October 2025

Experience of follow-up care post hospital discharge

National Voices

Written by Grace Haworth, Louis Horsley, Sammy McNamara, Sarah Sweeney: National Voices

October 2025

About National Voices

National Voices is a coalition of health and social care charities in England who advocate for more equitable and person-centred health and care, shaped by the people who use and need it the most. The organisation has more than 200 members covering a diverse range of health conditions and communities, connecting them with the experiences of millions of people.

Executive summary

In April 2025, the Care Quality Commission (CQC) commissioned National Voices to research patients' experiences of care following discharge from hospital. Our intention was to generate insights beyond those captured in current CQC surveys, with a particular emphasis on the ways older people living with frailty and people from groups experiencing health inequalities are supported following hospital discharge. The project centred on four key questions:

1. Transitions from hospital to community
2. Support mechanisms for staying well at home
3. Barriers to accessing quality health and social care
4. Impacts of unmet care needs

The research defined frailty as an age-related but not inevitable health state that renders individuals vulnerable to adverse outcomes following minor stressors. These outcomes include falls, disability, hospital readmissions, and reduced quality of life.

Findings from this research will be incorporated into CQC's annual State of Care report.

We used a mixed-methods approach to delivering the project by:

1. disseminating a questionnaire to 782 people who responded to the 2023 CQC Inpatient Survey and opted-in to be recontacted. We collected 144 responses; and
2. conducting a series of follow-up interviews with people who completed the questionnaire (nine interviews in total), complemented by eight supplementary interviews with people who are more at risk of experiencing health inequalities.

On the whole, the people who completed the questionnaire and took part in interviews reported having a positive experience when it came to being discharged from hospital and receiving follow-up care in the community. The majority of questionnaire respondents strongly agree or agree that the follow-up care they received allowed them to recover fully; regain or maintain their independence; and reduced the amount of support they required from their friends and family.

- 97% of all questionnaire respondents said they were happy with where they were discharged to.
- 80% of questionnaire respondents who received care after discharge agree or strongly agree that the care they received helped them stay independent.
- 87% of questionnaire respondents who received care after discharge agree or strongly agree that they felt able to raise concerns about their treatment if necessary.

However, several research participants shared issues that emerged from a poor discharge process. Delays, poor coordination and/or poor communication during the discharge process left some interview participants feeling confused and unhappy, which can negate an otherwise positive experience of treatment during their hospital stay.

- 19% of all questionnaire respondents didn't feel ready to be discharged.
- 33% of all questionnaire respondents said they did not receive a safety and welfare check on the day they were discharged and a further 8% did receive a safety and welfare check but not on the day they were discharged from hospital.

Whilst feedback on follow-up care tended to be positive, some negative aspects were highlighted:

- 15% of questionnaire respondents who received care after discharge either disagree or strongly disagree that the care they received met their emotional needs.
- 15% of questionnaire respondents who received care after discharge felt that the staff providing care did not take the time to discuss medical and non-medical needs as required.

The failure to take a holistic approach to care provision had a negative impact on the emotional wellbeing of some research participants.

Of the 64 survey respondents who did not receive follow-up care after being discharged from hospital, 55% felt that they did need follow-up care at the time. Not receiving follow-up care despite needing it led to wide ranging negative outcomes:

- 53% of questionnaire respondents who did not receive follow up care had to go back into hospital and felt that it was as a result of not receiving follow up care.
- 79% of questionnaire respondents who did not receive follow-up care agree or strongly agree that their friends/family had to take on unpaid caring responsibilities.
- 84% of questionnaire respondents who did not receive follow-up care agree or strongly agree that their emotional wellbeing deteriorated.

Introduction

Background and context

In April 2025, the Care Quality Commission (CQC) commissioned National Voices to deliver a research project to better understand people's experiences of follow-up care following an inpatient hospital stay.

Through this research, CQC and National Voices explored insights beyond those captured in current CQC surveys, with a particular emphasis on the ways older people living with frailty and people from groups experiencing health inequalities are supported following hospital discharge, particularly:

- How do people experience transition from hospital into the community?
- How are people supported to stay well at home?
- What are the barriers to accessing good quality health and social care in the community?
- What are the impacts when people do not get the care they need?

This research project only explores the experiences of follow-up care for inpatients – people who have spent at least 24 hours in hospital whilst receiving treatment.

For the purpose of this research, the following criteria is used to define frailty:

- Frailty is a state of health related to the ageing process but is not inevitable
- Can be mild, moderate or severe
- People with frailty lose their in-built reserves making them vulnerable to adverse outcomes following 'minor' stressors – for e.g. infections, changes in medication or environment
- Adverse outcomes include: falls, delirium, disability, hospital admission, need for long-term care, reduced quality of life, and death
- Phenotype model: unintentional weight loss, reduced muscle strength, reduced gait speed, fatigue, low energy expenditure
- Cumulative deficit model: during ageing, 'deficits' can accumulate and combine to increase a frailty index.

As part of its independent voice, CQC publishes an annual 'State of Care' report. The State of Care report provides an assessment of health care and social care in England, combining work which CQC have conducted during the year with additional analysis focussed on key messages the regulator wants to highlight.

Using the insights captured from this research, National Voices and CQC colleagues have worked to highlight people's experiences of health and care, both positive and negative, after a hospital inpatient stay, feeding this research into CQC’s State of Care report. National Voices also produced a series of anonymous case studies outlining feedback and findings on people's unmet care needs.

Methodology

The research team took a mixed-methods approach to meeting the research objectives:

1. Project scoping

- Conducted rapid desktop review of the evidence
- Held series of scoping conversations with key experts, including CQC team
- Convened trusted VCSE intermediaries to gather their insights
- Finalised recruitment quotas

2. Questionnaire

- Disseminated questionnaire to target audience.
- Gathered and analysed survey responses, identifying participants meeting set criteria for interviews

3. Interviews

- Developed and agreed interview discussion guides
- Delivered **9 interviews** from questionnaire participants
- Conducted **8 supplementary interviews** with key groups experiencing inequalities

4. Analysis and reporting

- Completed analysis framework
- Emerging findings presentation.
- Drafted final report, including case studies and quotes to support key themes.

Lived Experience strategic advice and input

1. Project Scoping

In the scoping phase we:

- Conducted a desktop review of existing research on this topic;
- Gathered insights on hospital discharge from National Voices' members, receiving feedback from 16 member charities
- Held a series of discovery conversations with CQC colleagues, as well as experts at Age UK, Carers UK and The Kings Fund.

We used insights gathered through the scoping phase to inform the design of the topic guide used in the interviews, to inform the sampling criteria; and to develop a better understanding of people's experience of care after hospital discharge.

2. Questionnaire

The questionnaire was developed collaboratively with CQC colleagues and performed three functions: developing an up-to-date evidence base on the topic, identifying interview participants and generating high level findings of people’s experiences of transitioning between health and care services and their unmet needs. The questionnaire was disseminated to a sample of respondents from CQC’s Adult Inpatient Survey 2023 which was completed by 63,573 patients who were in hospital in November 2023. Of those 63,573 respondents, 782 opted-in to be recontacted for further research; as well as identified as living with frailty and aged over 65. Our questionnaire was disseminated via text message to 704 people who had opted-in to be recontacted and provided a valid mobile phone number. To encourage people to complete the questionnaire, National Voices offered a random prize draw with two chances to win £250. In total 144 people responded to the questionnaire over the course of 2 weeks.

3. Interviews

After completing the questionnaire, respondents had the opportunity to register their interest in taking part in an interview to discuss their experiences of being supported to stay well at home, in more detail. A total of 9 interview participants were recruited through the questionnaire aiming for a mix of:

1. people who received and did not receive follow-up care
2. people with unpaid caring responsibilities
3. people in receipt of benefits
4. people living in areas that experience socioeconomic inequality according to the indices of multiple deprivation
5. geographic distribution across England

To ensure the diversity of participants, to guarantee the robustness of the findings and recommendations, an additional 8 supplementary in-depth interviews were conducted with participants from groups experiencing healthcare inequalities. Supplementary interview participants were recruited through specialist voluntary and community sector (VCS) intermediary organisations based on the following criteria:

- More likely to experience inequalities in care and support after leaving hospital
- Less likely to have participated in the CQC’s Adult Inpatient Survey 2023

Table 1 below provides an overview of participant numbers and how they were recruited.

Recruited through questionnaire	Number of participants	Recruited through VCS organisations	Number of participants
People who received follow-up care	8	People experiencing digital exclusion	1
People did not receive follow-up care	1	People living roadside	1
		People who don't speak English fluently	1
		People who are Blind	1
		People living in coastal areas	2
		Asian/British Asian people	2

Table 1 - Participant numbers

Key Findings from Primary Research

The findings in this section come from insights gathered via the questionnaire and interviews between June and July 2025. A total of 144 respondents completed the questionnaire, and nine of those respondents were then invited to take part in a follow-up interview. The original sample provided by CQC lacked representation from ethnically diverse communities and communities that are more likely to experience health inequalities. We therefore recruited eight supplementary interview participants from National Voices member organisations.

Experience of hospital discharge

The vast majority of total questionnaire respondents (95%) were discharged to their home; and a similar proportion of total questionnaire respondents (94%) lived there before they went into hospital. The small proportion of all questionnaire respondents who were discharged to somewhere new either went to a friend or relative’s home; a care home; or rehabilitation unit. Of the five total (3%) respondents who were not happy with where they were discharged to, four were discharged to their home and one was discharged to a friend or relative’s home. Just over three quarters (76%) of all respondents did feel ready to be discharged, with 19% of all respondents stating that they did not feel ready to be discharged (see Figure 1).

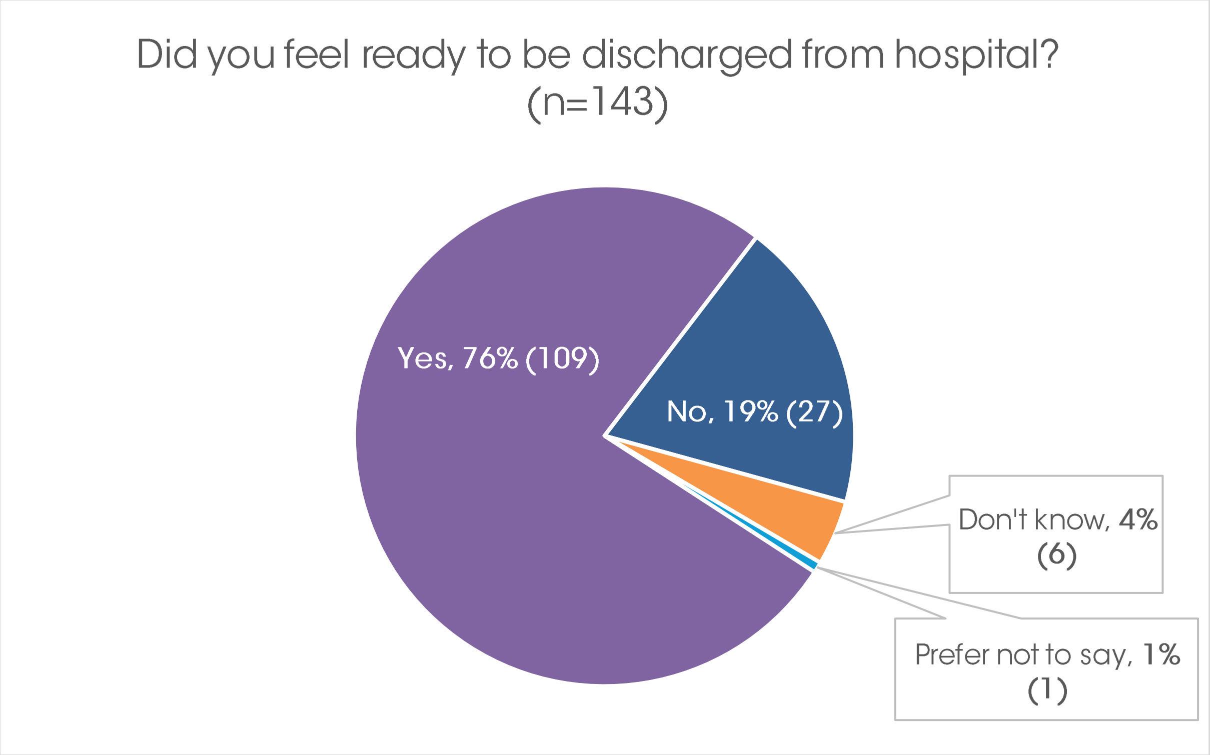

Figure 1 - Extent to which respondents felt ready to be discharged

Government guidance[1] says that 'anyone requiring formal care and support to help them recover following discharge should receive an initial holistic safety and welfare check on the day of discharge to ensure safety and care needs are met'. As indicated in Figure 2, a third (33%) of all questionnaire respondents said they did not receive a safety and welfare check on the day they were discharged and a further 8% of total questionnaire respondents did receive a safety and welfare check but not on the day they were discharged from hospital.

---

[1] Hospital discharge and community support guidance - GOV.UK

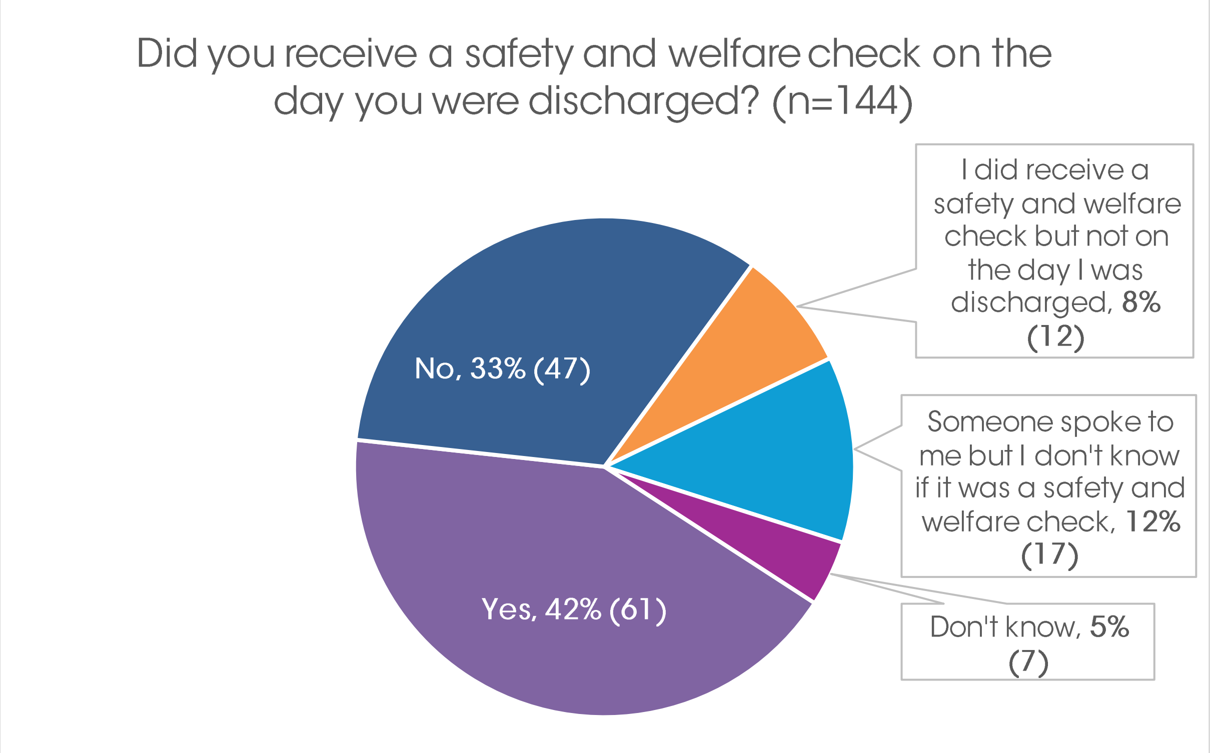

Figure 2- Proportion of questionnaire respondents who received a welfare check

Of the 41% total respondents who did not receive a safety and welfare check either on the day of discharge or at all, just over a third (21) of those same respondents went on to receive follow-up care after discharge. This suggests that the discharge process did not function as designed for some of these individuals. Several of these respondents highlighted the need for better planned discharge when asked to share what would have improved their experience of receiving care after leaving hospital.

> "Having a planned discharge from hospital would have been a good start. Having correct discharge information with my correct name, age and surgery, from both nursing, medical and hospital physio would have also helped. Not having fallen through the cracks and getting lost in the system until I chased [about] my [bone density] scan."
>
> - Questionnaire respondent

Government guidance also states that 'individuals should be supported to make fully informed decisions, in conjunction with their wider family or unpaid carers'[2]. However, of the 97% of total questionnaire respondents who said they were happy with where they were discharged to, 10% said they were not given a choice of where they were discharged to. One interview participant described how she had not been included in any decisions about follow-up care and was surprised when she returned home and had paid carers visiting.

Impact of inadequate discharge process

Research participants described experiencing several short, medium and long-term impacts as a result of receiving an inadequate discharge process which failed to take into account their needs. A delay in being discharged, a lack of coordination, or a breakdown in communication during the discharge process left some interview participants feeling confused and unhappy, which can negate an otherwise positive experience of treatment during their hospital stay.

> "All of a sudden, they said, 'oh you're going home'. I wasn't happy with that[…] It was causing enough anxiety as it was without having to worry about that[…] we haven't got transport, we had to rely on my wife's sister to come and pick me up. It was badly orchestrated."
>
> - Interview participant

One interview participant who had negative experiences of being discharged from hospital described how they were told they were 'bed

---

[2] Hospital discharge and community support guidance - GOV.UK

blocking' and so were being discharged regardless of whether they felt ready to leave.

> "The doctor who I hadn't seen had a look at my notes and deemed me fit for discharge at which point a physio came along and introduced me to a pair of crutches and said we've got to go down to the end of the ward and do the stairs[…] I couldn't manage the crutches, I was going in different directions, totally unsafe, so she dumped me in a wheeled commode."
>
> - Interview participant

Several interview participants described living with short-term pain which would have been avoided with the right discharge process. Recovery time and extent of recovery was also negatively impacted in the medium-to-long term, for example when a patient is discharged on the basis of inaccurate information about their care needs leading to a delay to receiving or total absence of follow-up care.

> "I was discharged with zero plan and my GP organised homecare - I required 148 days of carer visits before being deemed safe to get myself washed and dressed. My husband is also my full time carer."
>
> - Questionnaire respondent

An inadequate discharge process can also have an impact on emotional wellbeing, leading to a sense of frustration and/or heightened anxiety. One interview participant who eventually went on to have a good experience of follow-up care described how a poor experience during her hospital stay and discharge process left them feeling subhuman.

> "Two days after [discharge] a physio and a paramedic [came to see me]. The paramedic was doing the job of the OT and the nurse. The community physio actually burst into tears when she started talking to me because [I said that I] actually felt seen and I felt heard as a human being rather than a lump of meat, which is what I had felt for most of the time in hospital."
>
> - Interview participant

A poor discharge experience can be especially damaging for people who are more at risk of experiencing health inequalities as it can lead to exacerbating poor health outcomes and reinforces the sense that the healthcare system is not designed to account for their needs or lifestyle. One interview participant who is currently living roadside felt that their discharge process did not factor in their nomadic lifestyle leading to a sense of mistrust and neglect.

> "'They expect that anyone who lives [a nomadic] lifestyle dies earlier anyway"
>
> - Interview participant, living roadside.

Experiences of care in the community

Type of care provided in the community

Just over half of all questionnaire respondents were admitted to hospital for unplanned reasons such as falls and infections. Of the 144 people who completed the questionnaire, 54% said that they had received follow-up care after being discharged from hospital (Figure 3) which is a total of 78 respondents. For the purpose of this project follow-up care was defined as care provided by a professional, not an unpaid carer such as family member or friend. Examples of professional providers included a social worker, NHS staff member, a paid carer, or someone who works for a charity. The majority of questionnaire respondents received one type of care (e.g., paid carer visit) rather than multiple types of care simultaneously.

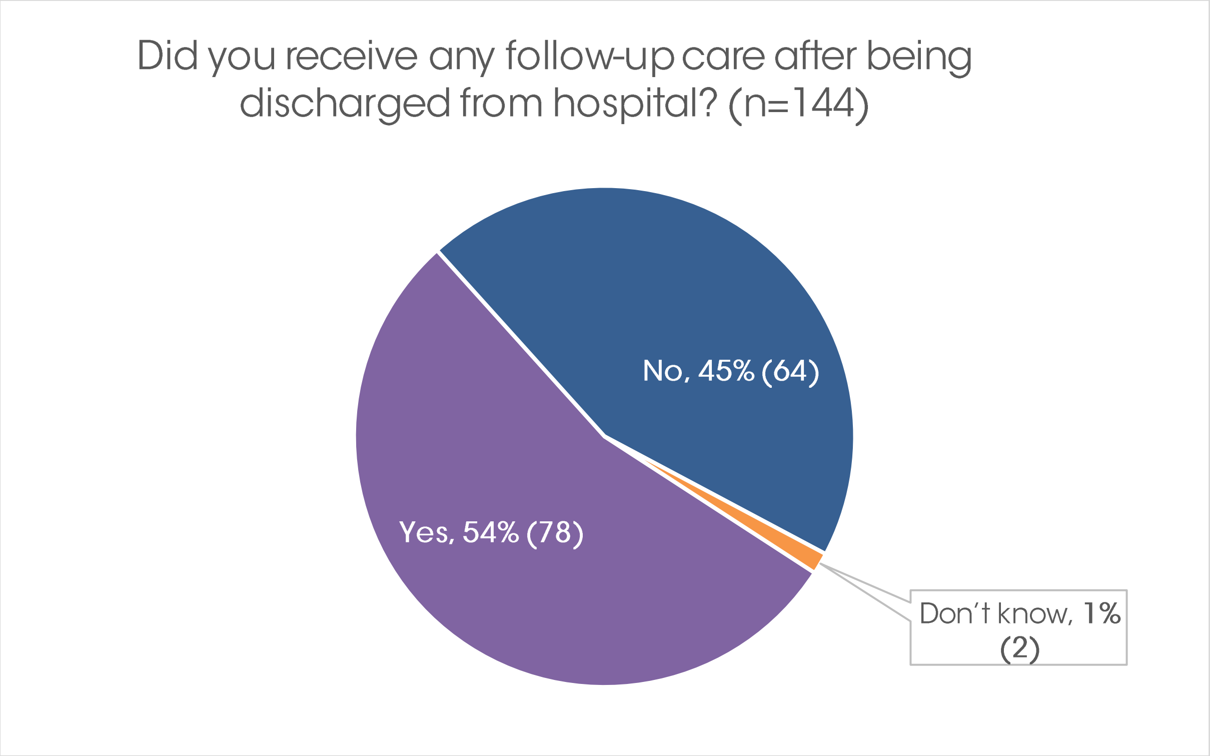

Figure 3 - Receipt of follow-up care after being discharged from hospital

The most common types of care respondents reported receiving after being discharged from hospital were a paid carer providing personal care; and NHS nurses providing medical care (see Figure 4). The most common types of care mentioned in 'other' were remote check-ups, such as phone calls and video calls from a health professional; visits from a paramedic (often organised by a GP); and one instance of a specialist nurse for patients who are fed through a tube.

Very few respondents who received care after discharge (4%) reported receiving care from a mental health professional, and those who did received mental health support alongside other types of care. This reflects the fact that all respondents were admitted for hospital for physical injuries or conditions.

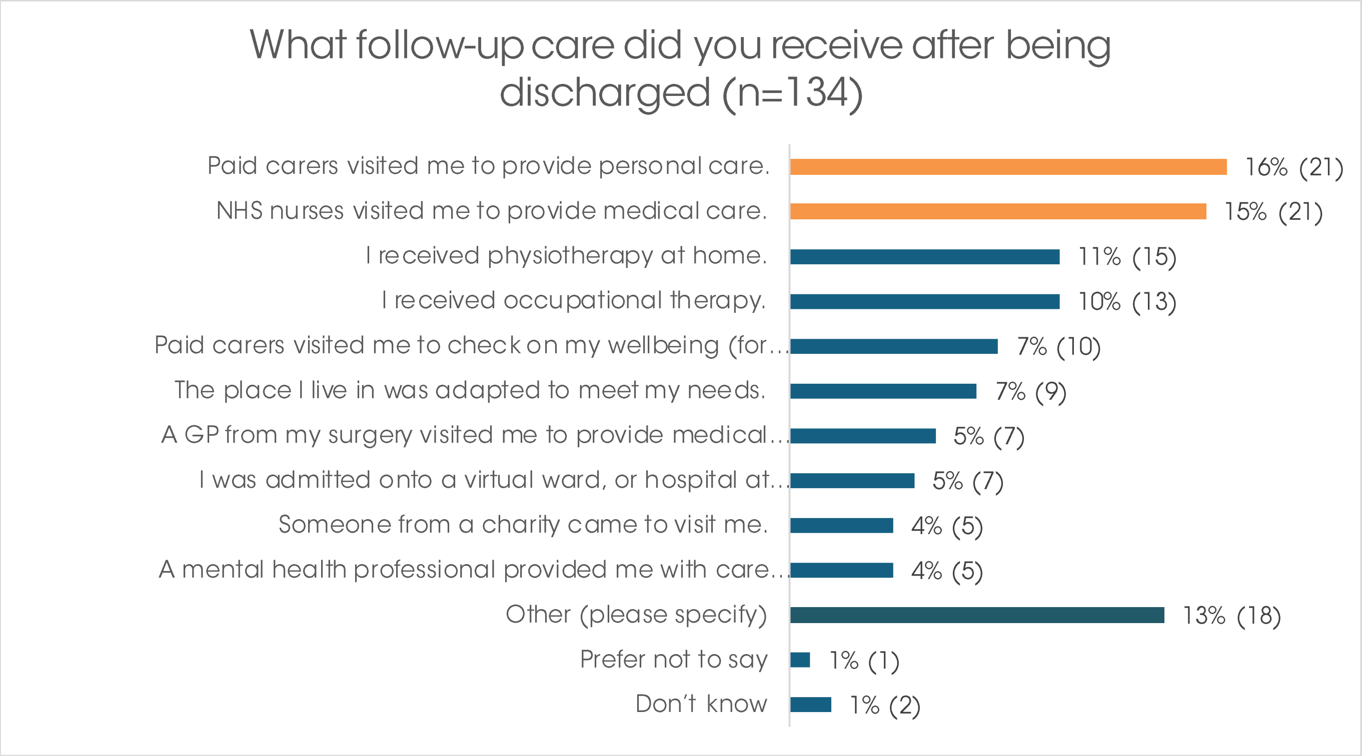

Figure 4 - type of care received in the community post discharge

Approximately one third of questionnaire respondents who received care after discharge reported receiving follow-up care for more than eight weeks and a further 7% received follow-up care for six to eight weeks. This indicates that 38% of questionnaire respondents who received follow-up care received it for longer than the maximum six weeks of reablement care[3](see Figure 5). Respondents who received follow-up care for longer than 6 weeks reported receiving more variety in the types of care (for example receiving physiotherapy, being visited by paid carers, and having their home adapted simultaneously) on average than the rest of the respondents, suggesting that either their recovery needs may have been higher or more complex

---

[3] Care after illness or hospital discharge (reablement) - Social care and support guide - NHS

(possibly due to living with frailty) and therefore only receiving reablement care would not have been sufficient.

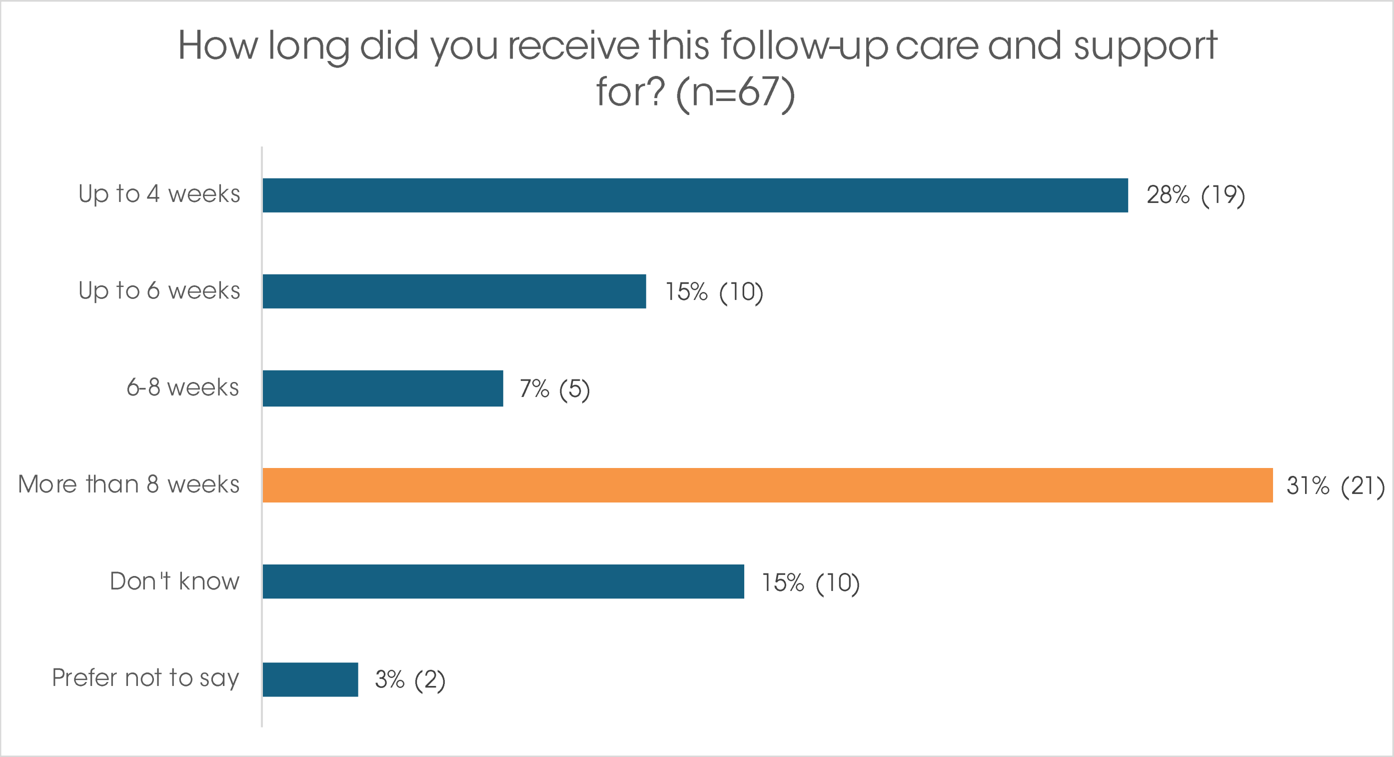

Figure 5- Duration of follow-up care

Feedback on care in the community

Overall questionnaire respondents were happy with the follow-up care they received after being discharged from hospital (see Figure 6). The majority of questionnaire respondents strongly agree or agree that the follow-up care they received allowed them to recover fully; regain or maintain their independence; and reduced the amount of support they required from their friends and family. Questionnaire respondents tended to have access to any medication or equipment they required in order to help them recover and live independently.

> “I really can't think of anything [that would have improved my experience of care after leaving hospital]. I was surprised how exceptionally good the physiotherapists (both at home and later in out patients) were.”
>
> - Questionnaire respondent

> “I was satisfied with the care and advise I received thank you very much NHS.”
>
> - Questionnaire respondent

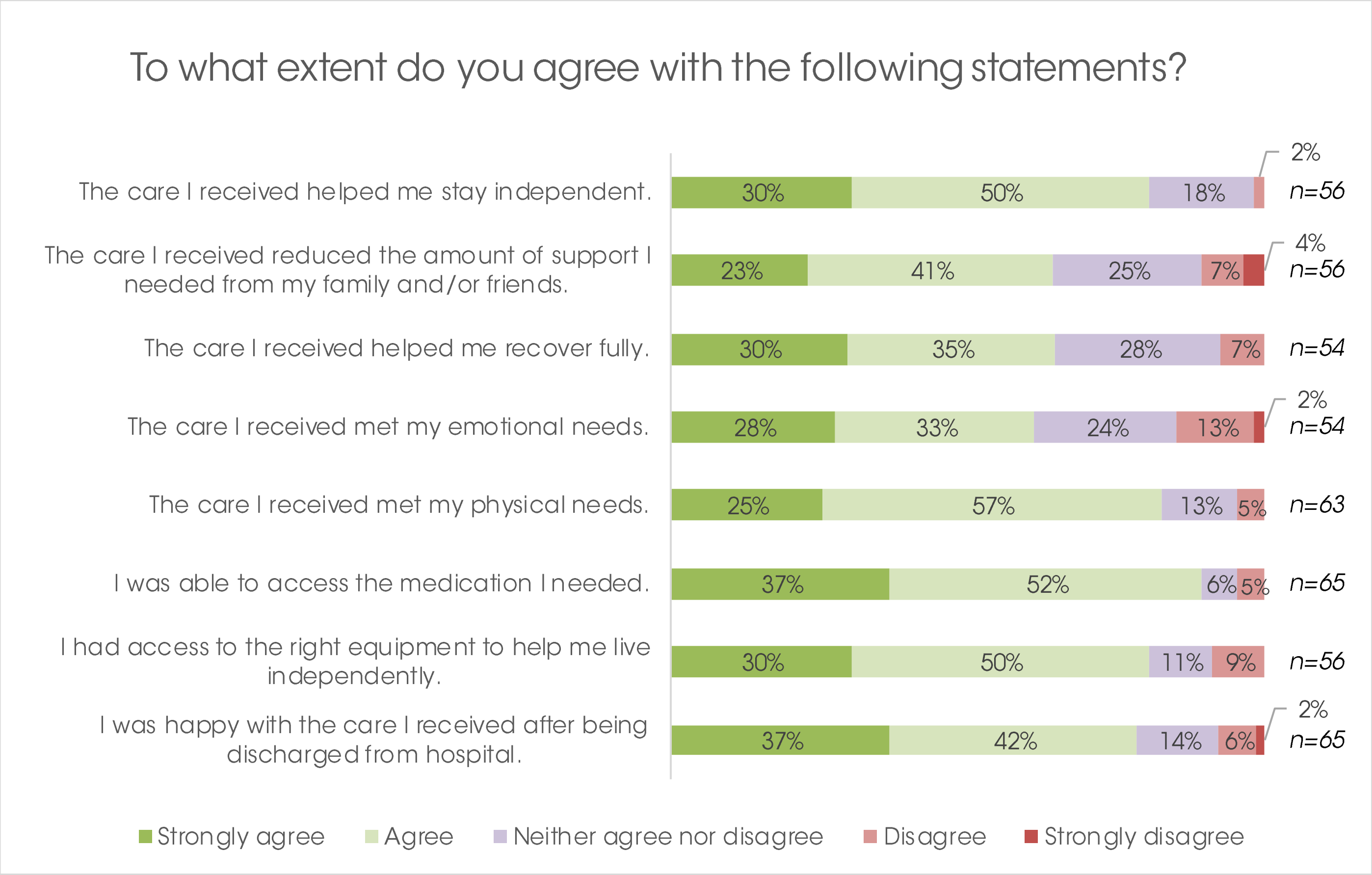

Figure 6 - Respondent feedback on follow-up care

The ability to maintain independence is very important for people who are older and living with frailty because in some cases an injury or condition that warrants an overnight stay in hospital can have a negative impact on an individual's sense of confidence, leading to social isolation and a fear of going out. One interview participant who is visually impaired and lives alone described how after contracting a chest infection whilst recovering from heart surgery they felt afraid to leave the house, despite previously leading an active outdoor lifestyle.

"I live out in the country and before I had my heart attack I used to call the taxi firm and go into town. But the last time I did any retail therapy was my last birthday in September. My lack of balance and lack of confidence is stopping me from going out. It's something that I've got to get over. It's since this chest infection that's knocked me back."

- Interview participant, coastal community.

She is reliant on paid carers visiting several times a day to feed her and help her with medication and has no family nearby. She has attempted to talk to her paid carers about non-medical issues but for the most part has been unsuccessful, stating "one or two of [the paid carers] do [talk about non-medical issues], but others it's in and out – you finish your meal and they're gone. Some of them I talk to them and they don't answer." The paid carers also seemed reluctant to help her be more mobile around the house for fear of being held responsible if she falls, further exacerbating her confidence issues. She had requested to be discharged to a care home temporarily whilst she got her confidence back but was denied.

"My physical recovery has been good, but my confidence has been knocked. My carers don't like me moving much when they're with me in case I fall and they're responsible for that."

- Interview participant, coastal community.

When asked what would have improved their experience of care, a very small number of questionnaire respondents said they had not received the correct treatment or level of care they needed. One questionnaire respondent described how they were left waiting a long time before receiving follow-up care.

> "I was supposed to have the stent/ stone removed after 4 weeks....it was removed after 4 months! I think I was missed but the care I received from staff on the op day was exceptional.
>
> - Questionnaire respondent

It should be noted that 15% of questionnaire respondents who received care after discharge either disagree or strongly disagree that the care they received met their emotional needs. A small number of questionnaire respondents who received care after discharge explained that whilst their physical needs may have been met, they did not feel treated as an individual or whole person by the professionals caring for them. Instead they reported feeling like a problem needing to be solved or task to be completed without their emotional needs being taken into account. Several interview participants also said that their paid carers were reluctant to have a friendly conversation with them, opting instead to work in near silence.

> "They don't see the human being they only see the problem/ aliment to be fixed. I may be old but I have lived a life. Never once did anyone ask me what I thought, what I felt, how I could be helped. I was a problem to address and not a person in my own right."
>
> - Questionnaire respondent

One interview participant described how several of the district nurses who visited them to change their dressings were often rude, refusing to engage in friendly small talk or even talk at all. This made the participant feel like a burden. Combined with the fact that they felt very vulnerable and isolated, the lack of compassion and human touch further exacerbated their poor mental health.

> "Some of [the district nurses] were really rude as if they're doing me a favour rather than working for the NHS. Couple of them were nice but most were horrible and rude."
>
> - Interview participant, South Asian community

Feedback on specific types of care

Figure 7 provides a breakdown of the extent to which questionnaire respondents who received care after discharge felt that the follow-up care provided by different professionals met their needs. Overall the majority of respondents who received care after discharge agree or strongly agree that the follow-up care they received met their needs. A roughly similar proportion of respondents who received care after discharge either disagree or strongly disagree with the statement that the professionals providing their care had the skills required to meet their needs, apart from NHS nurses which received the least negative feedback. It should be noted that a total of seven respondents provided feedback on the care they received from mental health professionals, so whilst feedback on this care was very positive, the overall sample size is small.

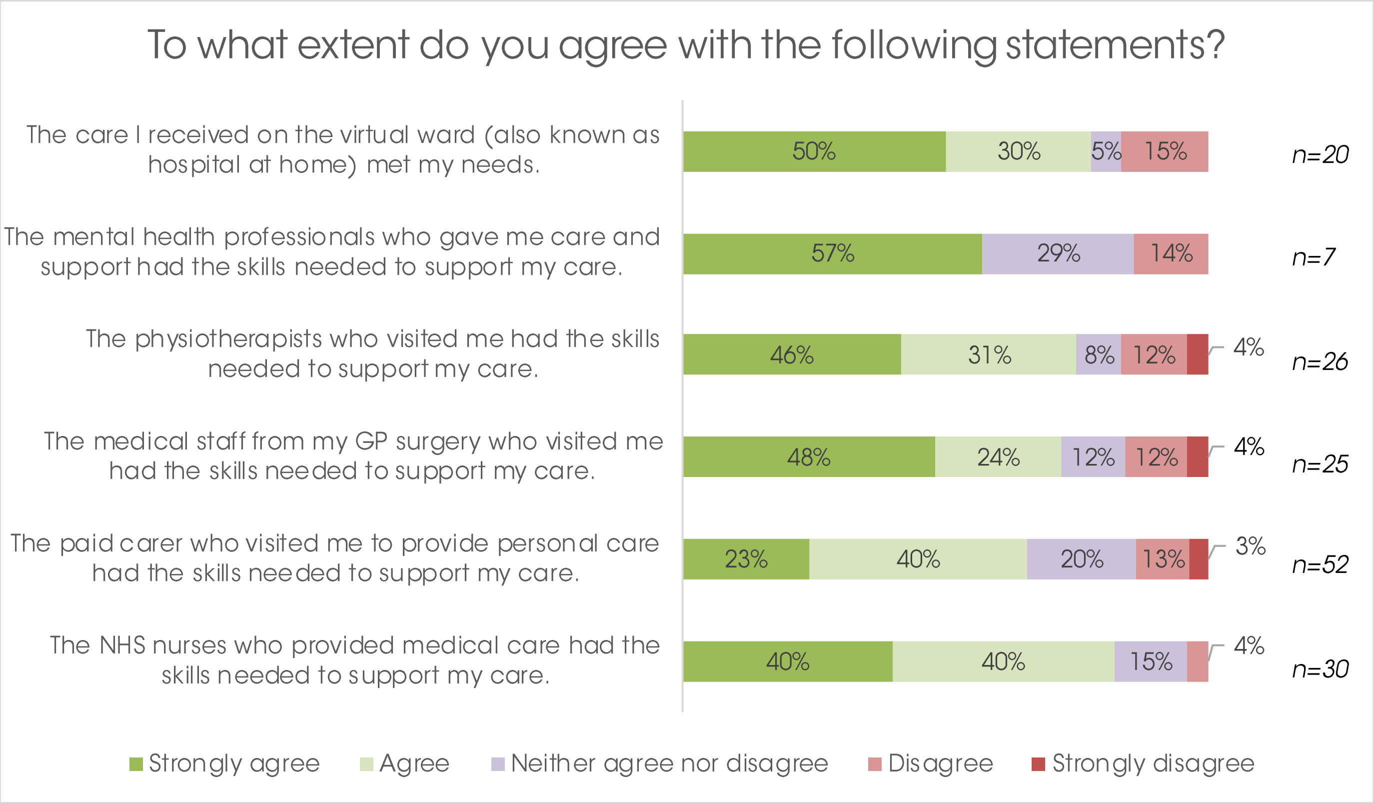

Figure 7- Respondent feedback on individual types of follow-up care received

Whilst not many interview participants had experience of accessing mental health support, those who did seemed to benefit from it. One interview participant who is autistic described how he had hugely benefitted from attending talking therapies and support groups provided by a local disability charity after being discharged from hospital. These sessions supported him to reduce the amount of pain medication he was taking and become more comfortable with the idea that he required care and support following discharge rather than trying to do everything independently.

> "[The therapist's] advice was to go to [a support group] and I went there for 10/12 weeks for a couple of hours a week and you would just talk about anything – and that was very good. At first it felt false but then it didn't in a very short period of time. And that's when I decided that all pain pills, I would rather do without."
>
> - Interview participant

Feedback on information and communication

Overall questionnaire respondents who received care after discharge tended to strongly agree or agree that the information they received about their treatment and follow-up care was clear and they also understood how to share feedback on the follow-up care they received or if their condition deteriorated. This was reflected in the interviews, with most participants explaining that they were given several means of contacting a healthcare professional if they needed information or support. For the most part these healthcare professionals were based at the hospital that initially provided the inpatient treatment (e.g., surgery team or occupational therapist) rather than a professional based in the community (e.g., district nurse).

> "The physio came to see me on day 2 or 3 of discharge and to check I was safe on crutches and get up and down the stairs. Also gave me a telephone number to go straight through to physio and not switchboard."
>
> - Interview participant, digitally excluded

This positive experience however was not shared by one interview participant for whom English is their second language. They attribute their lack of follow-up care in part to the fact that they did not have an interpreter present to communicate effectively with their GP and were therefore unable to request support from a paid carer. NHS guidance stipulates that anyone accessing primary care services must have access to an interpreter or translation services if required[4].

---

[4] guidance-for-commissioners-interpreting-and-translation-services-in-primary-care.pdf

> "I'm an immigrant here, English is my second language and when I go to the GP or hospital it's important have interpreter booked for me. And I needed care booked for me after my operation because I only have my daughter and she was very busy and couldn't help me after my operation."
>
> - Interview participant, person seeking asylum

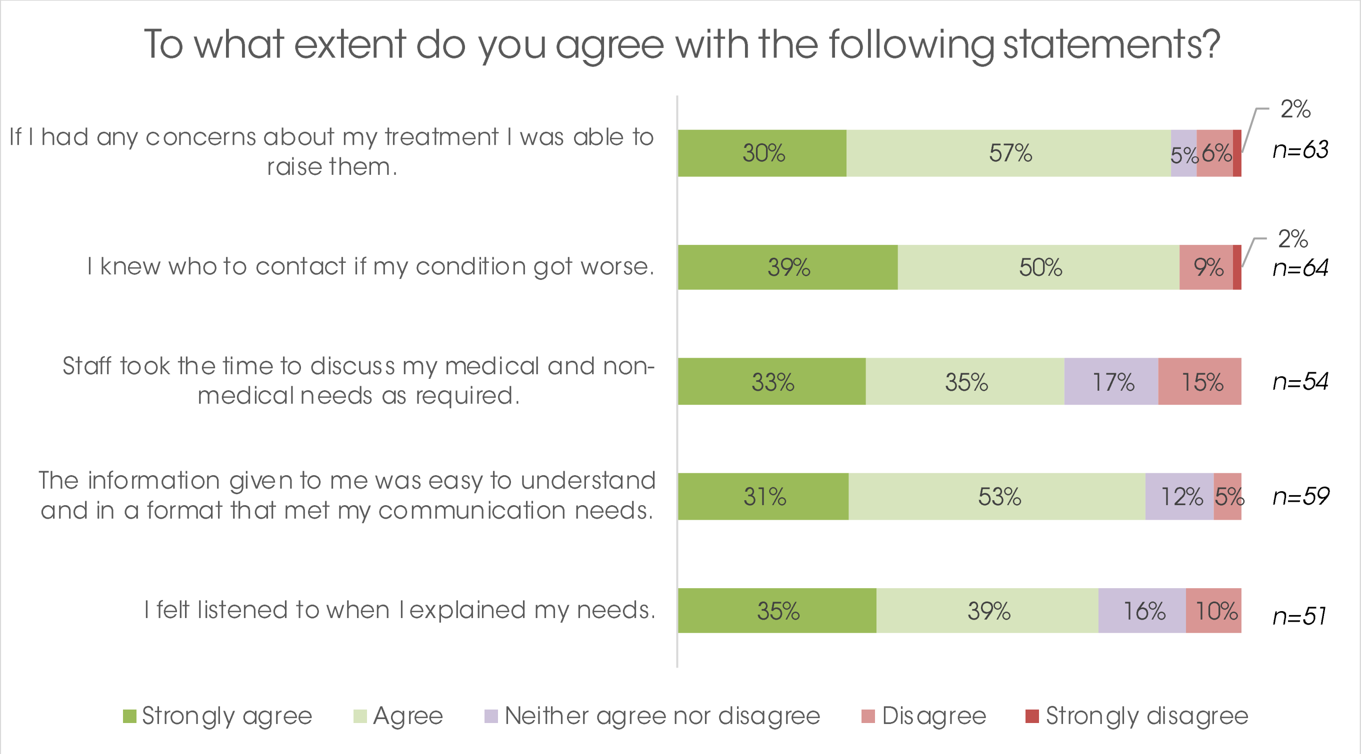

Figure 8 - Respondent feedback on information provision and communication

Figure 8 shows that a slightly higher proportion (15%) of respondents who received care after discharged disagreed with the statement that staff took the time to discuss both medical and non-medical needs as required. This theme of patients not having the opportunity to flag or get support their non-medical needs, whether that be emotional support or non-medical practical help (like food shopping), is reflected throughout the questionnaire and interview data. These issues are exacerbated for people who cannot easily access support networks of unpaid carers such as friends and family.

> "Some physical heavy lifting [would have been helpful], a bit of shopping, or kitchen floor mopping. Being further down the line so I could climb the stairs and have help with hair washing, showering."
>
> - Questionnaire respondent

Feedback on coordination and delivery of care

Feedback on the practical elements of their care was also overwhelmingly positive, with questionnaire respondents who received care after discharge tending to strongly agree or agree that the staff providing their care coordinated well with each other and turned up when they were supposed to; any missed appointments were rescheduled; and visits from carer providers were frequent (see Figure 9).

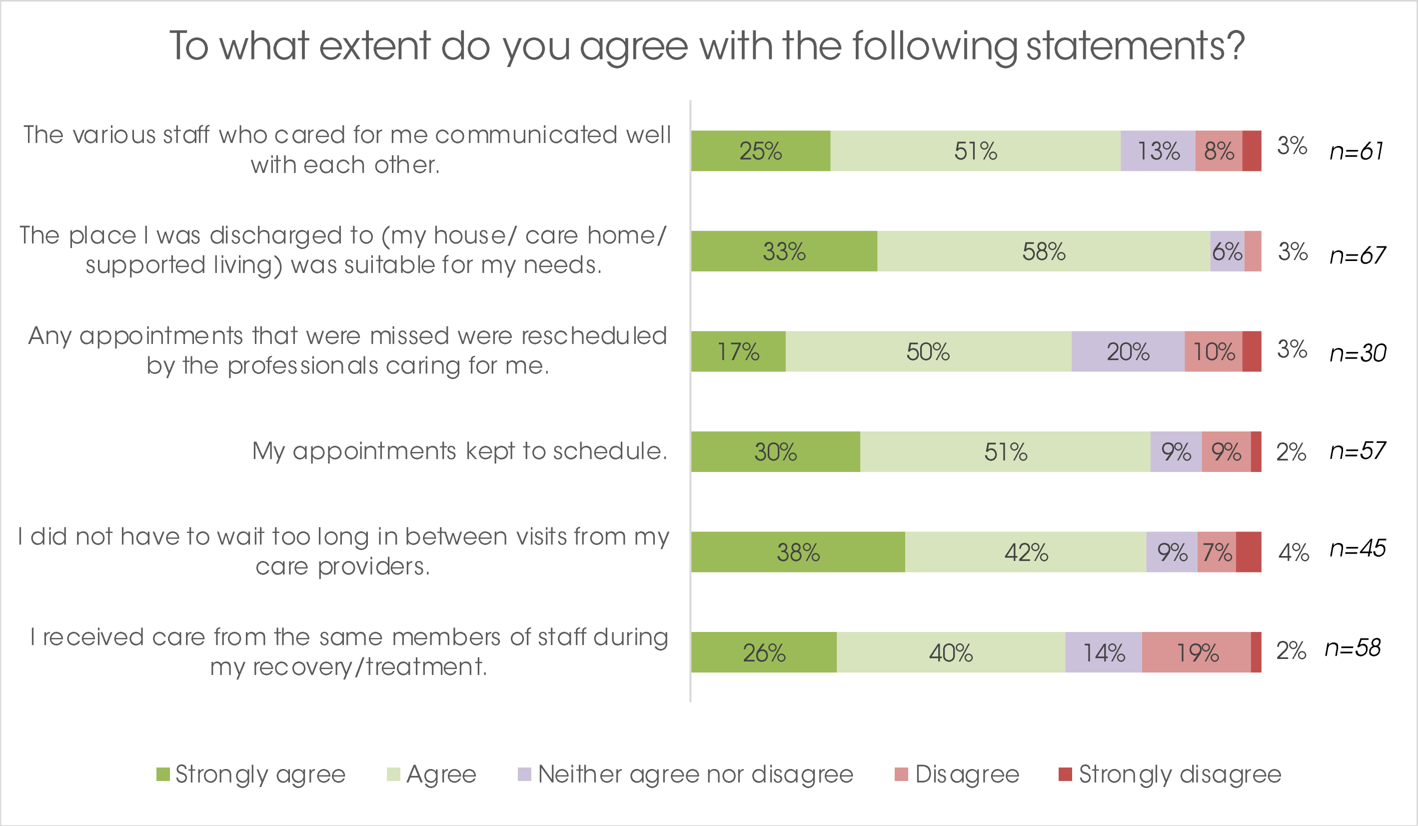

Figure 9 - Respondent feedback on coordination and delivery of care

This does not mean that experiences of follow-up care were universally positive. Several questionnaire respondents shared that they would have benefitted from more coordination between the various care providers, which led to them not receiving adequate care or having to repeat their story multiple times.

> "Better communication between consultant and physios [would have been beneficial]. There was virtually none and what the physio on a home visit did was wrong as he was not aware of the facts."
>
> - Questionnaire respondent

In a follow-up interview one participant explained that she had received contradictory information from her GP regarding the type of wound dressings she had been prescribed by the hospital trust; and the private specialist nurses responsible for her feeding tube did not seem to be communicating with her dietician who is based at her local GP surgery.

> "Nutricia nurse and dietician comes every couple of months, their visits are fine but I have to order the [liquid food] from the company Nutricia but they and the GP surgery and dieticians doesn't seem to link with each other."
>
> - Interview participant

A few interview participants flagged that they had experienced some form of breakdown in communication between the hospital in which the inpatient initially received care and their local GP practice. One interview participant explained how this issue was mitigated through the use of a messaging and record keeping digital platform, which allowed them to coordinate with various care providers after discharge, including managing appointments.

A fifth (20%) of questionnaire respondents who received care after discharge disagreed or strongly disagreed that they received care from the same members of staff during their treatment, however across the 17 interviews delivered this was not flagged as something that had a negative impact on the care received.

Experience of not receiving follow-up care

Of the 64 questionnaire respondents who did not receive follow-up care after being discharged from hospital, 55% felt that they did need follow-up care at the time (Figure 10).

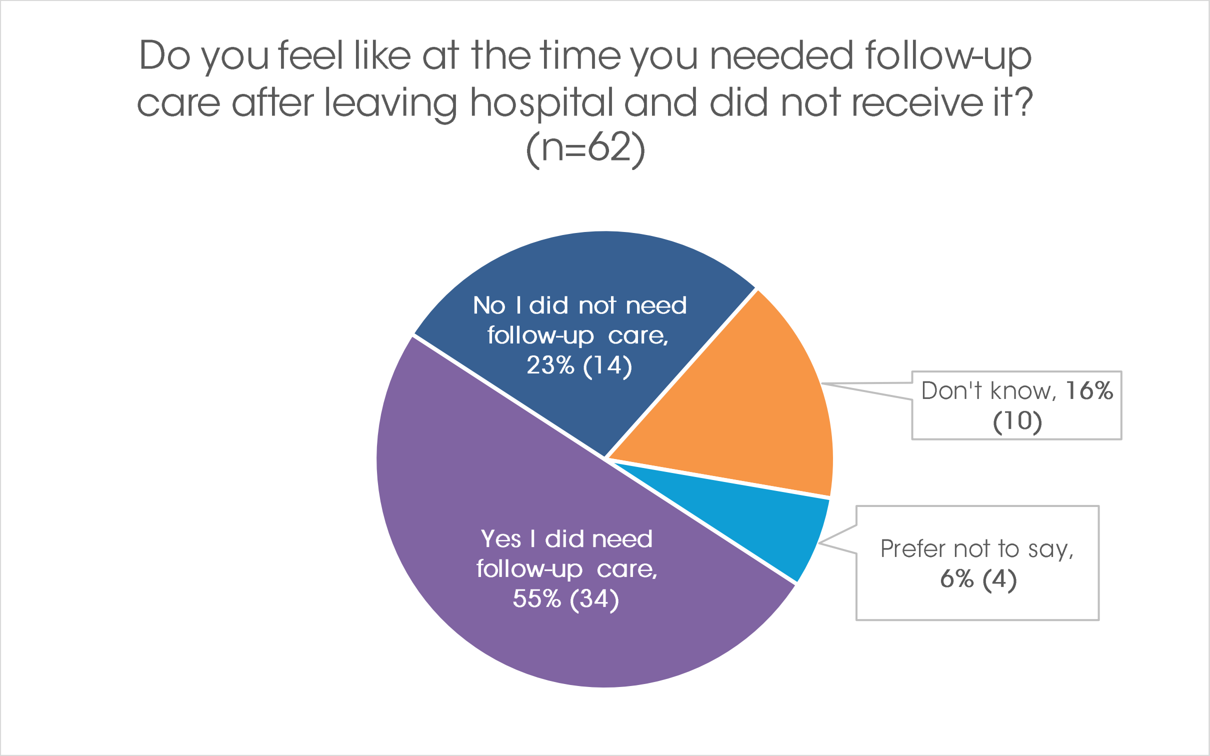

Figure 10 - Proportion of respondents who felt like they needed follow-up care but did not receive it

Figure 11 shows that the most commonly requested follow-up care by respondents who did not receive follow-up care (15%) was receiving physiotherapy and/or occupational therapy at home; followed by a visit from a GP to provide medical care (13%); and NHS nurses visiting to provide medical care. Respondents who selected 'other' suggested they would have benefitted from a follow-up phone call in the days following discharge; having a stairlift fitted; support for an unpaid carer; or were still waiting for treatment or diagnosis. Throughout the questionnaire and interviews participants said they would have benefitted from a simple follow-up phone call from the hospital or GP to check they were doing ok after being discharged.

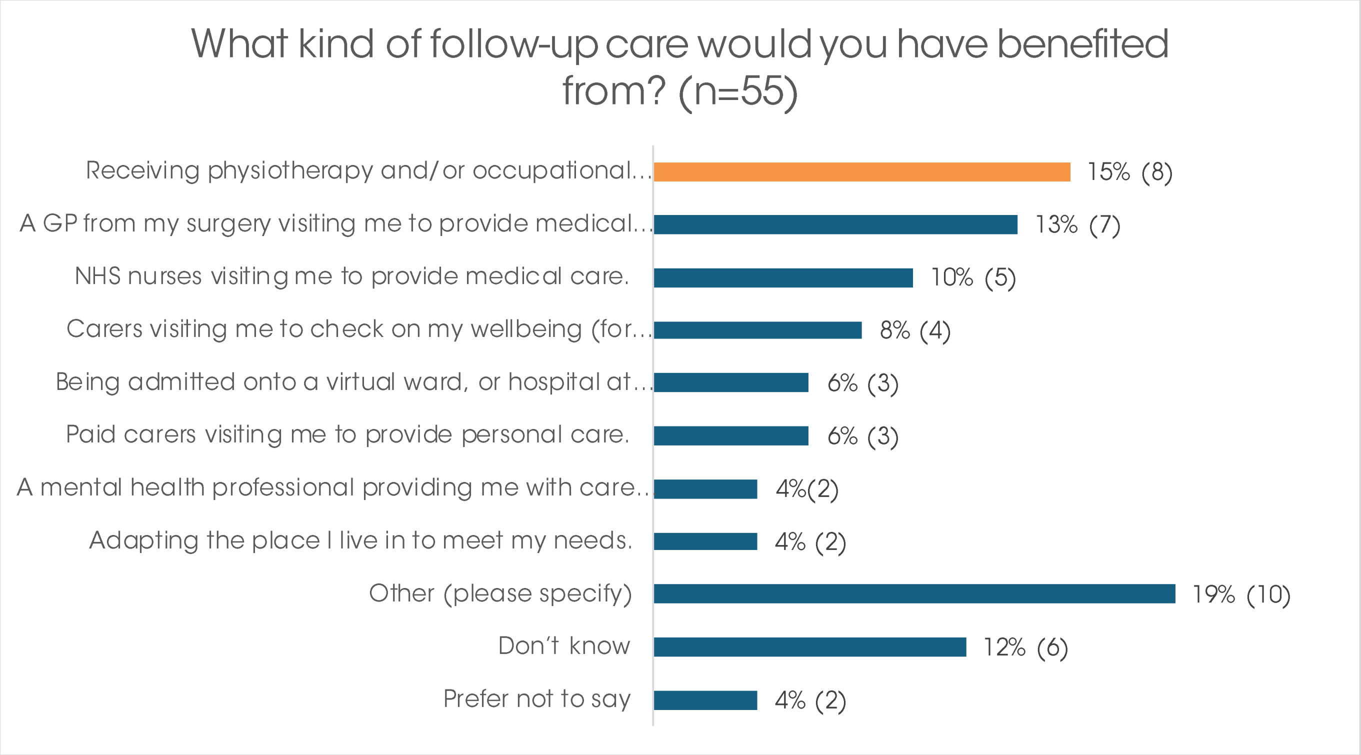

Figure 11 - Types of care that respondents felt they would have benefited from.

Respondents who did not receive follow-up care tended to agree that as a result of not receiving follow-up care their recovery took longer than it should have; their emotional wellbeing deteriorated; and their friends and family had to take on unpaid caring responsibilities (see Figure 12). Just over half (53%) of questionnaire respondents who did not receive follow up care had to go back into hospital and felt that it was as a result of not receiving follow up care.

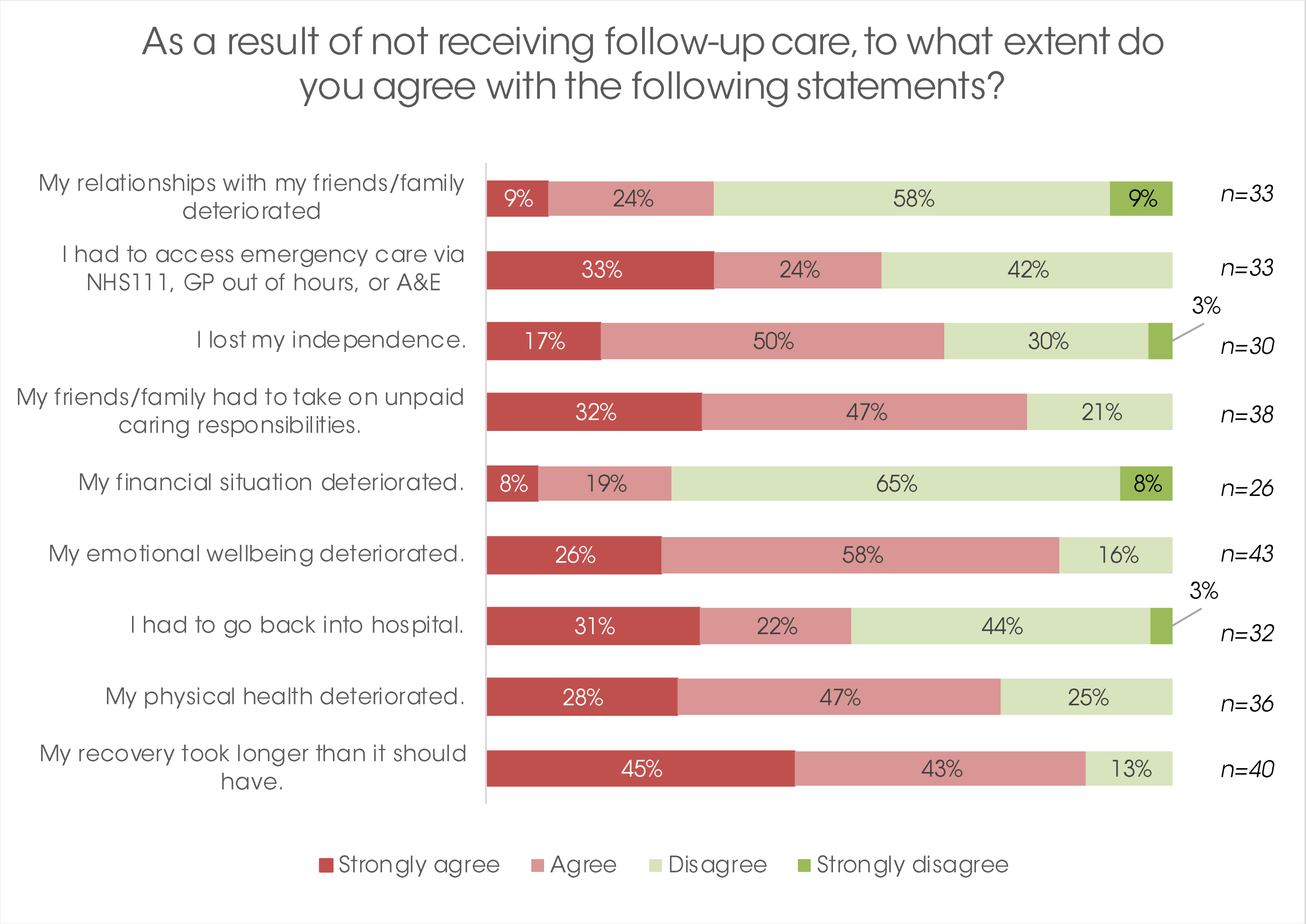

Figure 12 - Impact of not receiving follow-up care

The importance of physical rehabilitation

During interviews it became clear that where people were not given access to physiotherapy or rehabilitation support after being admitted to hospital, they often felt this impacted negatively on their recovery (see Figure 13). Participants often reported this had a knock-on effect on their confidence in their ability to be mobile, which in turn meant they had become less active and lost their independence. This can eventually lead to emotional and physical deterioration which ultimately has a negative impact on recovery. In some cases it may also lead the patient to needing more medical support in the future.

“Husband helped but is totally deaf and same age. Some of the [hospital] physio suggestions were impractical i.e. total rest for 6 weeks. Exercises, I could have done with some support and encouragement. No physio appointments organised. Felt isolated at times.

- Questionnaire respondent

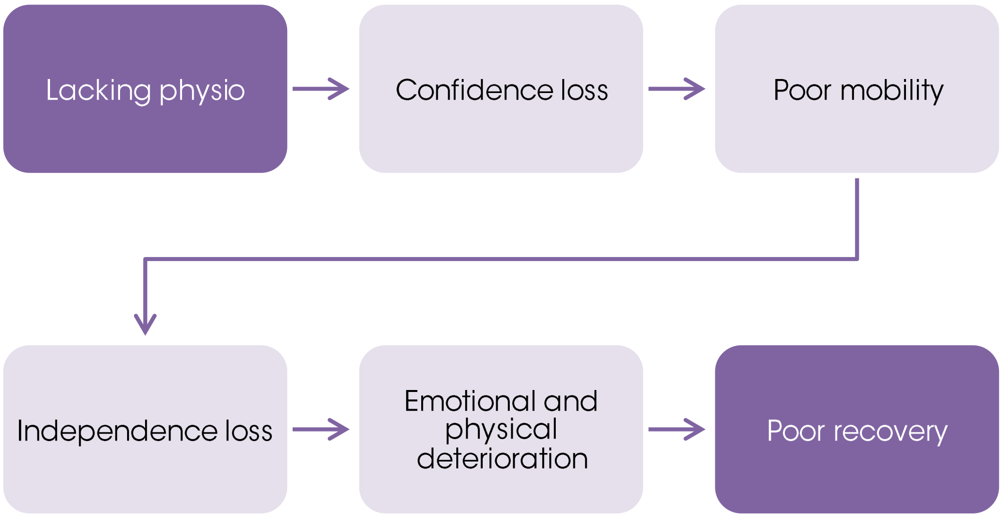

Figure 13 - Knock-on effect of not receiving care from a physiotherapist following hospital discharge.

Conversely, interview participants who had a positive experience with physiotherapists described how they were able to gain and maintain mobility which vastly improved their quality of life and/or reduced demand for support from their unpaid carer. One interview participant in her 80s who had been in hospital seven months for fractured vertebrae received home visits from physiotherapists after being discharged. When she was initially unable to do certain movements, the physiotherapists suggested an alternative approach which ultimately enabled the patient to regain some mobility and therefore independence. The physiotherapists also encouraged and supported her to walk down a ramp into the garden which meant she was able to leave the house for the first time in several months, further enhancing her sense of independence and reinforcing her self-belief in her ability to recover from her hospital stay.

> "Certain exercises I found very difficult to do – so one day they came with another young lady who asked me to try a certain way of moving. I did try it and I could actually turn over using this new way of moving, it took some of the pressure of the nerve. I was quite impressed with that."
>
> - Interview participant

Emotional and social needs

Not receiving follow-up care can lead to having a negative impact on the patient's emotional wellbeing, for example depression and anxiety. Several interview participants shared that in the short term, not receiving adequate support for dealing with pain and discomfort had a detrimental impact on their emotional wellbeing. After undergoing surgery on the nerves in her hand, one interview participant explained that she was not provided with any pain relief when discharged and had to rely on her daughter to buy off-the-shelf pain medication. Having to emotionally deal with both the inability to use her hand and the pain left her feeling sad.

Not receiving support from paid carers can lead to increased pressure on both the patient and their friends and family to juggle competing priorities and complete daily tasks such as cooking and cleaning, further exacerbating a sense of being overwhelmed. This is especially problematic for people who themselves are unpaid carers and have to resume this role once discharged from hospital.

> "I was back into full caring mode for [husband] but I was [recovering] from a double bypass and aortic valve replacement. I didn't have the physical or mental strength to cook, clean, wash, shop for us both [...]. Very depressed but no one I was able to talk to."
>
> - Questionnaire respondent.

Not receiving appropriate follow-up care also negatively affects the emotional wellbeing of patients in the medium-to-long term due to the risk of becoming increasingly isolated and losing independence. As illustrated in Figure 13, losing mobility, confidence, and independence can often lead to increased social isolation and loneliness. The relationship between loneliness and poor mental health has been well established [5].

> "I felt very vulnerable both physically and mentally. I had to rely on friends to do a lot as I don't have family nearby. I was unable to have a shower easily and found it difficult to climb stairs. I ended up seeing a psychologist due to PTSD post surgery."
>
> - Questionnaire respondent.

Whilst not common, some interview participants shared that they had faced increased financial pressure as a result of not receiving adequate follow-up support. This mostly occurred when patients were not provided with the correct equipment or modifications to their home, resulting in needing to purchase them privately. For example, one interview participant submitted a request to her local council to have a ramp fitted outside her front door and a walk-in shower fitted in her bathroom, but these were denied. This meant that she was required to spend thousands of pounds to ensure she was able to leave her house and take a shower independently. Likewise, the wheelchair she was provided was too heavy for her husband to lift into their car. After several months of being told she would be provided with a lighter alternative she opted to spend several hundred pounds to purchase one privately. This increased spending can lead to financial worries and stress, especially for people who are unable to work or experiencing financial inequality.

---

[5] Investigating factors associated with loneliness in adults in England - GOV.UK

> "I pay privately for a PA now, an hour 4 mornings a week for personal care, which uses up my PIP allowance and mobility allowance as I mostly have to get taxis to hospital and back costing £62 a round trip, which I sometimes can't afford."
>
> - Questionnaire respondent.

Impact on long-term physical wellbeing

A very small number of interview participants experienced long-term negative impacts to their physical wellbeing as a result of not receiving adequate follow-up care. There were some instances of people's physical conditions becoming avoidably deteriorated which limited their mobility in the long term.

> "I have a disability now due to lack of care in and out of hospital resulting in kyphosis of the spine and further fractures, none of which are treated now."
>
> - Questionnaire respondent.

It is difficult to unequivocally say that the interview participants would have completely avoided these long-term impacts if they had received adequate care as their condition might have deteriorated regardless, however what is clear is that the participants in question felt let down by the health and care system. People who are already living with frailty, a disability or long-term health condition are much more susceptible to having a long-term negative impact on their physical wellbeing if they do not receive the follow-up care they need.

"I enquired if it was the surgery that didn't work and they said not to worry. I still sometimes have pain sometimes when shopping with heavy bags in my hands or doing heavy jobs around the house like cleaning. I tried speaking to the dr about it and was just told 'the nerve is very sensitive' even though I'm in pain."

- Interview participant, person seeking asylum.

Impact on unpaid carers

Across all questionnaire respondents and survey participants who did not receive follow-up care, many people said they were more reliant on unpaid carers upon hospital discharge than they were before being admitted to hospital. There were many instances of people relying on friends and family to take up caring responsibilities regardless of whether they received follow-up care or not. These responsibilities ranged from ad hoc tasks such as collecting medication, through to providing daily support with washing and dressing.

"I moved to Southsea from Surrey 18 months previously, my grandson Sam lives here and is the only member of my family living. All my friends either live in Surrey or London, I could not call on them. Sam would call past every night on his way home from work. He still helps me thank The Lord."

- Questionnaire respondent.

Whilst Figure 12 suggests that for the most part relationships with friends and family did not deteriorate as a result of not receiving follow-up care, several interview participants explained how their partner had struggled as a result of taking on caring responsibilities whilst they recovered, or even indefinitely. Some research participants were almost entirely reliant on the person they live with, which can create additional challenges for this cohort of participants who are all over 65 and whose carers may require additional support themselves. These issues are compounded when the patient does not receive any follow-up care or the care they receive is inadequate.

Several interview participants explained that they don't know how they would cope without support from unpaid carers – this suggests that some of negative impacts of not receiving follow-up care are not felt to their fullest extent as a support network of friends and family rises to address this unmet need. However this can come with a cost for the care providers, with some participants describing how their partners were exhausted from the added responsibilities.

> "My husband who is in his 70s was exhausted, broken sleep having to assist with any of my toilet needs in the night, helping me manoeuvre as well as trying to cook etc and run the house."
>
> - Questionnaire respondent.

Considerations and recommendations

1. Reinforce need for discharge planning to take place at the start of admission, with a clear plan communicated and clear follow-up offered where needed. As this is already expected by the system, we recommend reinforcing this by empowering patients to understand the discharge process through a simple guide to their rights, which must be disseminated in both digital and analogue means, including in alternative languages. Staff members must also be upskilled to allow patients to challenge their rights without being dismissed or being deemed difficult.

2. Develop a more meaningful shared-decision making approach to discharge, to help prevent people being discharged when they were not ready to (as stated by 19% of all survey respondents), This should include an holistic approach to the person as a whole and consider physical and emotional needs, family and friends support and talking through what support is needed at home and by when to enable a positive discharge experience. This should include access to interpreters where needed to tackle health inequalities that may arise as a result of poor conversations

3. Create a meaningful co-designed and co-produced Neighbourhood Health Service approach to discharge care as this local level is where the majority of the discharge support will be delivered. This will ensure the offer responds to the needs of real people and communities and involving the VCSE sector will also be crucial to understand where gaps in knowledge and provision exist. Neighbourhood provision will likely include an expanding physiotherapy and occupational offer, offering better emotional support and a care coordinator for more complex needs.

4. Include data on discharge experience in the provider league tables that rank providers against key quality indicators, similarly include experience of discharge as part of the National Quality Board new remit on care quality.

National Voices

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 200 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

020 3176 0738
info@nationalvoices.org.uk
www.nationalvoices.org.uk
@NVTweeting

The Foundry,
17 Oval Way,
London
SE11 5RR