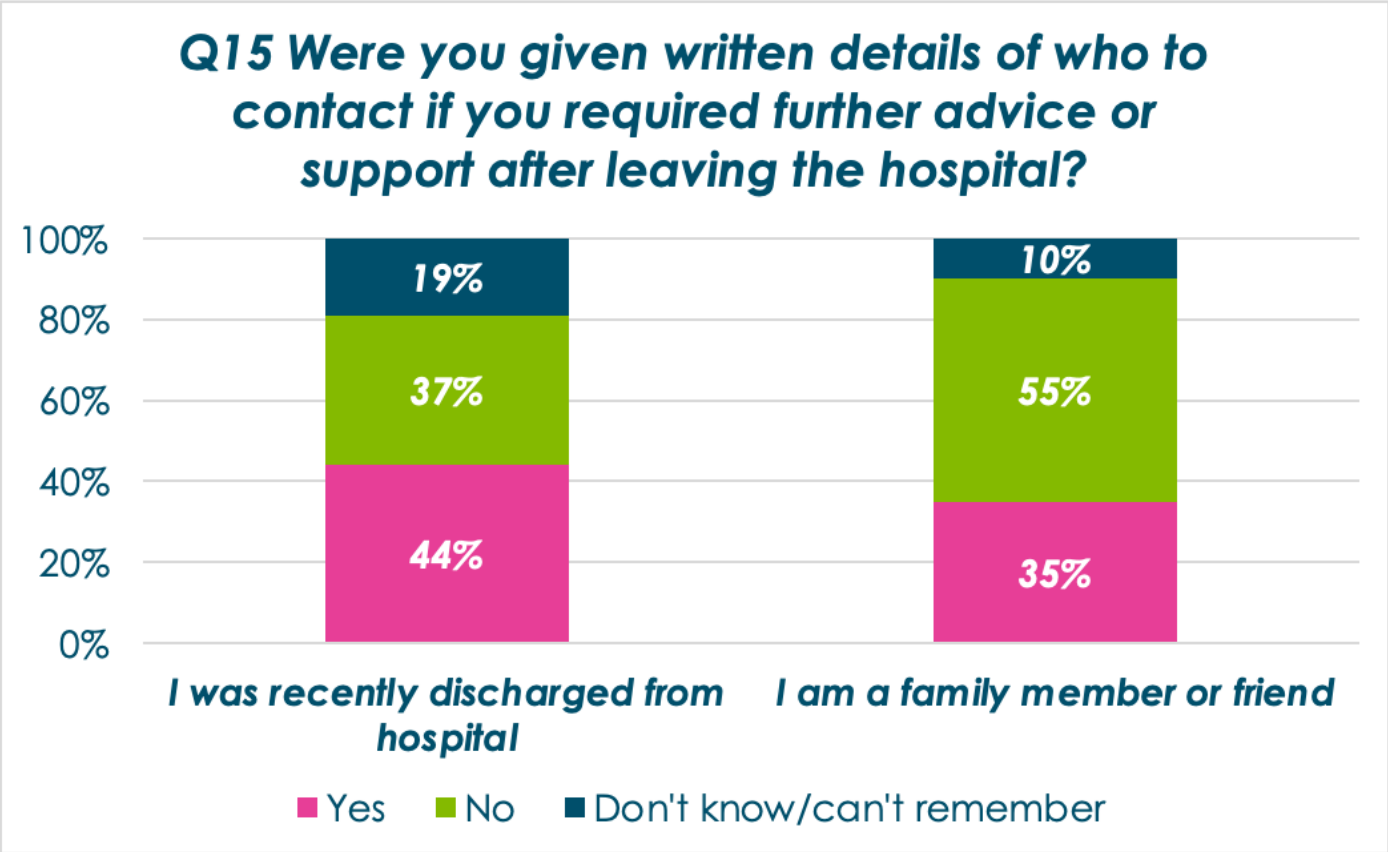
"My daughter asked what the procedure was for discharge and was told the ward did not know the date of his discharge, but we would be informed the day before. On Sunday we returned from church to find my husband sitting on a cold stone step in hospital pyjamas and the transport driver was asking my neighbours where I was. A message was on the landline answer machine from that morning saying he was already on his way home!!," family members



Of the 20 family members of people who had been discharged home, only two (10%) said that they had been told about Carer's Assessments.

What the 'Hospital discharge and community support' guidance[2] says:

"Hospital discharge teams should also consider unpaid carers' preferences and involve them to ascertain whether they are both willing and able to provide care and support post-discharge, before an assessment of longer-term needs. This should include an offer to refer to local carers' support services."
"A carer's assessment can be completed as soon as practicable after discharge but should be undertaken before caring responsibilities begin if this is a new caring duty or if there are increased care needs."



What the 'Hospital discharge and community support' guidance[2] says:

"Discharge planning should include information about post-hospital care, such as advice and information about community and voluntary sector organisations, housing options (such as home adaptations and possible alternative housing) and NHS or social care crisis response teams that can be contacted post-discharge."

Less than half of people who were discharged home (44%) said that they were given written contact details of who to contact if they needed any further advice following discharge. This was even lower for family members (35%), and lower still for people who were Deaf or had a hearing impairment (25%).

People discharged to a community care setting, care home or supported living

This section of the findings is based on the questions that were only asked of the 98 people who were discharged to a care setting other than their family home and 21 of their family members.

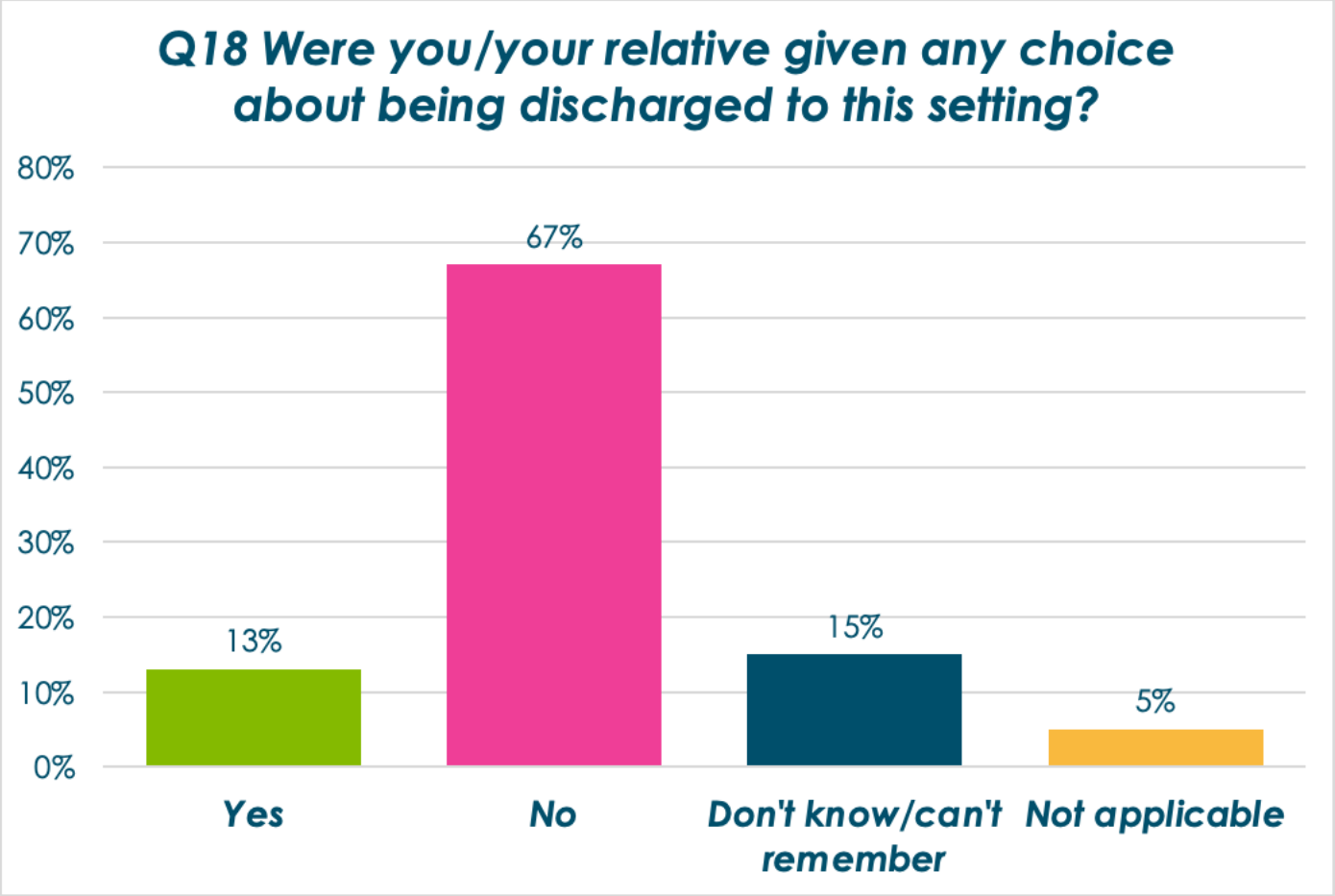
13 (62%) family members and 46 (47%) people discharged said that they were told in advance that they would be going to the care setting and the reasons why. Some of the people we spoke to on the enter and view visits said that they had been told beforehand that they were going to be going there to help them with rehabilitation and enable things to get set up at home ready for their return.

"I knew the hospital wanted to get him to a rehabilitation unit. The hospital staff rang at night and spoke to the family about this," family member

However, 34 (41%) people told us that they weren't informed in advance or told why they or their loved one was moving to the care setting, which for some people was disorientating and confusing.

"They just suddenly turned up and said, 'We're moving you', and I said 'Where?', so they said, 'Hasn't anyone spoken to you about it?' I only found out since I arrived here last night that I'm here for physio/recovery and to give them time to make adaptations for me at home," person discharged

"My mum was in this setting for one week before I even knew she had been discharged from the hospital trust. I found out by accident from a discharge co-ordinator. No-one bothered to explain to me what was going on," family member



The majority of people said they were not given a choice about which community care setting they or their relative were discharged to. There were various degrees of understanding about why this was, with some people understanding that it was due to where beds became available, and some saying they had just been told where they were going with no further explanation. Comments indicated that people were happier where they felt their preferences had been considered, even if what they wanted couldn't be guaranteed.

"Told the hospital I would prefer to stay somewhere in Yeadon and was luckily given the one I wanted. My choice was taken into account, but it was dependent on where the beds were available," person discharged

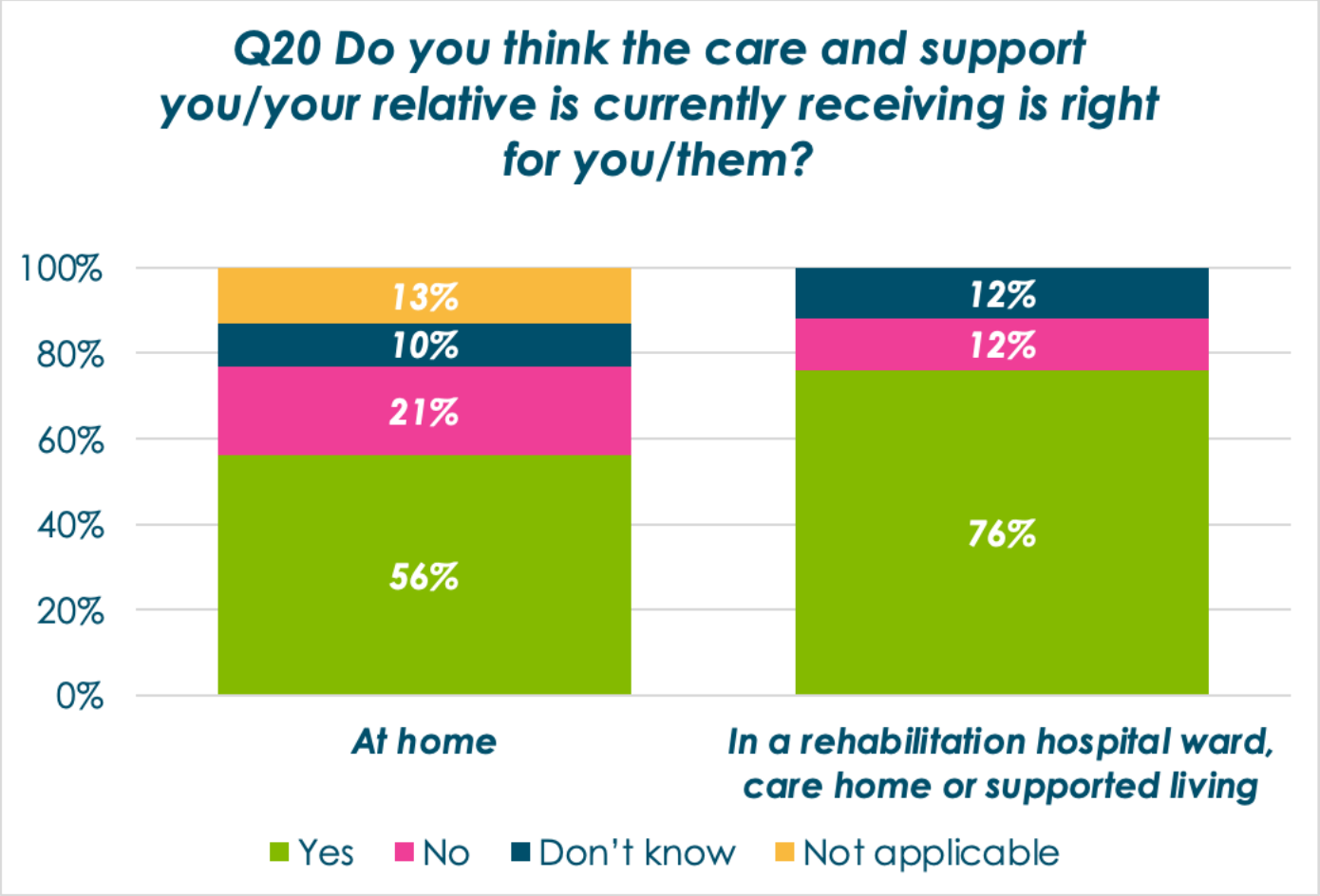
What the 'Hospital discharge and community support' guidance[2] says:

"On discharge from hospital people who have new or additional needs should be offered choices of onward care and support to aid their recovery... The choices offered should be suitable for their short-term recovery needs and available at the time of discharge."

"People in hospital should be supported to participate actively in making informed choices about their care… These conversations should begin early in a hospital stay, and not when a person is ready to be discharged."

"If a person's preferred placement or package is not available once they are clinically ready for discharge, they should be offered a suitable alternative while they await availability of their preferred choice."

Overall satisfaction



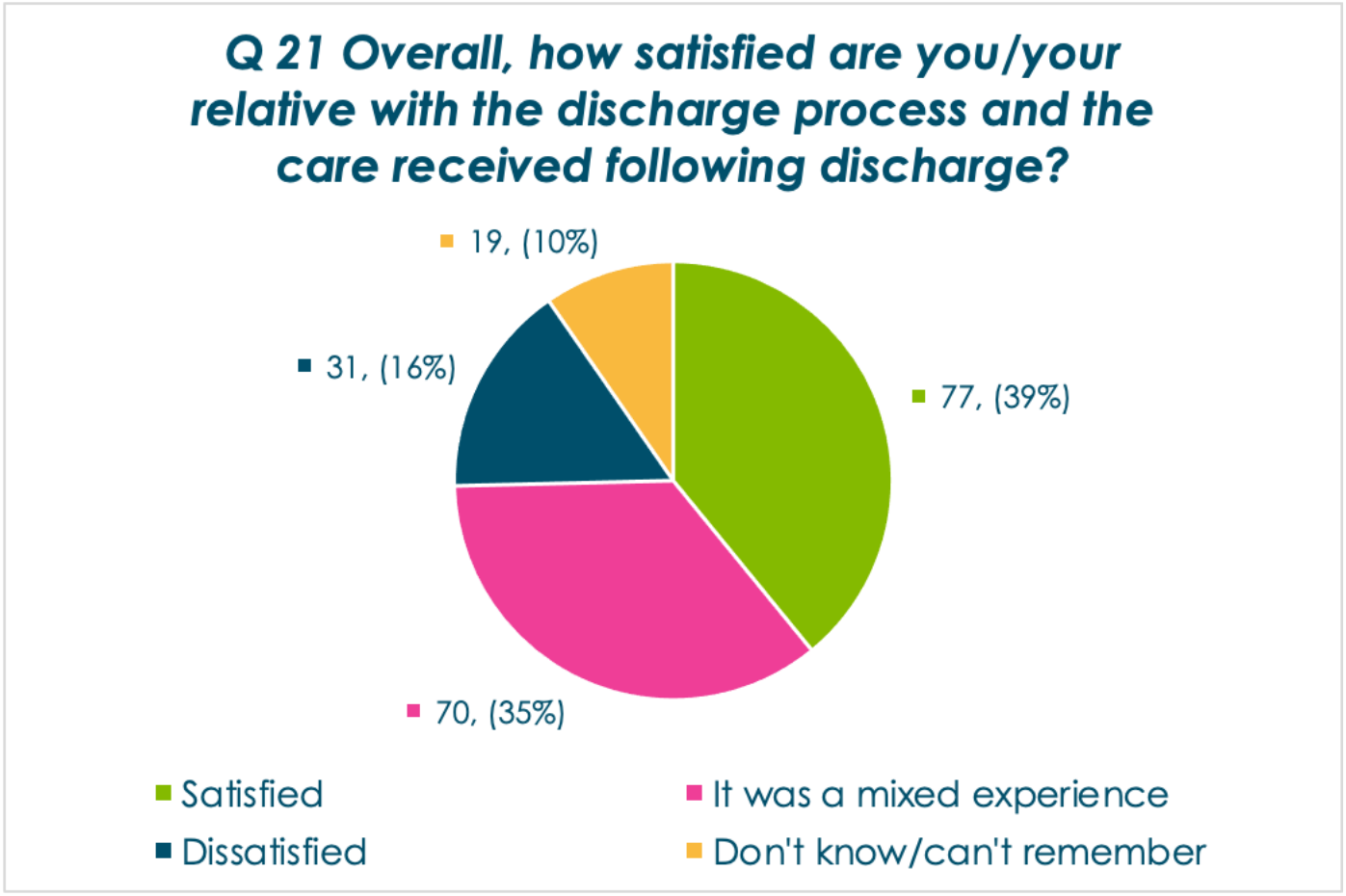
People who had been discharged to a community care or other residential setting were more likely to say that the care and support they were getting was right for them (76%) compared to those who had been discharged to their own home (56%). The comments indicated some of the possible reasons for this. These are related to better access to care and physiotherapy in *some* of the community care settings. Among people who were discharged back to their own homes, some reported a lack of follow-up and feel left to sort things out by themselves.

"On discharge Mum asked whether she would receive an outpatient appointment to see how she is getting on as she had major surgery. The nursing staff responded and said she will receive an outpatient appointment within 6 weeks after discharge but didn't

give me any contact number to ring. She has been home for 9 weeks now and have still not received anything," family member

What the 'Hospital discharge and community support' guidance[2] says:

"Health and care professionals who are facilitating hospital discharges should work together with individuals, and – where relevant – families and unpaid carers, to discharge people to the setting that best meets their needs. This process should be person-centred, strengths-based, and driven by choice, dignity and respect."



The above chart shows the overall satisfaction rates for the discharge process and the care and support received following discharge.

There was a difference between the responses from people and their family members who were discharged home and those who were discharged to a community care setting or step-down bed. Although the figures for people saying they were satisfied were very similar (around 40%), those discharged home were almost three times more likely to say they were dissatisfied with the overall experience (26% vs 9%).

Those discharged to a community care or step-down setting were more likely to say it was a mixed experience.

Poor communication about what was happening at discharge was twice as likely to be reported by people discharged to their own home compared to those discharged to a community care setting. People spoke about wanting better communication with family carers and more accessible information on discharge papers which they could easily understand and therefore use to inform the person's ongoing care.

"Was told with urgency to go home. At discharge there was no attempt to discuss home circumstances. I was still unable to walk without assistance, this was ignored throughout my stay, and I was taken in a wheelchair to the entrance," person discharged

"The care received after discharge was fine. The discharge process requires review. The discharge form is not discussed with you but put in the bag with your medication," person discharged

"Was happy with information given and that care was automatically put in place for discharge - it made the process much easier," family member

The other key reason given for differences in satisfaction levels between those discharged home and those discharged to a community care setting related to the provision of practical and professional support during and after discharge. Nearly all of the people who left negative comments about this had been discharged home.

"More help and support needed. Felt very isolated even though my husband had come to collect. No-one available to help transfer belongings to car," person discharged

"Poor discharge un-co-ordinated with ensuring there was a provision of district nurses for providing insulin injections and dressing of leg wound," family member

"Could have felt more confident going home. Since discharge neither the ward or my GP have contacted me to check all is ok," person discharged

Conversely, people in a community care setting were more likely to be positive about the provision and quality of aftercare they'd received, frequently mentioning the help they'd received from physio and occupational therapists.

"I now have a chart showing my long- and short-term rehab goals which also gives a date for my next review. This is a new scheme, just introduced which I find very helpful and am very pleased about," person discharged to community care setting

"I've had good care. The activities and physio here is good. There is a discharge plan and date in place, and I know when I'm going home. The social workers and staff are all very supportive," person discharged to community care setting

There were also some people who had been discharged home who talked about positive experiences of support they'd received from equipment services, reablement and neighbourhood teams.

"Within 10 mins of being home a District Nurse visited and offered me regular support. The physio has been great and the Meanwood Team have been fantastic at checking in on me and offering me OT support," person discharged

"The re-enablement lady was very helpful and thorough. She also changed the care from dinnertime (eve) to a night one as meal help is not needed," family member

Overall, how satisfied were you/your relative with the discharge process and the care received following discharge?					
	Number of responses	**Satisfied**	**It was a mixed experience**	**Dissatisfied**	**Don't know/can't remember**
Person discharged (overall response)	160	**41%**	34%	**14%**	11%
Family member (overall response)	37	**32%**	41%	**22%**	5%
Person discharged- Deaf or hard of hearing	19	**32%**	21%	**37%**	11%
Person discharged Blind or visual impairment	15	**40%**	27%	**27%**	7%
Person discharged – physical or mobility impairment	69	**29%**	41%	**22%**	6%

People who had a sensory or mobility impairment were more likely to express overall dissatisfaction (see above table). There was no obvious indication in the comments as to why this was.

Other factors affecting how satisfied people were with their discharge experience were:

- Long waits for medication and transport
- Lost belongings – eight people mentioned that they or their relative had been sent home without some of their personal belongings. These ranged from false teeth, glasses and clothes to large items such as a wheelchair and walking frame.

"It would be useful if a copy of items brought in/transferred with the patient was supplied to patient so a trace could be available," family member

- Feeling that hospitals were understaffed due to Covid and the resulting impact this had on communication and quality of care.

Experiences of Black, Asian and Minority Ethnic (BAME) communities

We received 19 survey responses from people from BAME communities. Sample sizes were too small to analyse data by different individual ethnic groups. However, when responses from people from BAME communities were compared to White British, there were no significant differences in people's experiences.

Our recommendations

- **Improve involvement of people in conversations about their discharge at all stages of their hospital journey.** A key aspect of this is making sure people have as much advance notice of their discharge as possible. **Under Section 91 of the Health and Care Act[1] which came into force on 1st July 2022, NHS Trusts now have a legal duty to involve all patients likely to need further care and support in discharge planning.**

> **"Tell the patient you are going to discharge them. Patients need to know this, NOT just left to wonder what is happening," person discharged**

- **Family members need to be recognised as an integral part of the discharge journey and should, where appropriate, be involved in discharge conversations from admission until the person gets home.** Many families provide vital support with everything from transport home, hands-on care and emotional support, as well as taking on a co-ordination role. **Section 91 of the Health and Care Act (see above) also extends to involving unpaid carers in discharge planning.**

> **"A sit-down conversation is needed with the relatives to explain the plans and what to expect," family member**

- **Routinely ask people receiving hospital treatment or care and their family members whether they have any communication**

needs and act on these in line with duties outlined in the Accessible Information Standard. Communication needs aren't always visible.

- **Improve identification of family carers and refer to Carers Leeds for information and support as required.** Work from the assumption that all family members might have a caring role. Carers should be clearly identified and flagged on the patient's record, with permissions actively sought prior to or during admission.

- **Ensure that everyone leaving hospital is given appropriate follow-up contact details for further support and advice.** This information should also be given to any family or unpaid carers who are supporting the person leaving hospital.

- **All partners involved in hospital discharge should review their discharge information, policies and procedures** to check that they involve both people staying in hospital and their family carers, where appropriate, at key points.

Service Provider Response

"Leeds City Council would like to thank Healthwatch for undertaking this piece of work. It's always good to hear people's experiences, so we can measure what we do. Working in collaboration with all partners across the city, we will continue to support the system and provide good outcomes for everyone," Michelle Cale, Commissioning Programme Leader Leeds City Council

Next Steps

The report will be shared with all key providers involved in the discharge process including Leeds Teaching Hospitals NHS Trust, Leeds City Council, Leeds Community Healthcare NHS Trust, Age UK, Carers Leeds, and individual providers of community care and step-down beds. It will also be shared with commissioners of these services at Leeds City Council and the Leeds Office of the West Yorkshire Integrated Care System (LOICS).

We will agree with them on the next steps to be taken in response to our recommendations and work with them to ensure any agreed actions are followed through and implemented. We will undertake any follow-up work required to ensure there are real changes made to the service so that it is a good experience for everyone.

The report will also be published on the Healthwatch Leeds website.

Thank you

We'd like to thank the following individuals and organisations who contributed to making this work happen:

All the people who took the time to complete a survey.

Everyone who participated in the videos: Ann Wilson, Eddie Martin, Jazz Edwards, Anne Betteridge, Dene Betteridge, David Schofield, Kim Bright, Nicola Spink, Heather Hawksworth, Royston Cooper, Rajbir Kaur Sagoo and Gurdip Kaur Manku as well as 'Carol' and 'Farah' who chose to remain anonymous.

Staff at the community care and step-down settings for working with us to help the enter and view visits run smoothly.

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Age UK and Carers Leeds helped get the survey out to people who had used their services.

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This report has been written by Harriet Wright, Community Project Worker at Healthwatch Leeds.

References

[1] https://www.legislation.gov.uk/ukpga/2022/31/section/91/enacted

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

[3] https://www.healthwatch.co.uk/report/2020-10-27/590-peoples-stories-leaving-hospital-during-covid-19

[4] https://www.carersuk.org/images/News_and_campaigns//Carers_experiences_of_hospital_discharge_report_2021.pdf

[5] https://nhssurveys.org/all-files/02-adults-inpatients/05-benchmarks-reports/2020/

[6] **Rosman, M., Rachminov, O., Segal, O. and Segal, G. (2015).** Prolonged patients' In-Hospital Waiting Period after discharge eligibility is associated with increased risk of infection, morbidity and mortality: a retrospective cohort analysis. BMC health services research, 15(1), 1–5. Tess, B. H., Glenister, H. M., Rodrigues, L. C. and Wagner, M. B. (1993). Incidence of hospital-acquired infection and length of hospital stay. European Journal of Clinical Microbiology and Infectious Diseases, 12(2), 81–86.

[7] https://www.kingsfund.org.uk/publications/delayed-transfers-care-quick-guide

[8] https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

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The Old Fire Station
Gipton Approach
Gipton
Leeds
LS9 6NL
www.healthwatchleeds.co.uk
t: 0113 898 0035
m: 07717 309 843
e: info@healthwatchleeds.co.uk
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