

# People's experiences of leaving hospital in Oxfordshire



November 2024

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# Executive Summary

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*“So the good care, it’s not just about healthcare, it’s about the quality of life and the relationship and everything – it’s just priceless.”*

*(Unpaid carer comment)*

Over the past year, informed by national guidance, the Oxfordshire health and social care ‘system’ has been working to develop new pathways to care and support for people when they leave hospital. This has included a shift towards rehabilitation and care for people in their own homes or usual place of residence, as a way of supporting speedier recovery and independence. This in turn helps to relieve the pressure on acute hospital beds, by reducing hospital stays and associated negative impact on recovery. There is focus on providing ‘joined-up care’, with support services planning and working closely together around the patient.

Between May and September 2024, Healthwatch Oxfordshire reached out to hear from people in the county about their experiences of this care and support. We heard from people via a combination of online and paper surveys, face to face outreach, and interviews. We focused on patients returning home via two pathways – Pathway 0 (going home without additional social care) and Pathway 1 or Discharge to Assess (D2A) (going home with additional social care before being assessed for longer-term social care needs).

In all, we heard from a total of 293 people:

- **206 members of the public** about their experiences of leaving hospital and any follow-on care and support they received after their stay
- This included the views of **22 unpaid carers**
- We also heard from **87 health and social care professionals** from primary and secondary care and social care.

What people told us:

## **What’s working well?**

- Parts of the process are working well for some patients. People valued the support and care from health and care professionals. What was clear was that good, consistent communication, being involved in decision-making about their care, effective follow-up care and aftercare, and high-quality care all made their experience of care positive. Most people told us they were happy to be back in their own home.

- Health and care professionals are finding effective ways of working together around patients' needs. Central to this is the coordinated approach taken in the Transfer of Care Hub and in multidisciplinary teams, to help get more people home with the support they need.

### **What could be better?**

- Some parts of the discharge process are not working well for everyone. There are challenges around consistent and clear communication, listening to people and involving their unpaid carers in decision making, delays in leaving hospital and getting care, and accessing follow-up care and aftercare from different services. There are also challenges around the quality and continuity of care provided.
- Some areas of joined-up communication across primary and secondary care can still be improved following discharge of a patient from hospital, including handing over care to GPs and district nursing teams.
- We heard that unpaid carers were not always included or did not feel listened to, and were not being offered support.
- Overall communication and information about the discharge support offer and expectations could be more accessible, both for patients and carers but also for the health and care professionals within the system.

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## **Recommendations**

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We would like to make the following recommendations based on what we have heard. They focus on building on existing good practice to improve the experience of patients and unpaid carers as well as system working.

- Recommendations are for response for all system partners – including Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) with Oxfordshire Place-Based Partnership, Oxford University Hospitals (OUH), Oxford Health, Oxfordshire County Council (OCC) and home care providers – as to how they will address them.
- For noting by Oxfordshire GP Network, Age UK Oxfordshire and Carers Oxfordshire.

### **1. To improve the experience of continuity and quality of care for patients:**

- a) Note this report, including the experiences and voices of patients and carers, and reflect on potential to improve services in light of this insight.

- b) The report has highlighted some gaps in joined-up care. Our recommendation is to use this report to identify gaps and inform the development of further service design and action plans to address them.
- c) Identify scope for providing more person-centred care and support to both patients and unpaid carers at each step of the discharge process. For example, patients have told us about problems with timing of home care visits.
- d) Build on the Health and Social Care Connections programme, to ensure that patients and unpaid carers continue to be involved in the co-design and future development of services.

## **2. Clear communication with patients and carers**

This report indicates where improvements to communication with patients and carers could be made. We would like to recommend the following:

- a) Improve communication about all aspects of the discharge pathway to ensure that patients and unpaid carers are fully informed about every step. For example, patients have told us that a leaflet and a single point of contact would be helpful.
- b) Ensure that communication and information about discharge is accessible to all patients and unpaid carers, in line with the Accessible Information Standard.

## **3. Improve support for and identification of unpaid carers**

Based on what we heard from unpaid carers, we make the following recommendations, noting OCC's Unpaid Carers Strategy:

- a) Improve recognition and understanding of unpaid carers' role and capacity to provide care, including proactive identification of unpaid carers, for example flagging unpaid carers on medical records.
- b) Improve holistic support to unpaid carers, including signposting to Carers Oxfordshire and other support.
- c) We heard that unpaid carers were not always involved in decision-making about discharge. Ensure that, where appropriate, unpaid carers are involved in decisions about discharge.

## **4. To continue to develop joined-up working across the system**

We saw that good progress has been made in services working together around discharge from hospital. The report identifies the following areas for continued improvement:

- a) We heard that health and social care professionals are not always clear about discharge pathways, including the D2A offer and follow-on healthcare. We recommend exploring ways to improve communication with staff to ensure consistency of approach.

- b) Work together to improve communication and understanding between services, e.g. interface between secondary care, GPs and district nursing teams when a patient is discharged, multi-disciplinary team handovers and discharge letters.
- c) Explore potential to build in better support for patients through greater involvement of other relevant partners, for example home care providers and extra care housing providers.

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## Background

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### Moving care closer to home in Oxfordshire

In recent years, national government policy has encouraged a shift towards more community-based care. Local health and care providers have developed ways to make health and social care services available to people near to their homes and communities, rather than in large hospitals.<sup>1</sup> In Oxfordshire, for example, this has included the development of ‘hospital at home’ services to enable people to be treated at home where possible<sup>2</sup>, rather than having to stay in hospital, and recent initiation of integrated neighbourhood teams within Primary Care, focused on community level support to help people stay well.<sup>3</sup>

There has also been development of a new approach to supporting adults who need support, rehabilitation and care immediately after leaving hospital. In the past, people often waited in hospital beds while their care needs were assessed, leaving hospital only when this assessment had taken place, and the care put in place. This could lead to longer waits in hospital while care was being arranged, sometimes with significant negative effect on people’s health and ability to recover.<sup>4</sup> Under the new system, people are now discharged to return home as soon as they are clinically ready – that is, they no longer need to be in an acute hospital bed to have their medical care needs met. Whatever care they need is

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

<sup>2</sup> <https://www.bucksoxonberksw.icb.nhs.uk/news/posts/bob-icb-news/september-2024/thousands-effectively-treated-by-hospital-at-home-services-according-to-new-evaluation/>

<sup>3</sup> [https://www.bucksoxonberksw.icb.nhs.uk/media/4312/primary-care-strategy-final-21\\_05\\_24.pdf](https://www.bucksoxonberksw.icb.nhs.uk/media/4312/primary-care-strategy-final-21_05_24.pdf)

<sup>4</sup> <https://www.nuffieldtrust.org.uk/news-item/understanding-delays-in-hospital-discharge>

provided at home, and the care assessment is carried out in their home once they are settled.

This new approach, called **Discharge to Assess (D2A)** not only reduces the length of time people stay in an acute hospital, but is proven to reduce the negative impacts of a long hospital stay on people's physical and mental health, as well as making more beds available for other people. People often feel happier in their own home, can return to independence and recover more quickly. Assessment of need done in a person's own home can support health and social care professionals to make more accurate decisions about the person's long-term care needs. D2A, first introduced as best practice by NHS England in 2016, was piloted in Oxfordshire from July 2023<sup>5</sup>, and rolled out across the county from November 2023–January 2024<sup>6</sup>. Timescales for care that were introduced early on – people were told they would have an assessment within 72 hours of getting home and would get free care at home for up to six weeks – were later changed to be more flexible according to people's needs.

In Oxfordshire, there are four pathways through which people are discharged from hospital (see diagram below).<sup>7</sup> Our report focuses on listening to experiences of adults leaving acute hospitals on what is known as 'Pathway 0 and Pathway 1 or 'Discharge to Assess' (D2A)'.

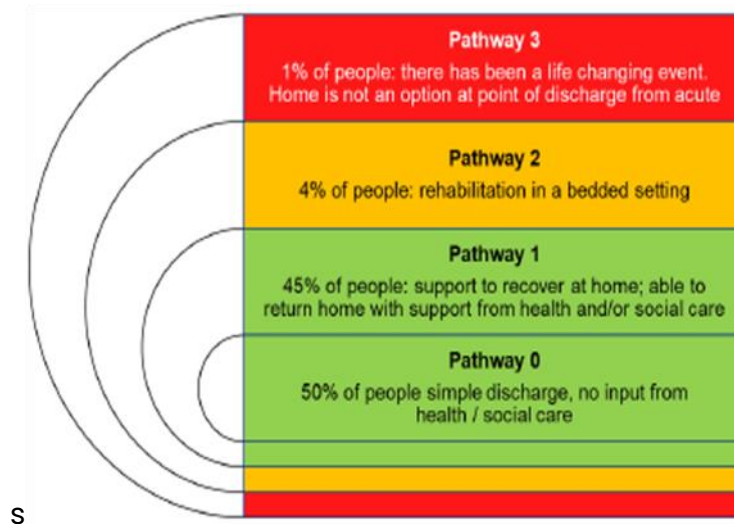
- **Pathway 0:** about half of people leaving an acute hospital are able to go home without any social care – this is known as Pathway 0.
- **Discharge to Assess – Pathway 1:** Around 45% go home with D2A, also known as Pathway 1. A small number of people leaving an acute hospital may need more social care or support than can be provided in their home and may move to a bed in a community hospital or care home for rehabilitation before going home (in which case, this temporary bed might be referred to as a 'step-down' or 'short stay hub' bed), or for long-term care.

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<sup>5</sup> <https://news.oxfordshire.gov.uk/new-programme-launches-in-oxfordshire-to-help-patients-leave-hospital-on-time/>

<sup>6</sup> <https://news.oxfordshire.gov.uk/update-more-oxfordshire-patients-being-supported-to-recover-from-hospital-stay-in-the-comfort-of-their-own-home/>

<sup>7</sup> Note: People leaving other hospital settings, such as inpatient mental health wards, children leaving hospital, people with some health conditions and people with some life circumstances (such as experiencing homelessness) may have a different journey out of hospital. These journeys are not covered in this report.



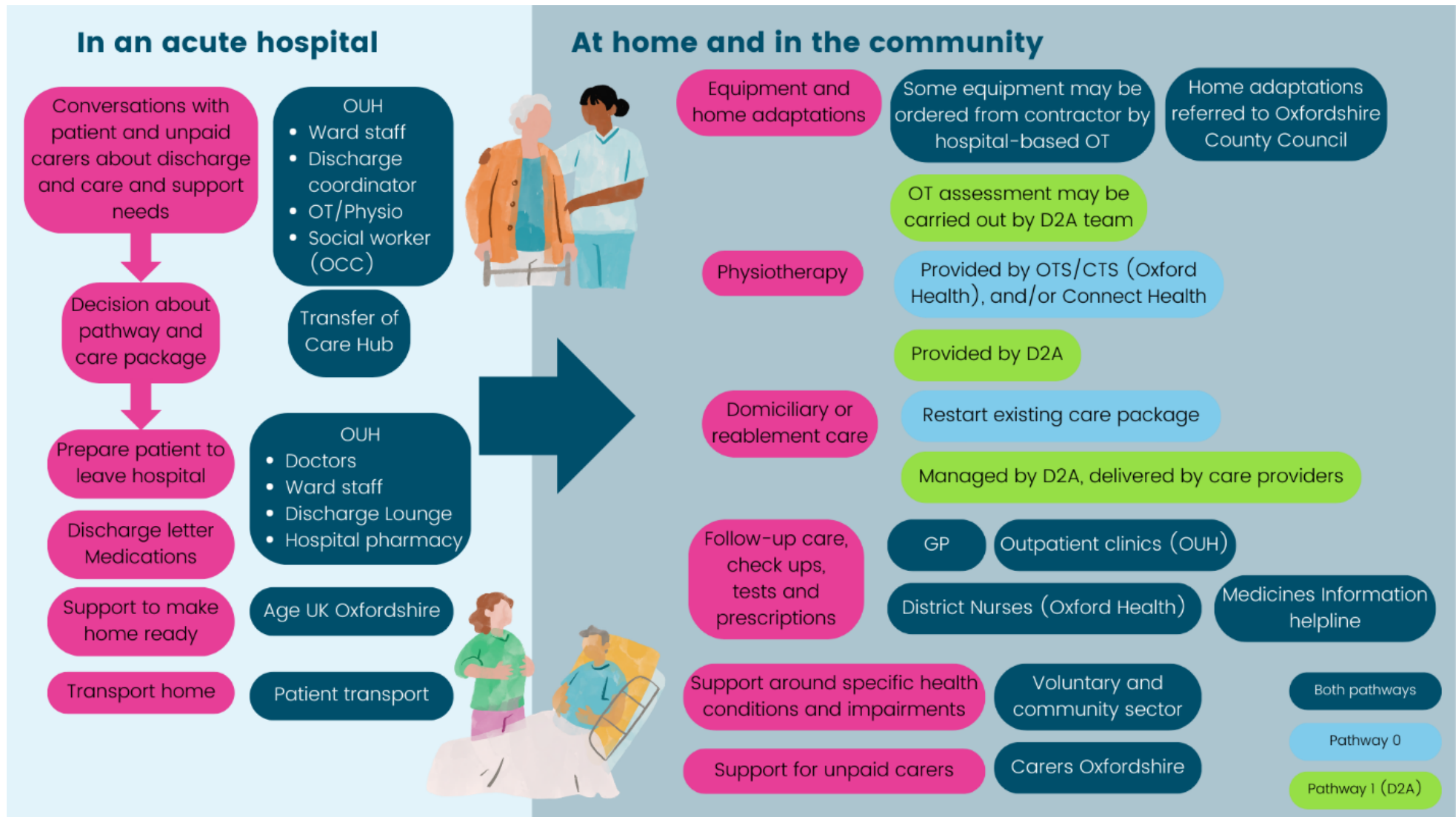
**Figure 1:** Discharge pathways in Oxfordshire. Source: Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board

Pathways 0 and 1 may involve patient contact with and coordination of care across a number of different health and care services, including:

- **secondary care acute hospitals** – in Oxfordshire, most people go to hospitals run by Oxfordshire University Hospitals (OUH) or hospitals in neighbouring counties, including Royal Berkshire Hospital (RBH) in Reading and Great Western Hospital in Swindon.
- **patient transport services** – provided by SCAS, EMAS and others
- **social services** – part of Oxfordshire County Council (OCC)
- **home care providers** – private domiciliary and reablement care providers contracted by OCC, including the four main ‘strategic providers’ offering reablement in Oxfordshire: AllCare, Agincare, Care Outlook and Eleanor Healthcare Group.<sup>8</sup>
- **primary care services** – e.g. GPs, community pharmacies
- **community care services** e.g. Occupational Therapy, District Nursing, – mostly provided by Oxford Health NHS Foundation Trust (OH)
- **voluntary sector organisations**, including commissioned support for people leaving hospital, provided by Age UK Oxfordshire, commissioned support for unpaid carers provided by Carers Oxfordshire, and organisations providing support for different communities and for specific health conditions and impairments.

<sup>8</sup> <https://www.oxfordshire.gov.uk/residents/social-and-health-care/adult-social-care/adult-social-care-services/living-home/home-first-oxfordshire/reablement>





**Figure 2** The Journey Home – Pathway 0 and Pathway 1 (D2A) in Oxfordshire

**National government guidance** on what people can expect from hospital discharge includes:

- Making sure unpaid carers and family members are included in decisions about discharge, where appropriate.
- Planning for discharge as soon as someone is admitted to hospital (or sooner if for a planned procedure).
- People should be discharged '*to the right place, at the right time, and with the right support*' to help the person recover as well and be as independent as they can in the long term.
- Discharge teams should make sure that people have transport to get home – usually this is with a friend or unpaid carer.
- People leaving hospital should be given information about who to contact if there are any issues with their care after leaving hospital.<sup>9</sup>
- Information should be shared 'across relevant health and care teams and organisations across the system in a secure and timely way to support best outcomes'.
- People should be given as much choice and control about their discharge as possible within what is appropriate and available to them, and their choice should be respected.

However, findings from the most recent Care Quality Commission (CQC) hospital inpatient survey suggests that people's experience of discharge has worsened since before the COVID-19 pandemic, including in areas such as being involved in conversations about discharge.<sup>10</sup>

### **Joined up working around the patient**

A report by The Kings Fund in 2024 called for commitment to making care closer to home a reality, rather than a narrow focus, for example on hospital targets. It highlighted the importance of multi-disciplinary working to provide holistic care to patients, and the risk of overlooking the importance of primary and community health and care services.<sup>11</sup> In Oxfordshire, local health and social care providers have been working together to deliver hospital discharge in a joined-up way that is centred around the needs and strengths of each person leaving hospital. This has been demonstrated for example in the close partnership work between

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<sup>9</sup> <https://www.healthwatch.co.uk/blog/2023-11-20/nhs-urged-do-more-help-patients-leave-hospital-safely>

<sup>10</sup> <https://www.cqc.org.uk/press-release/more-people-report-poor-discharge-experiences-and-deterioration-health-while-waiting>

<sup>11</sup> <https://www.kingsfund.org.uk/insight-and-analysis/reports/making-care-closer-home-reality>

health and social care to plan and allocate funding for integrated working, through the Better Care Fund.<sup>12</sup>

Development of the D2A approach has similarly involved significant partnership work across secondary, primary and social care, and has brought clear improvements in Oxfordshire's delays in discharge. This new way of supporting people represents a shift in the way services are provided. It also represents a cultural shift on the part of patients and families, and has been met with some reservations, as well as concerns over potential gaps in care, for example for rural areas, and for those at the end of life. Over the summer of 2024, health and care commissioners have carried out listening exercises, and conversations with the public to support better understanding and communication of these changes among the public, including taking part in Healthwatch Oxfordshire patient webinars.<sup>13</sup>

New developments in Oxfordshire's health and care system to promote joined-up working include the Transfer of Care Hub (TOC) and the Trusted Assessors scheme. The TOC brings together people from acute hospitals, community hospitals, care homes and social services and voluntary sector for meetings three times a day, to make real time decisions about where patients will be discharged to and identify the support they need. Trusted Assessors liaise between acute hospitals, social services and care providers, carrying out assessments of patients in acute hospitals on behalf of care providers.<sup>14</sup>

As well as health and care services, **unpaid carers** – people who informally provide care for other in their lives, often friends, relatives or neighbours – play a key role in the supporting people leaving hospital. Carers' rights are protected in law – including the right for an adult to choose whether or not to be a carer for another adult, and the right to choose what caring tasks they are willing to do. The Oxfordshire Unpaid Carers Strategy 2023–26 sets out priorities for supporting unpaid carers over the next three years.<sup>15</sup> In Oxfordshire, the main sources of planned support for adult unpaid carers are via Carers Oxfordshire, Dementia Oxfordshire and Oxfordshire County Council. The wider voluntary and community sector also plays an important role in supporting patients and unpaid carers.

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<sup>12</sup> <https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/better-care-fund/>

<sup>13</sup> <https://healthwatchoxfordshire.co.uk/news-and-events/patient-webinars/>  
<https://www.bucksoxonberksw.icb.nhs.uk/health-and-social-care-connections/>

<sup>14</sup> <https://www.oacp.org.uk/trusted-assessors-in-oxfordshire>

<sup>15</sup> <https://www.oxfordshire.gov.uk/sites/default/files/file/plans-performance-policy/OCCUnpaidCarersStrategy.pdf>

Healthwatch Oxfordshire wanted to understand how changes in discharge and support were being experienced by people leaving hospital in Oxfordshire. We have researched and written this report to bring to the fore the voices of patients and unpaid carers about what it is like leaving hospital on Pathways 0 and 1 in Oxfordshire – what is working well and what could be better.

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## What did we do?

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We used a mixed methods approach to hear from a range of people across Oxfordshire, including people who have recently left hospital and unpaid carers of people who have left hospital. We heard from people between March and September 2024. Our methods included:

- An **online survey**, developed with input from unpaid carers and representatives of system partners including Age UK Oxfordshire, Carers Oxfordshire, Oxford University Hospitals and Oxfordshire County Council. The survey ran from May–September 2024 and was shared widely using our networks and social media. It was advertised in local newsletters, such as Age UK Oxfordshire’s *Engage magazine*, and *Round & About*. We shared posters with GP practices, community noticeboards and libraries. We provided print versions of this survey to people who requested them
- During face-to-face outreach, we used a simplified **outreach survey** to record responses. This included speaking to people during our ongoing schedule of outreach and engagement events across Oxfordshire, including Witney Pride, play days and visits to patient participation groups. We also carried out targeted outreach to hear from groups most likely to have experienced health inequalities, including Action for Deafness and an OX4 BAME elders’ group, or to have recent experiences of leaving hospital, including older people’s groups, Banbury Royal Voluntary Service, a Carers Oxfordshire support group, and extra care housing schemes
- Outreach surveys were also given directly to patients and unpaid carers by Age UK Oxfordshire’s hospital team, social workers from Oxfordshire County Council, and staff in the discharge lounge at the John Radcliffe hospital.
- **In-depth conversations** with people who were put in touch with us (with their consent) by the Discharge to Assess team and Carers Oxfordshire, who shared their contact details in the survey, or who contacted us directly
- An **online survey for health and social care professionals** – staff working to support patients through the discharge process, circulated widely including through staff networks at OUH, Oxford Health and OCC, and via

Oxfordshire Community and Voluntary Action and the Oxfordshire Association of Care Providers

- **Observation of Transfer of Care meetings** – a member of the Healthwatch Oxfordshire staff team observed two meetings of the Transfer of Care Hub, which take place on Microsoft Teams three times a day
- An **Enter and View visit** to the Discharge Lounge at the John Radcliffe Hospital in August 2024.<sup>16</sup>

Once collected, we compiled the data and carried out a thematic analysis of the qualitative responses.

## Who did we hear from?

We heard from a total of **293 people**:

- 122 people through our full online survey for patients and unpaid carers<sup>17</sup>
- 27 people through our simplified outreach survey for patients and unpaid carers
- In depth conversations with 6 D2A patients and 7 unpaid carers – the stories collected have been published [on our website](#).
- Around 30 people through outreach visits to community groups
- 14 people via phone through our signposting service
- 87 health and social care professionals through our staff survey, including follow-up interviews with 6 respondents.

**Of those who responded to our surveys:**

Who are you?					
Patient			Unpaid carer		
127			22		
When did you leave hospital?					
Before April 2023	April-June 2023	July-September 2023	October – December 2023	January-March 2024	Since April 2024
2 (14%)	15 (10%)	15 (10%)	24 (16%)	33 (22%)	59 (40%)

<sup>16</sup> Our Enter and View report on the Discharge Lounge at the John Radcliffe has been published separately [on our website](#).

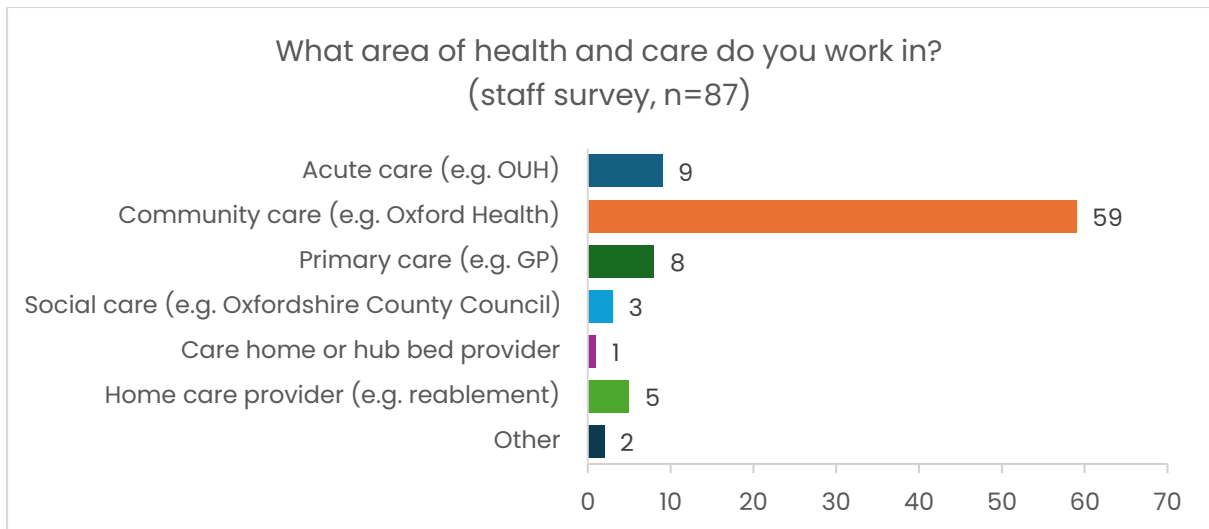
<sup>17</sup> We heard from another 6 people about experiences of being discharged from mental health inpatient settings, which is outside the scope of this report and which we will report on separately.

Which hospital did you stay in?					
John Radcliffe (JR)	Churchill	Nuffield Orthopaedic (NOC)	Horton	Royal Berkshire (RBH)	Other
74 (50%)	19 (13%)	10 (7%)	23 (15%)	12 (8%)	11 (7%)
Pathways home from hospital (inferred from responses)					
Pathway 0 (home without additional care and support)		Pathway 1 / Discharge to Assess D2A (home with additional care and support)		Pathway 2 (rehab in bedded setting e.g. care home or community hospital)	
115 (80%)		26 (18%)		3 (2%)	

Of the **patients and unpaid carers** we heard from, who told us about their gender, ethnicity, age and location:

- Most (77%, 96 out of 124 people) were women
- Most were White British (86%, 105 out of 122 people) or said they were from any other White background (8%, 10 out of 122 people). We heard from small numbers of people who are Arab, Chinese, Indian, Pakistani, another Asian ethnicity, or have a mixed ethnic background
- The biggest age groups were ages 65-79 (52 people, 43%), 80 or over (31 people, 26%, of whom two were unpaid carers, and at least 6 were aged 85 or over), and 50-64 (25 people, 20%). We heard from 12 people aged 25-49 (10%)
- People were fairly evenly distributed across Oxfordshire's five districts. The most common postcodes we heard from were in Banbury, Oxford, Wantage and Henley.

In the **survey for health and social care professionals**, we heard from a younger set of people: over half (48 people, 59%) of those who told us their age were 25-49. We still predominantly heard from White British people (62 people, 82%) but had responses from several people with Chinese, Indian, Pakistani, and Black African backgrounds. We heard from people working across the sector, including acute care, community care, primary care, social care, and home care providers. Community care (predominantly Oxford Health) was best represented, accounting for 68% of responses.



**Figure 3.** Graph showing breakdown of respondents to our survey for health and care professionals by area – including acute care, community care, primary care, social care and home care providers.

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## What's working well?

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We heard that many people had positive experiences of part or all of the process of leaving hospital, particularly around:

- Good communication, being kept informed and up to date, and being given helpful advice
- Being listened to and involving unpaid carers
- Proactive and high-quality follow-up care and aftercare
- Support from charities and voluntary organisations
- Care and support at home for D2A patients, especially the friendliness and professionalism of carers and the coordination of care provision
- Being happy to be home.



**Figure 4:** What's working well?



## **Good communication and information**

People told us they valued good communication from health and social care professionals about when they were going to leave hospital and what would happen next with their health and social care.

*“Everything explained very well to me and my husband.”* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

We heard that people appreciated it when they were given relevant information and advice, especially when this was explained in person, and in an accessible, practical way.

*“The Physio was the best explainer. She talked through not being able to drive for 6 weeks (that’s so hard) and also talked through all the different physical challenges and how to solve them.”* (Pathway 0 patient, online survey, JR, Oct-Dec 2023)

*“I knew when I was due to leave, given useful advice about what to do and how to do it e.g. physio & medications.”* (Pathway 0 patient, online survey, NOC, Jan-Mar 2024)

*“A lady from the company the hospital arranged came to see me at home and was v helpful.”* (D2A patient, online survey, NOC, Jan-Mar 2024)

*“Following a total hip replacement, I was a little concerned about mobility – was greatly reassured by promise of physio and by clear instructions about exercise regime.”* (Pathway 0 patient, online survey, NOC, since Apr 2024)

People also said it was helpful to be given information in different formats – like a letter as well as a conversation – and to be given contact information in case they had any questions or concerns after leaving hospital.

*“I was given a lot of info about my condition, treatment, medication, what next. It was too much to remember. The letter of discharge was a great help, when I received it 2 weeks later.”* (Pathway 0 patient, online survey, JR, since Apr 2024)

*“I was given contact numbers in case I had any concerns.”* (Pathway 0 patient, online survey, JR, Oct-Dec 2023)

## **Being listened to and involving unpaid carers**

Several people told us they felt listened to and that their preferences around leaving hospital were heard and respected.

*“My discharge from the John Radcliffe was excellent and all questions I had or worries were answered.”* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

*“After one night in hospital I wanted to get home as my husband and I are unpaid carers for my [son]. A lady whose role I can't remember was very helpful in arranging all tests and scans I had to have before discharge very quickly.”* (Pathway 0 patient, online survey, JR, Jul-Sept 2023)

We also heard positive comments about how health and social care professionals worked to make sure that unpaid carers were involved in decision-making and kept informed.

*“My wife was kept informed at all stages.”* (D2A patient, online survey, Oct-Dec 2023)

*“There was the discharge coordinator on the ward most of the time who I could always talk to.”* (Unpaid carer of D2A patient, interview, JR, since Apr 2024)

## **Follow-up care and aftercare**

People told us about good experiences of follow-up care from the hospital or their GP and highlighted how much they appreciated being contacted proactively by health and social care professionals.

*“GP rang me after a day or so (when she had had the hospital letter) to check how I was and how it was going.”* (Pathway 0 patient, online survey, Churchill, Oct-Dec 2023)

*“My doctor returned my call quickly when I had concerns at home. Sorted me out!”* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

*“I knew I could phone the ward with any problems or concerns. After a week I could phone my GP or III.”* (Pathway 0 patient, online survey, JR, Oct-Dec 2023)

*"The Churchill Hospital have been superb in fixing problems post leaving the hospital." (Pathway 0 patient, online survey, JR and Churchill, since Apr 2024)*

*"Community physio and all absolutely amazing – all phoned every couple of days to ask me." (Pathway 0 patient, outreach survey, JR, before Apr 2023)*

### **Support from charities**

One person told us about the support they had had from a charity around managing a specific health condition:

*"A terrific example of what I'm talking about is Headway. Where they have time. And my wife even said afterwards, Wasn't that a terrific experience? You can't buy that, you know, that's priceless. It's a woman who is a skilled practitioner, who knows what she's about, but has got time. And she's communicating and she looks optimistic as well. And that matters, believe you me, in all this, optimism." (Unpaid carer of D2A patient, interview, RBH, Jan-Mar 2024)*

### **Care and support at home**

People shared positive experiences of different aspects of their care, including the coordination of the care, the promptness with which the care started after getting home, the friendliness and professionalism of carers and the quality of the care itself.

*"The social worker who arranged my care was excellent. She was based at the JR. The social worker made sure that I had adequate care and that it continued until I could manage independently." (D2A patient, online survey, NOC, Jan-Mar 2024)*

*"I had to wait for care to be arranged because I live on my own. Because of this, I was in hospital longer than was necessary and there was a weekend in between. But once the care was arranged, it was brilliant. I had hospital transport home, and the care agency lady came to see me about two hours after I'd returned home, and she informed me about the care package." (D2A patient, interview, NOC, Jan-Mar 2024)*

*"Excellent care from a care agency." (D2A patient, online survey, JR, Jul-Sept 2023)*

*“The care providers were all extremely caring and professional.” (D2A patient, online survey, JR, Oct-Dec 2023)*

*“I was pleased to have the care package, and even more so when I was able to tell the social worker that I no longer needed them!” (D2A patient, online survey, NOC, Jan-Mar 2024)*

*“The carers first time around [March 2024] different carers and times very variable, which older people find difficult to deal with. The second time [May 2024] much improved continuity of carers and timing very good. Overall very impressed with overall care and support given.” (Unpaid carer of D2A patient, online survey, JR, since Apr 2024)*

*“I was supposed to go to a community hospital – but wanted to go home even though they wanted me to go to Bicester to continue rehab – but none of my family drive and I would be isolated up there so that made me say no and go home. OT assessment (OCC) and now have physio and have request for walk in shower alterations. Normally 3 week wait but had assessment very quickly. Everything worked well, it was non-stop care, didn't have to wait at all, happened all at once.” (D2A patient, outreach survey, JR, since Apr 2024)*

*“Very good carers – reliable and trustworthy.” (D2A patient, outreach survey, JR, since Apr 2024)*

*“All the girls that come to see me are all nice, friendly girls, so I'm quite happy with those.” (D2A patient, interview, JR, since Apr 2024)*

One person also noted how health and social care professionals had worked together to help her achieve her goals, reflecting a good example of person-centred care:

*“The community people found out what was happening and brought me a wheelchair and a mattress – I'd never had a mattress like that before, I didn't sleep very well the first night but it's lovely now. They asked me what I'd like to do, and I said I'd like to get out, because I hadn't been out for six months, so they got me a wheelchair and I go out once a week, I go to the market, and it's been lovely.” (D2A patient, interview, JR, since Apr 2024)*

### **Happy to be home**

People overwhelmingly said that they felt safe and happy to be home. 16 people, 84% of respondents to the online survey who got additional care and support at

home, said they agreed or strongly agreed to the statement 'I felt happy to be home'. People told us about the difference being home made to their recovery.

*"I felt better with my home comforts, my daughters helped with my meals and showers."* (Pathway 0 patient, online survey, RBH, Apr–Jun 2023)

*"Pleased to recover and be back at home with my family."* (Pathway 0 patient, online survey, Churchill, Jul–Sept 2023)

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## What could be better?

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We also heard about things that were not working so well or could be better at each stage of going home from hospital. These included:

- Room for improvement in people's experience of **discharge planning**, such as people not feeling involved in decisions about their discharge, not being kept informed, and delays to being discharged
- Problems experienced on the **day of discharge**, including people being discharged before they felt ready, delays with medication, paperwork or transport on the day of discharge, a lack of information about what would happen next or where to get help, problems with medication and with patient transport, and being discharged late in the evening or at times that did not work for patients or unpaid carers
- Gaps around **follow-up care**, including people not knowing who to contact or who would provide aftercare, challenges accessing aftercare from acute hospitals, GPs or District Nurses, a lack of follow-up from health services, difficulty accessing support from charities, delays to getting physiotherapy and equipment, and people not being offered or getting additional care and support at home despite feeling they need it.
- Gaps and challenges around **home care for people on the D2A pathway**, including delays in receiving care, problems with routine and timings of care visits, problems with the quality of care received, care not being tailored to patients' needs, a lack of information about social care provision, delays and confusion around getting physiotherapy and occupational therapy assessments.



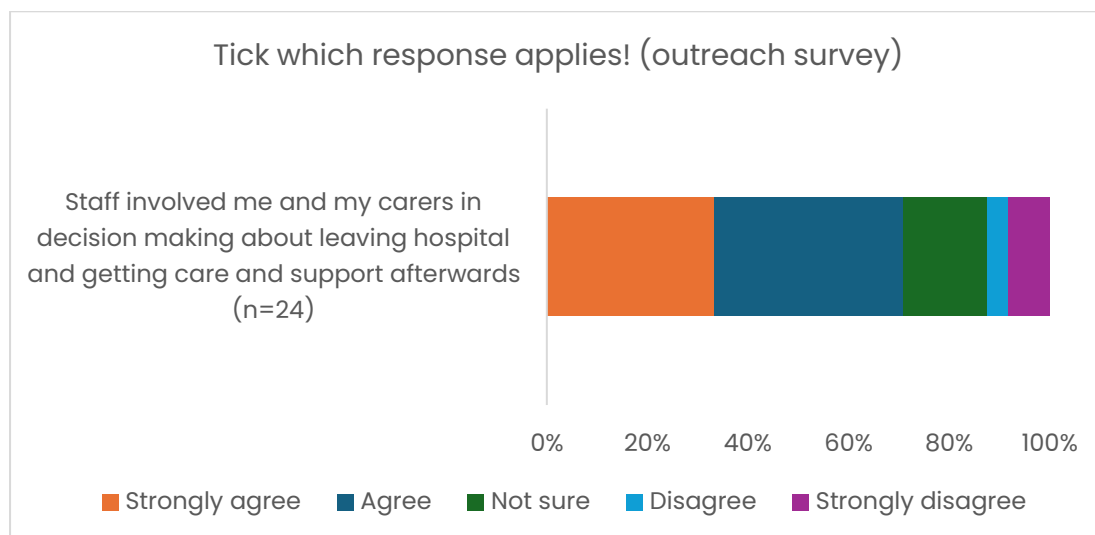
**Figure 5:** What could be better?

What we heard suggests that there is a **lack of consistency** in people's experiences of discharge and D2A – when everything comes together it works well, but gaps in communication and care provision mean that not everyone is having a good experience.

## Preparing to leave hospital

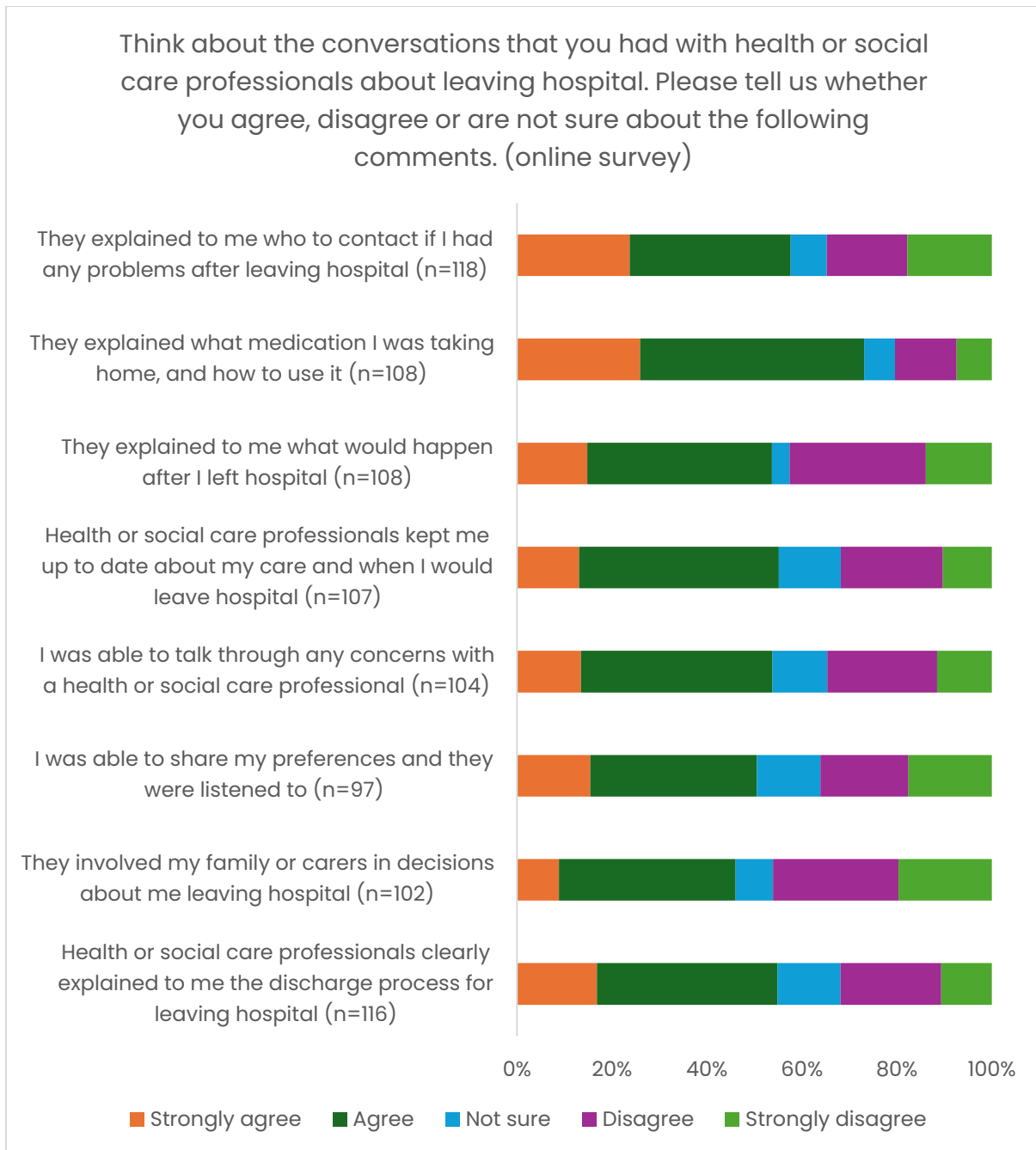
### Conversations about discharge

We asked people to tell us about the conversations they had with health or social care professionals about leaving hospital. Most people (17 out of 24, 71%) who responded to our outreach survey said they agreed or strongly agreed that staff had involved them and their carers in decision-making about leaving hospital and getting care and support afterwards.



**Figure 6:** Graph showing responses to our outreach survey question about whether staff involved the patient and their carers in decision-making about leaving hospital and getting care and support afterwards.

In our online survey, a narrow majority of people gave positive responses (agree or strongly agree) to statements about conversations with health professionals about leaving hospital, but there was also a significant proportion who gave negative responses – particularly to statements about involving family or carers in decisions (47 people out of 102, 46% said 'disagree or strongly disagree'), whether health or social care professionals had explained what would happen after the person left hospital (46 people out of 108, 43%), and who to contact if they had any problems after leaving hospital (41 people out of 118, 35%).



**Figure 7:** Graph showing responses to online survey questions about conversations with health and social care professionals after leaving hospital.

Things that made conversations about discharge unsatisfactory ranged from a lack of suitable spaces to have these conversations, **to people not feeling listened to** or feeling their circumstances or preferences were ignored.

*“Discharge discussions took place in a very busy corridor.”* (Pathway 0 patient, online survey, RBH, since Apr 2024)



*“None whatsoever. Was told the hospital was full.”* (Patient discharged from emergency department, online survey, JR, since Apr 24)

*“It was never fully explained to me what help could be made available.”* (Pathway 0 patient, online survey, NOC, Oct-Dec 2023)

*“[Staff] don't bother to read written instructions from other departments; I kept on telling them I was supposed to see certain people to be checked out before discharge, but they don't listen to patients. As a consequence, it must have cost a lot of money to have to send a car to bring me back in the next day.”* (Signposting email about discharge from the JR, May 2024)

*“The pre-op nurse has told me that I will need a person to drive me home after the surgery and someone to supervise me for 24 hours after the surgery at home. When I told her my neighbour is going to do it, she said it cannot be my neighbour. This was before asking me if my neighbour was a close friend or if she was going to stay in my house or hers. She said if I do not find someone else, they could cancel the surgery.”* (Signposting call about the JR, April 2024)

One person also told us they were concerned that discharge **decisions were made without a proper assessment of their home situation.**

*“There was no, or seemingly no assessment of me, my capability, our home for safety and so on. Nobody ever mentioned any of those things. So [my wife] could have been exiting to a very unsafe house.”* (Unpaid carer of D2A patient, interview, RBH, Jan-Mar 2024)

We heard from several people who said they felt they were **not listened to when they expressed concerns about going home without any additional care** and support.

*“No one discussed it with me even though I had told them several times I would be alone at home and was very worried about this. No one cared once they had discharged you.”* (Patient, online survey, JR, Jan-Mar 2024) – this person said they paid for a private post-operative care bed because they could not be looked after at home.

*“I am frail [and] vulnerable. No one listened or was concerned about not being able to look after myself. I was in a great deal of pain still got discharged. No care until ambulance called via my alarm two days later*

*cos I couldn't breathe, diagnosed with pneumonia.” (Pathway 0 patient, online survey, Churchill, Jan-Mar 2024)*

*“My partner was having cancer care and he shouldn't have been looking after me, and I told the hospital this but no one listened and no one cared!” (Pathway 0 patient, online survey, JR, Jan-Mar 2024)*

We heard that **unpaid carers were not always included**, or did not always feel listened to, in conversations about leaving hospital and care and support afterwards, including in situations where the patient was very elderly, or unable to retain information, or was struggling to make those decisions themselves – so involving unpaid carers would better support the patient.

*“My mother is elderly and a little confused, I asked several times to be involved and informed instead she was the only person involved and also signed a DNR she didn't understand and has since ripped up still not understanding it's on a computer now! I specifically asked her nurse for 24 hours to find another home [nearer family], but hospital went ahead and discharged her anyway.” (Unpaid carer of Pathway 2 patient, online survey, JR, Oct-Dec 2023)*

*“Only my mother was involved in discussions - and she was still in a poor mental state following a serious, and unexpected, operation.” (Unpaid carer of D2A patient, online survey, JR, Oct-Dec 2023)*

*“Carers should be allowed in with their partner, especially if partner is non verbal, so that they can explain things to the nurses and provide reassurance to their partner and make sure they are comfortable. Nurses should discuss patient's needs with family carer as they are best placed to give them the information they need re positioning, continence, diet, comfort generally. Carers should be kept informed and updated re discharge as they need to be sure they have adequate supplies of essentials (pads, medication) and because they have responsibilities at home. They shouldn't just be abandoned.” (Unpaid carer of Pathway 0 patient, online survey Horton, since April 2024)*

*“I was not listened to about discharge risks and was in fact told ‘if you're so worried you can stay with her overnight’. No one had asked if that was even possible. It was a highly stressful few days chasing up referrals and trying to ensure Mum took her medication. I missed work and had to get childcare.” (Unpaid carer of D2A patient, online survey, JR, since Apr 2024)*

One person told us that health and social care professionals had **not made reasonable adjustments** to ensure good communication with unpaid carers (this is discussed in more detail under [Communication](#) below).

*“There wasn’t always a consideration for the issues of whom they were speaking to be that the patient or the carer. Even the carer has issues with hearing and mobility so the whole picture needs to be considered. [...] It’s difficult combination of the patient not having good recall due to cognition issues, a mother that cares for him that has hearing issues and uses an aid and a sister that can only be there as soon as work and family allow to pick through the details from the other two and then realise that not all the facts were heard or understood and so to gather a nurse or doctor again to get some sense of the full picture, which from the health care professional’s point of view believe they have already communicated to the patient a their carer!”* (Unpaid carer of Pathway 0 patient, RBH, Jan–Mar 2024)

### **Contradictions and differences between expectations and reality**

We heard that sometimes **people were told they could expect one thing, but then something different actually happened**. This could cause uncertainty and dissatisfaction. Sometimes this highlighted inconsistencies in communication between professionals or departments, as well as in communication with patients.

*“I had a major operation and expected to stay in hospital for at least 2/3 days. I was asked to give up my bed, which I was happy to do, and went home less than 24 hrs after the surgery. I literally went from morphine to paracetamol.”* (Pathway 0 patient, online survey, Churchill, Jan–Mar 2024)

*“Dr said happy to discharge me but I was able to stay another night if I was happier doing that - I agreed. Nurses discharged me that day anyway.”* (Pathway 0 patient, online survey, JR, since Apr 2024)

*“Theoretically, someone did explain most steps to me, but the reality was very different. I kept on being told what should happen, but had no way of checking up on what was happening.”* (Pathway 0 patient, online survey, JR, Jul–Sept 2023)

*“I felt communication was poor between nursing staff and patient. Doctor was clear as to when I could leave but then followed many hours of no communication between patient and nursing staff.”* (Pathway 0 patient, online survey, Churchill, since April 24)

## Delays to discharge

We heard from several D2A patients that after they were medically ready to go home, there were **delays while a package of care was put together**.

*"I stayed in hospital longer than I needed to because they wouldn't let me go home without a carer. I was ready to go home after about 5 days but I was in there about 9."* (D2A patient, interview, JR, since Apr 2024)

## The day of discharge

### Being discharged before being ready

We heard from several people who felt they had been **discharged before they were ready**. Readiness meant different things to different people, including feeling like they did not get enough notice that they or the person they look after were going to be discharged, or feeling they were rushed out of the ward without time to pack their belongings or get themselves ready.

*"My wife had little time to get my bed ready as she had an appointment that day."* (D2A patient, online survey, JR, Oct-Dec 2023)

Three others told us they had been **discharged despite feeling that they still required acute hospital care**, meaning that they had to return to hospital.

*"I was discharged before I was ready, with catheter still in place despite having already blocked during one night."* (Patient, online survey, JR, Oct-Dec 2023)

*"I had an infection which wasn't picked up and had another 3 1/2 weeks back in hospital."* (D2A patient, online survey, NOC, Jan-March 2024)

*"I was sent home without seeing a certain doctor, although it was written in my notes. I was then phoned and told I would have to return to the JR at 7.30am the next morning."* (Pathway 0 patient, online survey, JR, Jul-Sept 2023)

### Delays on the day

People told us about delays on the day they were discharged, between being told they would be leaving (and often being asked to leave the ward) and actually leaving the hospital. For most people, this was due to waiting for paperwork, medications, transport, or a combination.

*“The discharge process took a long time. I was told mid-morning that I would be going home but didn't go to the “departure lounge” till late afternoon and was there for two hours waiting for my medication.”* (Pathway 0 patient, online survey, JR, Oct-Dec 2023)

*“Was taken from the ward around lunch time and taken to a discharge bay - where we had to sit and wait for hours for everything to be sorted. I was told around 10am that I was going to be discharged so got my Granddaughter to come up to collect us, but we didn't end up leaving until around 5pm.”* (Pathway 0 patient, online survey, JR, April-June 2023)

*“Having to wait until 8-9pm for medication when I'm due to be discharged at 12pm after the ward round!”* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

We heard that people would have liked **more communication about what was happening** while they were waiting.

*“Nurses could have been more communicative. E.g. ‘we now have your meds but are still waiting for blood test results.’ Had we not asked at 7pm and requested an update, not sure what would have happened. As it was, I got home after 10pm.”* (Pathway 0 patient, online survey, Churchill, since Apr 2024)

*“We were misinformed and led to believe that we were going home in the early hours when this could not have been the case as patient transport do not operate in the early hours. [...] There seemed to be no contact between the doctor who assessed my partner and the nurses arranging patient transport. We were left for hours not knowing what was happening and if we would get home that night. It was very distressing.”* (Unpaid carer of Pathway 0 patient, online survey, Horton, since Apr 2024)

We also heard that for some people, a lack of hospital capacity and focus on clearing beds made them feel like **care was less centred around patients**. One person also noted the impact of industrial action on hospital capacity.

*“I felt that the left hand did not know what the right hand was doing and the staff just wanted to get rid of me.”* (Pathway 0 patient, online survey, RBH, since Apr 2024)

*“The system is about targets not the patient.”* (Pathway 0 patient, online survey, Churchill, Jan-Mar 2024)

*"In short stay ward, they were desperately short of staff and extremely busy. Their mission was to discharge patients as quickly as possible which was not compatible with my operation."* (Pathway 0 patient, online survey, NOC, Oct-Dec 2023)

### **Information about what would happen next**

People told us they would have liked to have **more information about what would happen next** with their healthcare, how to manage their condition or medical appliances, and where they should go for support.

*[What could have been better?] "Given care plan and conversation explaining what to expect re: Hemovac [drain]. I had to google it to find out what it was."* (D2A patient, Churchill, Jul-Sept 2023)

*[What could have been better?] "Someone taking the trouble to explain what would happen with future appointments and what would happen."* (Pathway 0 patient, online survey, RBH, since Apr 2024)

*[What could have been better?] "Provision of central phone no. to ring if any problems or queries would have given me more confidence when at home."* (Pathway 0 patient, online survey, JR, since Apr 2024)

*"Until I asked, I was not provided with a sling for my arm. I had no advice about pain relief, and none was provided [which was OK, I had some at home]. The nurse gave me no advice about what to do when I got home, and what to expect. I was not given any advice about how to get in touch if I had a problem. I was surprised not to be given a leaflet with some basic information about self-care after my operation - for example what to do about showering/bathing with my arm in a full bandage."* (Pathway 0 patient, online survey, JR, since Apr 2024)

*"I wasn't informed of services I was entitled to (PIP, volunteer drivers, blue badge etc)."* (Pathway 0 patient, online survey, Churchill, Jul-Sept 2023)

### **Medications**

We heard about **problems with getting medications to take home** from hospital, including errors.

*"Discharge medicines not correctly given. My wife had to return to the ward next day for correct package."* (Pathway 0 patient, online survey, RBH, Jan-Mar 2024)

*"My medications were a mess. I was taking 8 paracetamol a day but discharged without any. I weaned off [medication] but was given a full box of 60 and only used about 10. It was really unclear what I was meant to be taking as some medications were missing. My daughter managed to figure it out and write me a chart."* (Pathway 0 patient, online survey, JR, Jan-Mar 2024)

What people told us about problems and delays with medication echoed what Healthwatch Oxfordshire heard in a previous project, [Leaving hospitals with medicine](#), in January 2023.

### **Transport**

People also told us about problems with **patient transport**, including delays.

*"The transport arrived with the wrong equipment, so I had to wait (up to 48 hours!) to get the correct transport."* (D2A patient, online survey, Horton, since Apr 2024)

*"The actual discharge from the John Radcliffe to Abingdon Hospital was a nightmare. Waiting for transport from mid-morning eventually left in the evening. Wintertime, it was dark. This completely disorientated my Mum on arrival to Abingdon hospital and took her nearly a week to settle again."* (Unpaid carer of Pathway 2 patient, online survey, JR, Jan-Mar 2024)

*"I waited a long time for transport with was stressful for me."* (Pathway 0 patient, outreach survey, Horton, since Apr 2024).

We also heard from staff working in acute care that a lack of patient transport availability is contributing to delays in people leaving hospital.

### **Timing of discharge**

We heard from several people who had been **discharged at night**, which affected their access to medications or was a source of stress.

*"Meds were not available as late discharge."* (Pathway 0 patient, online survey, Horton, Jan-Mar 2024)

*"I was discharged from A&E at 3am, they sent me up to the main entrance to book a taxi. I got home and couldn't wake my husband and I had no cash on me, fortunately I had a back door key so I was able to get in and*

*find money to pay the taxi that way.” (Comment from Carers Oxfordshire coffee morning, August 2024)*

People told us they found the **information in discharge letters confusing, and sometimes inaccurate and incomplete**, with implications for joined-up care, including between secondary and primary care.

*“Discharge letters don’t tell the story or connect the dots. From reading discharge letters my GP was completely unaware that one surgeon had started surgery and then had to call a different surgeon as the thought of my issue was not the case. What actually happened made a difference due to the length of time I was left. There needs to be some narrative around what actually occurred.” (Pathway 0 patient, online survey, JR, since Apr 2024)*

*“The discharge summary didn’t make a lot of sense. It stated I had been admitted with a fall – not true. It was as though much of it was cut and pasted. I had a very large brain tumour removed, but the discharge summary stated I could return to work in 6 weeks and fly! Whereas I was told I would take 6-12 months to recover.” (Pathway 0 patient, online survey, JR, Jan-Mar 2024)*

*“The operation was carried out Feb 23. They noticed a brain tumour and did not tell me. [This year] another scan was done I was notified that I had a brain tumour for the past two years.” (Pathway 0 patient, outreach survey, Churchill, Jan-Mar 2024)*

*“There is a lot of information from a stay in hospital. It would have been great to have a summary of what happened and the follow up action and signposts for information to take away with us, not to be emailed later or for two or three different teams to contact us at random, unexpected times on a landline and then a mobile and then email. Having someone with long term health issues is difficult enough without having to manage all the different inputs from different parts of the NHS and hospital.” (Unpaid carer of Pathway 0 patient, online survey, RBH, Jan-Mar 2024)*

## **Follow-up care**

For Pathway 0 patients who shared their experiences with us, one of the most common issues was around **a lack of follow-up care or aftercare** from primary care, community services or hospital outpatient care, after leaving hospital. This is likely a reflection of the fact that people are being discharged from hospital into a stretched system, where there are already capacity challenges for example, long



waits for appointments with GPs and for referrals. In some cases, it also seems to be linked to barriers to communication and joined-up working, discussed in more detail in [Joined up working](#) below.

### **Who to contact**

People told us they were not always sure about who to contact after leaving hospital, if they had any questions or concerns.

*“I do not know who to ask about follow up matters – GP (3 day delay)? For example my wound leaking blood. Would have been nice to have a number to call for reassurance.”* (Patient, online survey, RBH, since Apr 2024)

We heard that people were **not always sure about would provide aftercare**, for example changing wound dressings, catheters). In some cases people just did not know, or in others they got **mixed messages from health and social care professionals or were signposted to or fell between multiple services**. This meant that some people felt unsupported and uncertain in after care.

*“[I] came out with a temporary catheter that needed to be removed at a specialist clinic called Trial Without Catheter Clinic (TWOC). However the TWOC is run by Urology, and since their staff did not put the catheter in, they were not going to be responsible for removing it at a TWOC Clinic. Alternative arrangement was that the District Nurses would remove the catheter, but they were unable to remove it on time, or even tell me when they could come to remove it. Leaving a catheter in the bladder longer than necessary increases clinical risk considerably. The outcome was that I removed it myself.”* (Patient, online survey, Churchill, since Apr 24)

*“My husband had a serious pressure sore on his heel and who would provide aftercare and treatment was very unclear. [...] We were bandied around between GP practice, district nurses, diabetic clinic and podiatry department.”* (Unpaid carer of Pathway 0 patient, online survey, NOC, since Apr 24)

*“No one explained who to contact, I came out with a gall bladder drain and only 14 days of stuff to flush clean. When contacted the hospital could not help and my doctor's surgery knew nothing about it.”* (Patient, online survey, RBH, since Apr 2024)

### **Difficulty accessing aftercare from acute hospitals**

People told us about challenges getting aftercare from outpatient care services – including **not being given care, transport issues** and **long waits** for appointments.

*“Was told to go back and get blood thinning injections and be shown how to use them. Rude nurse refused to do so.”* (Patient, online survey, Churchill, Oct-Dec 2023)

*“When teams expect you to come back every other day for continued tests but now have to pay for public transport and have no one accompanying you due to short notice – poor planning.”* (Patient, online survey, JR, Jan-Mar 2024)

*“Very little help!! I was told to go home and book an appointment. I got an appointment six weeks after I was discharged.”* (Pathway 0 patient, outreach survey, JR, Oct-Dec 2023)

*“I had a bilateral mastectomy [last year]. The actual surgery went well, but there was zero aftercare. Oh, I had multiple hospital appointments, which were never on time. I had to travel a relatively short distance, 25 miles each way, but the traffic and parking meant 1.5 hours travel time, so effectively half a day each time. All I ever got told was 'it's normal' or 'everyone is different'. No constructive help with seroma, iron bra syndrome, or scar management. Every bit of help I got was paid for by me or from charities.”* (Signposting call, April 2023)

Coordination of **cross boundary support** was also noted. We heard from one person from out of county who had trouble getting outpatient support from their local hospital due to communication issues with OUH.

*“Was discharged and told to contact [my local hospital] if I had any issues – when I did contact them they hadn't received any of my notes nor had my GP. Then had to spend time co-ordinating with JR and GP and [local hospital].”* (Pathway 0 patient, online survey, JR, Apr-Jun 2023)

### **Difficulty accessing aftercare from GPs**

People told us about problems **contacting and making appointments with their GP practice** after they left hospital. Examples included for wound dressing, as well as transport issues getting to the GP.

*"I needed to change my bandage, called the doctor's surgery. The nurse was not available, when I needed the dressings changed. Called the hospital, they told me that they could not change my dressing. I then tried and tried my surgery, eventually, they accepted me, but the nurse was not dealing with me appropriately." (Patient, online survey, NOC, Jan-Mar 2024)*

*"Getting to see my GP is impossible and they are my medical link when at home." (Patient, online survey, JR, Jan-Mar 2024)*

*"I needed to use taxis for the first couple of weeks, to get to the GP and pharmacy. I can afford this but the cost could be difficult for less fortunate people." (Pathway 0 patient, online survey, JR, Jan-Mar 2024)*

### **Difficulty accessing aftercare from District Nurses**

We also heard about challenges getting aftercare – mostly with wound dressings – from the District Nursing teams (part of community care services provided by Oxford Health<sup>18</sup>). This highlighted some of the system communication pressures between secondary and primary care. Again, some people were given **contradictory information** about who could treat them and where.

*"Very hard to get a district nurse which I was told had been organised so called 111 to get the district nurse to attend." (D2A patient, online survey, Horton, since Apr 24)*

*"Initially a lady came to dress pressure sore, dressing was not large enough so left uncovered, she said as dad was mobile in wheelchair he needs to attend clinic at GP for further dressings, Dad explained they change his catheter at home as he can't use their trolleys. She insisted, two days later he attends and they are unable to treat him there and a DN referral is requested. He then has to wait till they're able to visit." (Unpaid carer of D2A patient, online survey, Horton, since Apr 24)*

*"Was told district nurse would come but didn't. 1st time was told 'you are mobile so come to the surgery'. I wasn't and had to borrow a wheel chair so daughter could bring me. 2nd time district nurse came 2 days after I was told to expect her. Needed dressing changed every day but my surgery couldn't fit me in for 12 days. Had to do it myself which was v difficult as I couldn't see what I was doing and the wound in my thighs was v big." (D2A patient, online survey, NOC, Jan-Mar 2024)*

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<sup>18</sup> <https://www.oxfordhealth.nhs.uk/wp-content/uploads/2020/03/OH-147.20-District-Nurse.pdf>

### **Lack of follow-up**

People told us about **a lack of follow-up** from health and care services – both in terms of appointments or calls they had been told to expect, and in terms of a courtesy check-in from health and care services for reassurance, particularly when no other follow-up or support had been arranged.

*“They said I would have follow up in 6 months and may be physio but I never heard anything at all ever.”* (Patient, online survey, JR, July–Sept 2023)

*“No contact was made from either the hospital or the GP. I was in shock from the surgery and could have done with some support even if by phone. I had lost a kidney but had no aftercare on diet and GP finally referred me to a dietician which has not yet taken place.”* (Patient, online survey, Churchill, Jan–Mar 2024)

*“Although discharging nurse very helpful, no support offered or received from hospital or GP once at home. Left feeling “exposed” if any problems.”* (Patient, online survey, JR, since April 2024)

### **Difficulty accessing support from charities and support groups**

People also told us about **gaps in terms of support from charities and support groups** – which may reflect a lack of information and signposting as well as limited capacity.

*“No after care or support other than being able to contact Macmillan if needed. That involved leaving a message and waiting for call back which didn’t always happen.”* (Pathway 0 patient, online survey, Churchill, Jan–Mar 2024)

*“Really needed a support group, or champion to help me to adjust to being disabled.”* (Pathway 0 patient, online survey, Churchill, Jul–Sept 2023)

### **Physiotherapy and equipment for Pathway 0 patients**

People who went home on Pathway 0 told us about **waiting days or weeks to receive physiotherapy, equipment and home adaptations**, or both.

*“I asked my GP to refer me to OT, but it took them almost two months to contact me.”* (Pathway 0 patient, online survey, JR, Jan–Mar 2024)

*“Community physio referral took seven weeks. I didn’t have any rails, or all appropriate equipment that I needed as a newly disabled person.”*  
(Pathway 0 patient, online survey, Churchill, Jul–Sept 2023)

In some cases, this led to **additional pressures on unpaid carers**, including children, to ensure that the person could safely move around their home.

*“The only help I had was my 10-year-old daughter. I had no equipment, no help and no care. I was non weight bearing with a broken leg. I was unable to get upstairs. Was discharged home with no commode or frame to help. My daughter had to get me a saucepan to use as a toilet. The hospital should have checked who I was living with and help with basic equipment such as a commode. I eventually referred myself to the community therapy team in Oxford Health, who after 5 days at home, came with a commode and a frame.”* (Pathway 0 patient, online survey, Horton, since Apr 2024)

*“My wife has MS and balance problems. They wouldn’t let her out [of hospital] until they knew what she had at home. I had two calls from the physios and she was grilled in hospital. I’m a practical person, so I put up rails and parallel bars and so on around the house. The community therapy service visited today and there’ll be a follow up visit with the manager in a week. Two and a half weeks had gone by and I said to my wife “we won’t hear anything now”, and then we had a call from them.”*  
(Comment from Carers Oxfordshire coffee morning, August 2024)

### **Not getting care and support at home**

We heard from at least nine patients who were discharged on Pathway 0 but **felt they would have benefited from additional care** and support at home.

*“I was fine about leaving hospital, but care once home was non-existent and I had to phone ambulance and two trips to A&E after which was horrendous after an operation to sit and wait for hours to be seen. Very little support and it was scary.”* (Pathway 0 patient, online survey, RBH, Apr–Jun 2023)

*“What I was promised as going to happen “when you get home” hardly happened. I was left with very limited eyesight, after picking up a hospital acquired infection. I am still unable to cook a meal, and haven’t been able to afford a carer come in – so haven’t had a hot meal for the past 10 months. As for help in getting mobility back – forget it.”* (Pathway 0 patient, online survey, JR, Jul–Sept 2023)

*"My husband was at home and has mobility issues. I was not offered any other care but friends and family kept in touch with me." (Pathway 0 patient, outreach survey, Horton, Oct-Dec 2023)*

*"I have very limited mobility and the hospital could have offered me help. They just don't care! When you are old it is really hard when no one cares for you." (Pathway 0 patient, outreach survey, Cherwell Hospital, Oct-Dec 2023)*

*"I am 74 years old and live alone. I could not even sit up in bed. My son was at the house overnight and helped me climb the stairs. I've not had any home care offered and physio was just once." (Signposting call about discharge from Cherwell Hospital, July 2024)*

*"The pre-op team said I could stay in for a few days after my hysterectomy because I had no help at home. The post-op surgical team sent me home the day after my operation even though they knew I had no help. Pre and post op should have a joined-up plan. Vulnerable patients should not be discharged." (Feedback received by Healthwatch Oxfordshire at Didcot Play Day on 22nd June 2024)*

*"There's such a difference between discharge for day surgery and staying in hospital as a trauma patient. After day surgery I had no help at all, and I mismanaged my medication and ended up back in hospital again. Recovering means you have to look after yourself but I couldn't look after myself because I was running round caring for people. Then I broke my hip and I got such amazing care afterwards, carers twice a day and physio at the end." (Comment from Carers Oxfordshire coffee morning, August 2024)*

*"I would not have recovered so well if I had not paid for care, if I had gone home and something had gone wrong I would not have been able to access help. I would also have gone hungry as I did not have the energy to care for myself." (Pathway 0 patient who paid for a private rehab bed, online survey, JR, Jan-Mar 2024)*

## **Care and support at home – D2A pathway**

Many of the people we heard from who went home under D2A, or are the unpaid carer of someone who did, were generally positive about the care and support they got within this pathway. However, there were several recurring areas for improvement, mostly around the timing of when they got care and support, and communication about it.

### **Delays in receiving care**

People told us about **delays in receiving care** after getting home. This included **differences between what they had been told to expect and what actually happened**.

*“Initially the carer only did an assessment and the caring started 36 hours later. I had been informed that the carer would have been at my home three hours after leaving hospital.”* (D2A patient, online survey, Horton, since Apr 2024)

*“None, relied on family to help. After a week care was offered but it was too late and family had a plan in place.”* (D2A patient, outreach survey, Horton, since Apr 2023)

One person also told us about a **gap between reablement care and long-term care** while a care plan was put in place.

*“Hospital staff were very keen to free up the bed. They did their best. Lack of resources at the end of the post-op care meant the gap in care was six-eight weeks. The burden fell on my husband. The delay in obtaining a care plan in place was extremely stressful.”* (D2A patient, outreach survey, Horton, Apr-Jun 2023)

### **Routine and timings**

One of the most common negative comments about care was around the **timing of visits from carers** from home care providers. Patients are usually allocated a **four-hour time window** for each visit. This can make care **unpredictable, disrupt people’s routines, is not always patient centred**, and can **increase pressure on unpaid carers**, including them taking on more of a caring role in order to maintain the person’s routine.

*“I was initially given home care twice a day, they were lovely, but they tried to put me to bed at 3pm. The second time I was discharged I opted to go without home care and accept friends and family support.”* (D2A patient, online survey, Churchill, Jul-Sept 2023)

*“They were v helpful but I never knew when they would arrive.”* (D2A patient, online survey, NOC, Jan-Mar 2024)

*“When carers did come you could not choose a time. So I had to get up at 10am and back in bed at 7pm.” (D2A patient, outreach survey, Horton, since Apr 2024)*

*“I was told by the agency my care was erratic because I was not paying for it, so carers came at very different times. Sometimes 7am and sometimes 11am to get me up. The same thing happened in the evening 5 pm to go to bed or maybe 10pm or any time in between. A more regular time frame would have been better.” (D2A patient, online survey, JR and NOC, Jan–Mar 2024)*

*“On a couple of days my morning carer arrived after 12:00 to help me get up, have a cup of tea and breakfast but the afternoon carer arrived at about 13:30 so I had all my meals in a very short period of time.” (D2A patient, online survey, JR, Oct–Dec 2023)*

*“It would be good if the carer could ring the person they’re coming to and let them know they’re on their way, so you’re not waiting around. That would be a sensible thing. Because not knowing when someone’s going to come through your door, it’s just...” (D2A patient, interview, JR, since Apr 2024)*

*“Timing of visits did not work well. [My mother] would have benefited from less visits if she had been given a smaller window of when to expect carers.” (Unpaid carer of Pathway 2 patient, online survey, JR, Oct–Dec 2023)*

### **Experience and quality of care**

We also heard comments about people’s experience of care. As well as the positive comments included in [What’s working well?](#) above, people told us that care visits were sometimes **rushed or too short** to help the person reach their reablement goals. They also told us about challenges around **carers’ lack of experience, cultural and language barriers**, and **perceived rudeness** or inappropriate behaviour.

*“The carers were lovely but rushed and some were inexperienced with British food which made getting my lunch and dinner a bit hit and miss depending on who it was.” (D2A patient, online survey, JR and NOC, Jan–Mar 2024)*



*“There wasn’t much conversation with the carers but they may have had limited English and were pushed for time.” (D2A patient, online survey, NOC, Jan–Mar 2024)*

*“My mother found it hard to understand some of the carers and thinks they probably felt the same of her.” (Unpaid carer of Pathway 2 and D2A patient, online survey, JR, Oct–Dec 2023)*

*“Nothing really worked well and I had been told they couldn’t cook for me without a microwave. Made me feel I had done something wrong because they couldn’t help me – stressful.” (D2A patient, outreach survey, JR and Churchill, Apr–Jun 2023)*

*“I’ve seen people coming out of hospital and there are these young people coming in to help them who have no experience and no manners.” (Comment from BAME elders’ group)*

*“We didn’t get any say about the care provider and I see that they have a CQC rating of ‘needs improvement’. We have had carers playing explicit songs and wearing outside coats while they are helping my mum, and not noticing that she has wee on her nightie.” (Signposting call, April 2024)*

*“I think the biggest difficulties I had with the care company was that I never really knew who was coming. I also never really knew exactly when they were coming. For a few of them, English was at best their second language, might even have been the third language. I didn’t have any problems with them personally, but the level of basic care was just that, basic, but the communication was a considerable problem. It was difficult to communicate quite a lot of the time and led to misunderstandings.” (D2A patient, interview, JR, Oct–Dec 2023)*

We heard from a health and social care professional about a patient who was **readmitted to hospital** because he did not seem to be getting the care he needed.

*“Poor quality [package of care], we had a [patient] who was readmitted after falling when trying to get out of the chair he had been sat in for several days after going home.” (Acute staff, online survey)*

We heard from someone who found **having carers in their home** difficult, and from an unpaid carer who noted the impact of a **lack of continuity of carers** on their own wellbeing as well as the person they look after.

*“Not easy – support in home where usually in charge.” (D2A patient, online survey, Churchill, Jul–Sept 2023)*

*“We had – I counted in my head – for a period of three weeks, 22 different carers. Every time somebody new came round, I got a knot in my stomach, because I had to show them how the microwave worked, and I’d have to show them where everything was and explain M’s situation. What would happen would be, some of them would be really good and they really engaged with M, but they were meeting him for the first, second or third time. The others were just disengaged.” (Unpaid carer of D2A patient, interview, JR, since Apr 2024)*

### **Care tailored to patient’s needs**

We heard about delays and challenges around getting **carers who could meet specific patients’ needs**, including having female carers to assist women with personal hygiene.

*“I could have left hospital earlier if a care provider who could do my neck brace was available.” (D2A patient, outreach survey, JR, since Apr 2024)*

*“My elderly mother would have appreciated female carers to help with her hygiene needs. She saw females on a very few visits so did not get the appropriate help and support she needed. Timing of visits did not work well. She would have benefited from less visits if she had been given a smaller window of when to expect carers.” (Unpaid carer of Pathway 2 and D2A patient, online survey, JR, Oct–Dec 2023)*

*“I, in exasperation, phoned [the care provider] and said, ‘Enough is enough, just out of ten days of care, six days have been with a lady and was satisfactory, three days were men who I had turned away and the last day was a no show.’ And quite honestly, I didn’t know where I was, and my wife certainly didn’t know where she was. So that was that, end of the care, we’re now on our own.” (Unpaid carer of D2A patient, RBH, interview, Jan–Mar 2024)*

We heard from an unpaid carer and a community care professional about concerns about whether some D2A care providers are able to offer **adequate support for people with dementia**.

*“I realised in retrospect that although [the night carer] was very experienced, she had absolutely no idea how to handle somebody with*

*dementia. I think the “care” was harmful. Now we’ve got [private] carers that we’ve selected that have experience of dementia or who are doing courses in it, M’s nights are very much better. They’re not problem-free, they’re still problematic, but he’s treated in a humane way.”* (Unpaid carer of D2A patient, interview, JR, since Apr 2024).

*“Patients being discharged from hospital without adequate care provision on the D2A pathway. Vulnerable patients that have dementia for example that need 24hr care and not safe to be living alone and sent home with [four times a day] care package. Very stressful for patients, family and also health care professionals. I am not a social worker and been out to patients that do not have a therapy needs, but it is social. Having to phone D2A social worker to sort care out for patients.”* (Community care professional, online survey)

We heard from some health and social care professionals and patients a concern that rehabilitation support at home is limited, and that carers do not always have the training, experience or time to support patients with reablement.

*“Care providers are quick to discharge people stating they are independent – when in fact they are not. They often decline care as the carers are very late for visits. Carers are meant to be reablement carers and more often than not, people are not given time for their exercises, nor do carers or care providers take the time to find out what exercises are prescribed if any.”* (Social care professional, online survey)

*“The carers used do not appear to be trained or confident in delivering a reablement model of care that is required. Therefore, patients do not have access to the rehab needed to improve their function.”* (Community care professional, online survey)

*“No help, the carers just sat and watched me struggle. The time before the pandemic the carers were great showed me how to help myself i.e. use the grab stick to put my pants on, things I still do. The last time I just felt they couldn’t sign me off quickly enough.”* (D2A patient, online survey, JR Apr–Jun 2023)

### **Lack of information about social care provision**

People told us that they were **not clear about what social care would be provided** when they or the person they look after got home. There was uncertainty about **time frames for assessments, if and when they would have to pay for care, and how long care would last.**

*"No pamphlets for social care on what is the process when getting home."  
(D2A patient, online survey, Horton, Oct-Dec 2023)*

*"A very simple thing that would have helped would have been just two sheets of A4 about what Home First is, what you can actually expect – because I expected an evaluation after three days of being at home. Because it's going to take a long time for the new government to get the health service turned around again. I think that sheet of paper has to be really realistic about: your social worker, your care worker that's going to look after you, might not be able to talk to you for two or three weeks. It has to be realistic – I kept thinking, I'm going to get a call from somebody soon." (Unpaid carer of D2A patient, interview, JR, since April 2024)*

*"Families are not given enough information about live in carers. What are families needing to provide – bed? bed linen? food? They only meet the live in carer who is going to live with their loved one on day of discharge."  
(Care home staff, online survey)*

This contributed to some people experiencing **the end of D2A care as abrupt and sometimes upsetting**, or **feeling anxious about having to pay for care**.

*"Abruptly care ceased so employed private care through sterling help of family who were not able to give practical help." (D2A patient, online survey, Churchill, Jan-Mar 2024)*

*"I was abruptly notified that my six weeks were nearly up and that was on a Friday which left us in a bit of a pickle. Basically, my six weeks were up in effect and my wife had to be shown very quickly what to do in order to help me out of the bed and into the bed etc... This meant it was left to my wife helping me morning and evening. We then had to get my own carer back on board to give me bed baths. It didn't really upset me but it very much upset my wife more because it was so, so abrupt." (D2A patient, interview, JR, Oct-Dec 2023)*

*"A carer came every day at 10.30 and then they just stopped coming. I've still got the forms. I was supposed to have night time care too, two visits a day, but that never happened. Suddenly there was nobody." (D2A patient, interview, JR, since Apr 2024)*

*"I think the worry about money on top of everything else was the thing that almost finished me. Because if we hadn't got Continuing Health Care*

*(CHC), I knew that I could only pay the carers for nine months, and then all our savings would have been gone, it would have got M's savings down to £23,000. After that, I was told, we would be eligible for social service care but they couldn't provide a night carer and they could only provide visits during the day, they couldn't provide live-in. I worried about that constantly, 'How are we going to do it? I don't want to sell the house to pay for this care.' Those financial issues are important."* (Unpaid carer of D2A patient, interview, JR, since Apr 2024)

We also heard from one person who was (seemingly incorrectly) told they were **not eligible for any care and support** at home.

*"I was in hospital over Christmas and New Year. Three days before I was discharged the nurse came round and said "sorry but you're not entitled to anything", because I'm not on pension credit. My son and my family helped me."* (comment from outreach with BAME elders group)

### **Physiotherapy, Occupational Therapy and equipment for D2A patients**

People told us about **delays in getting support** from physiotherapists and Occupational Therapists, and **confusion about who would provide support** with physiotherapy.

*"A home/bathroom/physio/O.T. assessment was promised within two days of discharge. This did not happen for two weeks. Adaptions needed to be made to enable my mother to access the shower."* (Unpaid carer of Pathway 2/D2A patient, JR and NOC, Oct-Dec 2023)

*"Mum needed an OT to help her with getting in and out of bed safely and this still hasn't happened. [...] Mum still isn't sleeping in her bed as she doesn't feel safe to do so, despite having leg ulcers which need to be elevated. Without a family member leaving work and sleeping on her floor for days she may well have fallen at home or been unable to take her medication, and this is still an ongoing risk."* (Unpaid carer of D2A patient, JR, since Apr 2024)

*"Was discharged and told I would have physiotherapy at home, as happened when I had same condition and discharged from another hospital, but this turned into being told carers would do this - they refused of course."* (Feedback Centre review of Abingdon Community Hospital, August 2024)

We heard about delays in people being provided with the equipment they needed, and in one case, a refusal to provide equipment the person requested.

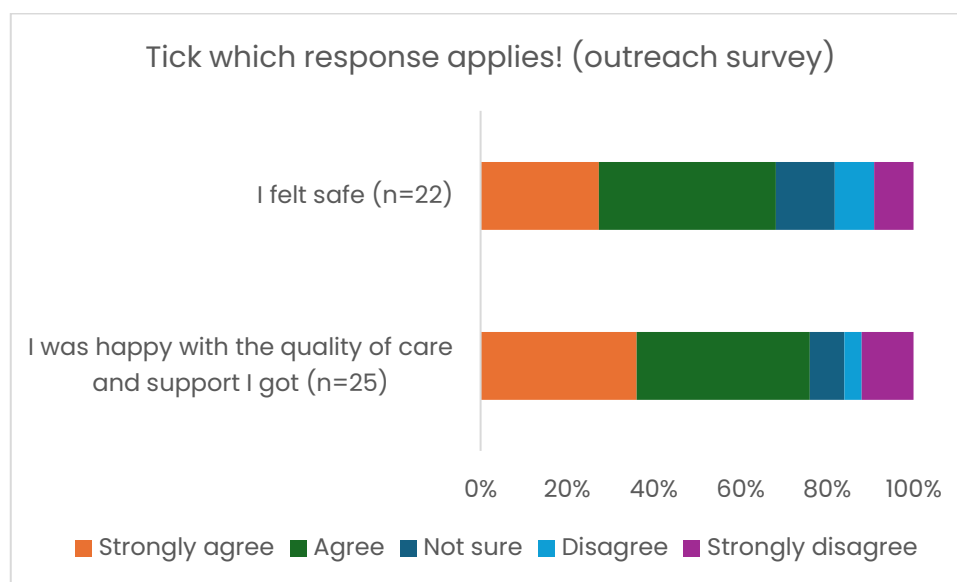
*"I was refused aids [such as a walker frame], so I had to buy my own from Amazon!"* (D2A patient, online survey, Horton, since Apr 2024)

We also heard from one person about extremely long waits to get a grant for longer term home adaptations.

*"We are constantly fighting to get help, firstly it was equipment so could access upstairs so could shower. We were told it would take 18 months to get a grant and I simply couldn't have my [partner] going without a shower for 18 months so a friend very kindly crowd-funded so we could get a lift and wet room."* (Signposting, April 2023)

### Mixed experiences

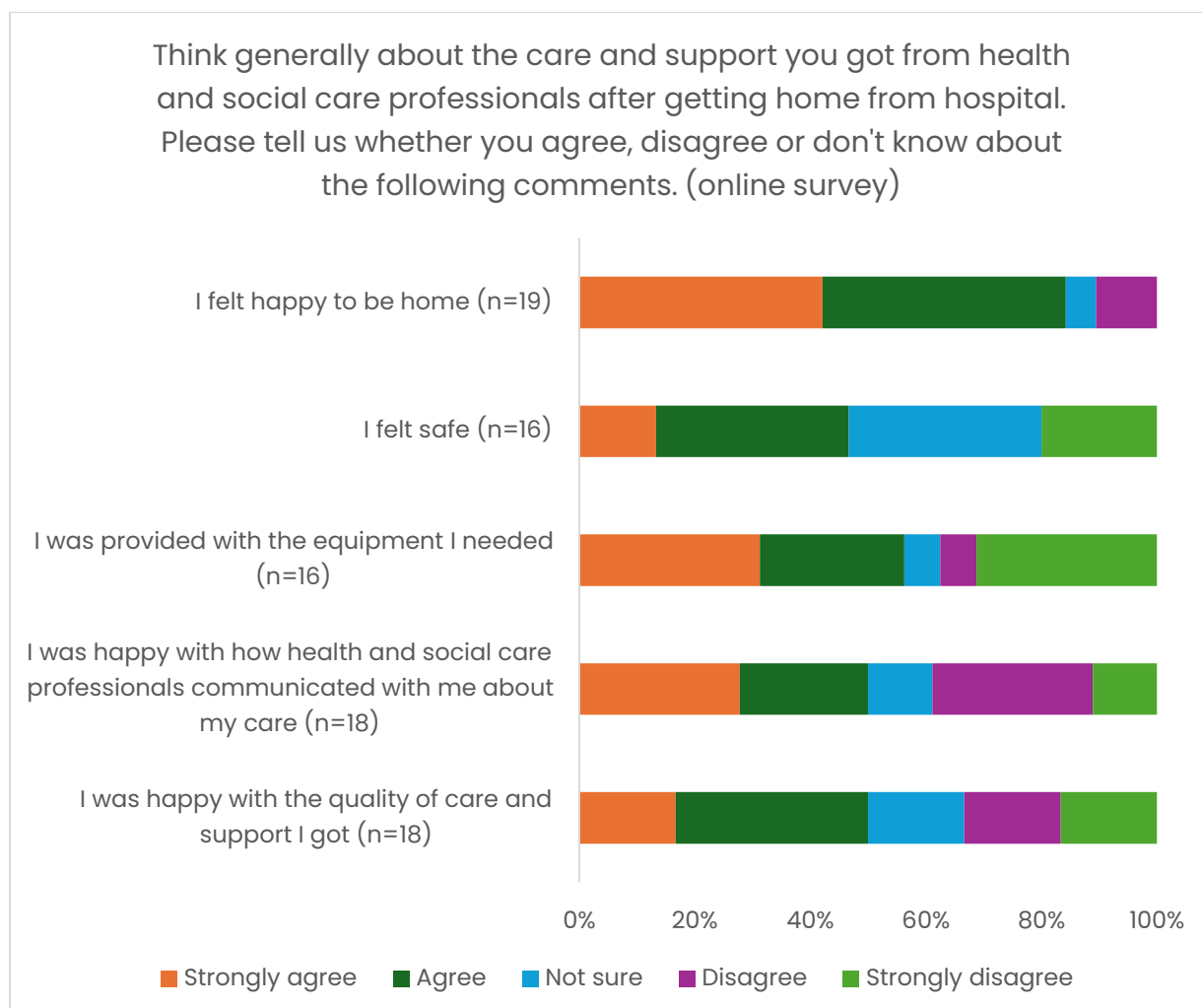
Of the people who got additional care and support at home, many gave positive responses to questions about the care and support they got. Responding to our outreach survey, 19 out of 25 people (76%) said they agreed or strongly agreed that they were happy with the quality of care and support they got, and 15 out of 22 people (68%) said they felt safe.



**Figure 8:** Graph showing responses to outreach survey questions about how people felt about the quality of care and support they got at home, and whether they felt safe.

Similarly, most people who responded to our online survey agreed or strongly agreed that they were happy to be home (16 out of 19, 84%). However, only half of

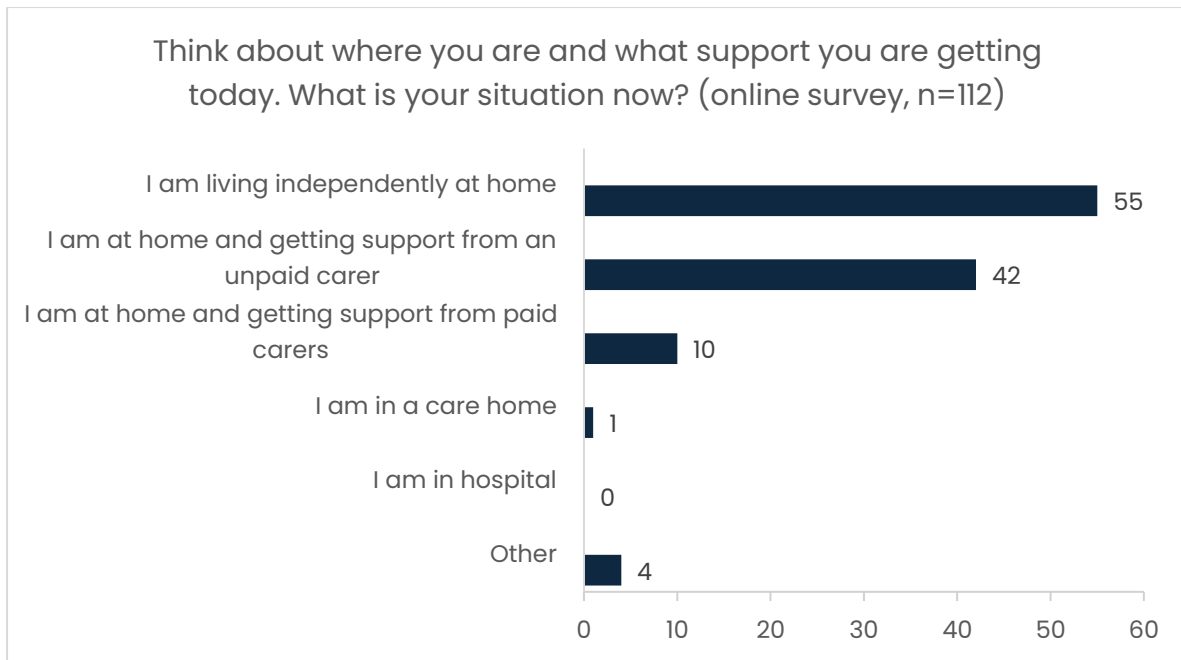
respondents said they were happy with the quality of care and support they got and how health and social care professionals communicated with them about their care. Less than half said they felt safe (7 out of 15 people, 47%).



**Figure 9:** Graph showing responses to online survey questions about how people felt about the care and support they got from health and social care professionals after getting home from hospital.

### Outcomes for patients following discharge

We asked people responding to our online survey about what their situation is now at the time of response. Most of them told us that they are now living independently at home (55, 49%) or with support from an unpaid carer (42, 38%). A small number are living at home and getting support from paid carers (10, 9%), have passed away or are now living in a family member's home.



**Figure 10:** Graph showing responses to online survey question about where patients are now and what support they are getting now.

Four people we heard from had had to go back to hospital soon after being discharged. We also heard from the unpaid carer of someone for whom home was not the right place for them long-term.

*“Mum is now in a care home permanently after a monumental battle to get her there and further falls at home.”* (Unpaid carer of D2A patient, online survey, Horton, Oct-Dec 2023)

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## Cross cutting themes

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Across all the responses from all sources, key cross cutting themes were clear:

- Communication
- Support for unpaid carers
- Health inequalities
- Continuity of care and joined-up working across the health and care system.



## Communication

A theme that weaves through people's experiences was communication. Where there was clear, consistent and accessible communication with patients and unpaid carers, and between services, people had a better experience. When there were problems with communication, people were more likely to have a negative experience and face gaps or challenges in getting the care and support they needed.

The main areas where there were communication issues were:

- Conversations around discharge planning
- Information about social care provision
- Information about follow-up care and aftercare – who, when and where
- Keeping patients and carers informed and up to date about what was happening
- Discharge letters and referrals into other services
- Accessibility and reasonable adjustments.

## Accessibility and reasonable adjustments

We heard concerning feedback from members of the d/Deaf and hard of hearing community about a lack of accessible communication and access to interpreters in their experiences of hospital discharge and home care.

*"I was in hospital for seven days I asked daily for an interpreter but there was no interpreter available. [...] I was discharged with medication but I had no instructions so I went to my GP two weeks later but there was no record of my hospital admission. My GP had to ring the hospital and I found out from my GP the reason I was so unwell."* (Comment from Action for Deafness coffee morning)

*"I was discharged from hospital, and I had some care professionals coming to help me to dispense my medication and had the key box fitted. They couldn't really sign only just a bit so communication was really difficult but the service was good."* (Comment from Action for Deafness coffee morning)

*"My worries are about home care - a lot of people who are home carers English is not their first language and it makes it difficult to communicate home carers should have some training in BSL when needed."* (Comment from Action for Deafness coffee morning)

*"You could improve discharge by making sure information is translated by an interpreter and use simpler language not jargon and lots of long words."*

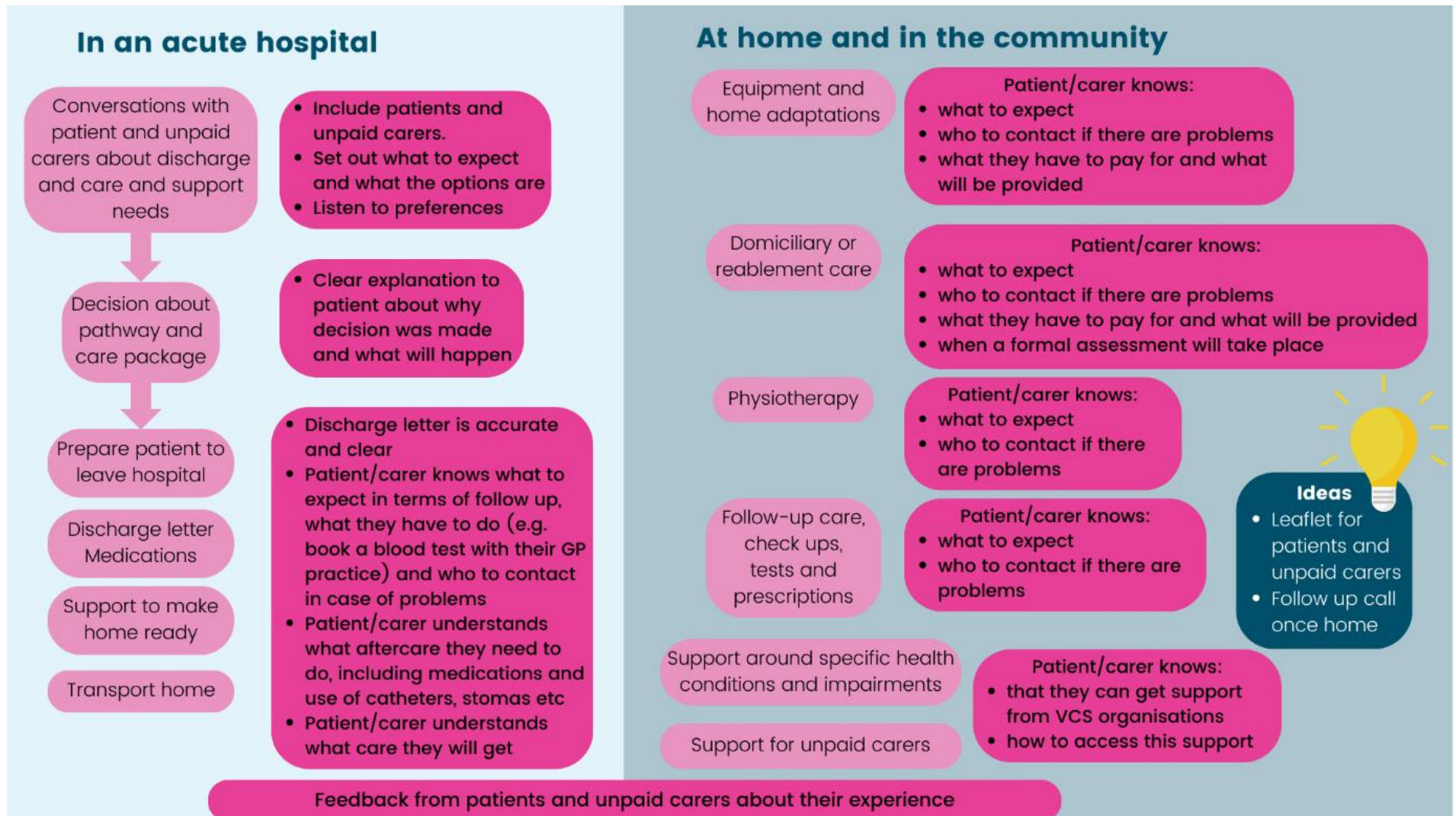
*Medication should be fully explained by an interpreter.* (Comment from Action for Deafness coffee morning)

### **Suggestions**

Ideas for improving communication around discharge included a leaving pack with signposting information, and a follow up call or visit after discharge.

*“Having a leaving pack from hospital with key agencies that can help you.”* (Patient, outreach survey, Horton, since Apr 2024)

[What would make a difference?] *“Even one good visit after you’ve been in hospital to talk through what to do and what to take, instead of coming out of hospital slightly woozy and trying to understand it all.”* (Comment at Carers Oxfordshire coffee morning, August 2024)



**Figure 11:** What would good communication look like at each stage of leaving hospital?

## **Unpaid carers**

Another recurring theme in what people told us was about gaps and challenges facing unpaid carers, who can play a crucial role in supporting someone through the process of leaving hospital and making a recovery. What we heard included:

- Unpaid carers are not always included or listened to in decision-making about care for the person they look after
- Some people felt decisions about their care placed an unfair burden on their unpaid carers – this included both people going home on Pathway 0 and with D2A
- Sometimes assumptions seemed to be made that a patient had someone who could provide unpaid care at home, which was not always the case
- Unpaid carers were not always offered support with their caring responsibilities
- Caring had a significant impact on unpaid carers' own health and wellbeing, and unpaid carers were not always offered support to look after themselves – although when they were, it made a real difference.



**Figure 12:** What are the challenges for unpaid carers supporting someone leaving hospital?

## **Involving unpaid carers in decision-making**

Although as noted in [What's working well?](#) above, people told us about examples of good practice in involving unpaid carers in decision-making, we also heard that it could be challenging for unpaid carers to take part in decision-making about care for the person they help look after.

*"Family members were not listened to or included unless they took time off work to be physically present at appointments. This was made difficult as the times of appointments were not communicated."* (Unpaid carer of D2A patient, online survey, JR, since Apr 2024)

When unpaid carers were able to share their preferences, these were not always listened to.

*"We expressed concerns about my mum falling and having difficulties taking her medicines and taking care of herself. These were totally ignored and only the paramedics engaged with us, telling me to call 999 if there were any problems."* (Unpaid carer of D2A patient, online survey, JR, since Apr 2024)

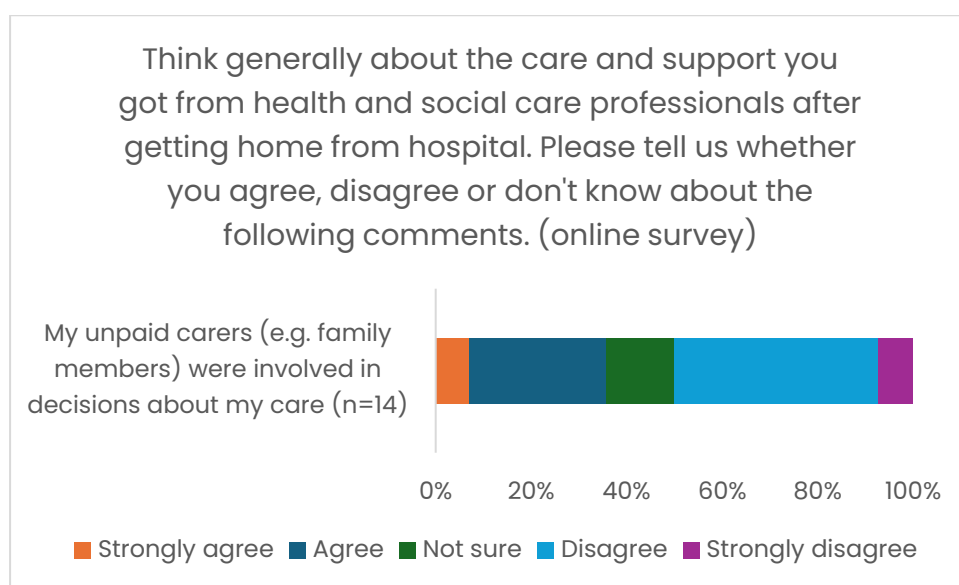
*"They kept us updated and messaged us to say she's doing well, she's progressing, but she can't go upstairs so she will need to have carers and we've got to put bed in. Okay, it sounded promising so I asked when they would be sending her home. They told us it would probably be next week sometime - we pointed out to them that I [and my brother-in-law] were due into hospital [that week], so we said whatever you do, leave it. We actually ended up with a phone call on the Wednesday, just before the Thursday morning that I'm going into hospital saying we're discharging her today. Can you have someone there?!"* (Unpaid carer of D2A patient, interview, since April 2024)

We also heard that involving unpaid carers in decision-making can be a difficult balance – patients did not always want their relatives to be consulted or agree with unpaid carers.

*"I told staff that I would be ok on leaving hospital if a care worker would visit soon after I got home. Instead someone phoned my son telling him I would be home alone and needing care. I DID NOT NEED CARE as the care worker was visiting. My son was greatly inconvenienced by being called to care for me. That was totally unnecessary."* (D2A patient, online survey, JR, Jul-Sept 2023)

*“We need to educate the public and families regarding capacity and what that legally is. Also we need to educate the wider public re. unwise decisions and that they cannot stop these if their relative has capacity.”*  
(Acute care professional, online survey)

People who responded to our online survey suggested that while some unpaid carers are involved in decisions about the care of the person they look after, this was not always the case. Half of respondents (7 out of 14) said they disagreed or strongly disagreed that unpaid carers were involved in decisions about their care.



**Figure 13:** Graph showing responses to online survey question about whether or not unpaid carers were involved in decisions about people’s care in the time after they got home from hospital.

### Expectations of unpaid carers

We heard from some people that they felt that decisions about care and support leaving hospital put the **burden onto their unpaid carers**.

*“I had a major op and couldn’t walk far but it was left to my husband to get me downstairs and across the car park.”* (Pathway 0 patient, online survey, Churchill, Jan-Mar 2024)

*“My daughter had to care for me which was very stressful for her.”*  
(Pathway 0 patient, online survey, JR, Jul-Sept 2023)

This was the case in several instances **even where there was a package of care** in place, with **unpaid carers filling in the gaps around short carer visits**.

*"In [four weeks of care] I was never showered as their Risk Officer deemed it too unsafe for them to help me out of the shower but the officer did tell my wife - 76 years old - that she could help me out of the shower!" (D2A patient, online survey, OSRU, Apr-Jun 2023)*

*"I can't see how within half an hour you can get someone who is elderly washed and dressed. I was getting my mother dressed." (Unpaid carer of D2A patient, online survey, since Apr 2024)*

*"87 year old husband was providing personal care 24/7." (Unpaid carer of D2A patient, online survey, Horton, Oct-Dec 2023)*

*"Without my neighbours I would have been struggling to cope." (D2A patient, online survey, Horton, since Apr 2024)*

*"I was given 24 hours notice that my husband would be bought home by ambulance. During his eight week stay in hospital I had to make sure the downstairs room was turned into his bedroom as he would not be able to get upstairs. [...] No-one actually checked either verbally or in person that the home was suitable for him to return to. My husband, having had a stroke, was now a very different person to the one I had been with. He had great difficulty with mobility, undertaking everyday tasks and even remembering things. Suddenly I was expected to look after and care for him and I felt that I had been thrown in to a very deep end and left to sink or swim. So it was not just me I had to sort out but also to ensure my husband was properly looked after too." (Unpaid carer of D2A patient, online survey, OSRU, Apr-Jun 2023).*

### **Assumptions about unpaid care at home**

People also told us about assumptions made by health and social care professionals about the support that they had at home.

*"It was assumed I had someone at home to look after me... which I didn't." (Patient, online survey, JR, Jan-Mar 2024 – this patient paid for a private post operative care bed)*

*"They knew that I had no one to support me, but it seemed that there were no communication between departments. So, at first, they placed me in a day case ward. Then I insisted that I did not have support at home. I forced myself in hospital stay for a few days. It felt as though, I was just making excuses to stay for no good reason. Eventually, as soon as I was given equipment to become a little more mobile, I have decided that in the*



*interest of the facilities being available for other patients, I would leave. So, my stay after the operation was not longer than four days. So, my relations had to come to Oxford to take me to London (with no facilities to attend health professionals) to care for me. There were no community care homes in Oxford. I have tried to find a reasonable care home, but they were extortionate in price. I could not afford it with just a state pension. I would have preferred to stay on in Oxford.” (Pathway 0 patient, online survey, NOC, Jan–Mar 2024)*

### **Supporting unpaid carers with their caring responsibilities**

We heard that unpaid carers would have liked more support, training or guidance from health and care services in what they should be doing to help.

*[What could be better?] “Some basic help sessions for me before he came home on how to help him in and out of the car, bed, etc. How to help him with his exercises. Also, a list of contact, phone numbers of where to go for help/assistance. I had no idea what was out there that I could call on for guidance/assistance.” (Unpaid carer of D2A patient, online survey, OSRU Abingdon, Apr–Jun 2023)*

*“I felt extremely alone and frightened. I felt abandoned and my husband wasn’t sure what he should be doing to help.” (Pathway 0 patient, online survey, Churchill, Jan–Mar 2024)*

### **Impact on carers’ wellbeing**

We heard about the significant impact that being an unpaid carer could have on people’s mental and physical health and wellbeing.

*“Now I have a lot of friends. [But] even I have low moments where you feel a bit overwhelmed. And it’s an unbelievable feeling that who do you actually go to? Who do you turn to? I mean everybody, I’ll say will do the shopping for you or fetch this. But it’s the emotional support that you need.” (Unpaid carer, interview, RBH, Jan–Mar 2024)*

*“Increased the load and diminished my life. I am depressed but have no alternative to carrying on.” (Unpaid carer, online survey, Horton, since Apr 2024)*

*“I am now caring for a disabled person who has great mobility issues and could easily become housebound soon as I will be unable to get him out of the house to get him into the car/wheelchair. As for my health, I’m absolutely exhausted and permanently shattered. I try to have some time*

*for me each day but this very often gets squeezed out as other issues need dealing with first.” (Unpaid carer of D2A patient, online survey, OSRU, Apr–Jun 2023)*

### **Supporting unpaid carers with their own wellbeing.**

Of the 23 unpaid carers who responded to our full survey, 12 told us they had not been offered any support. Several of those who had been offered help mentioned Carers Oxfordshire. Other barriers to getting support included not being able to attend support sessions due to work. However, we heard that when people did get support from Carers Oxfordshire and other organisations, they found it extremely helpful.

*“None until I became aware of Carers Oxfordshire last year and are now on their lists and do know that there is somewhere I can go for advice/help.” (Unpaid carer of D2A patient, online survey, OSRU, Apr–Jun 2023)*

*“Age Concern [Age UK Oxfordshire] always responded to me immediately, they were so helpful. A person from Age Concern came to see me on the ward a couple of times and helped as much as she could, and tried to get a social worker to talk to me and things like that.” (Unpaid carer of D2A patient, interview, JR, since Apr 2024)*

*“Once you get on the first rung of the ladder and get known a bit, things start to open up. I found [carer] through South Oxfordshire Carers, she told me about the blue badge, personal allowance, Carers Oxfordshire.” (Comment from Carers Oxfordshire coffee morning, August 2024)*

*“I sent the [Carers Oxfordshire] questionnaire in [and] I got an almost immediate response, regular phone calls, and then a lovely interview with lots of ideas about reduction of council tax, lots of resources, cheaper holidays. And then I got a gift from the council, this beautiful box of toiletries to use in the bathroom to relax. I suddenly felt that there was somebody that I could contact. I don’t anymore, but it was just feeling that there was somebody there for you, and understanding the importance of respite. I’ve just had four nights away for the first time. That support from the council – it must be difficult for them, because I know they’re cash strapped, but it’s really important that there’s somebody there for you. Because actually very few care workers, when I took M to see them, would say, “And how are you?” There was only one other person who did that, and that was the physiotherapist who first helped me. But the council were saying ‘How are you?’ and ‘We recognise how difficult it is, and also what*

*you're doing is really important.”* (Unpaid carer of D2A patient, interview, JR, since Apr 2024).

## **Health inequalities**

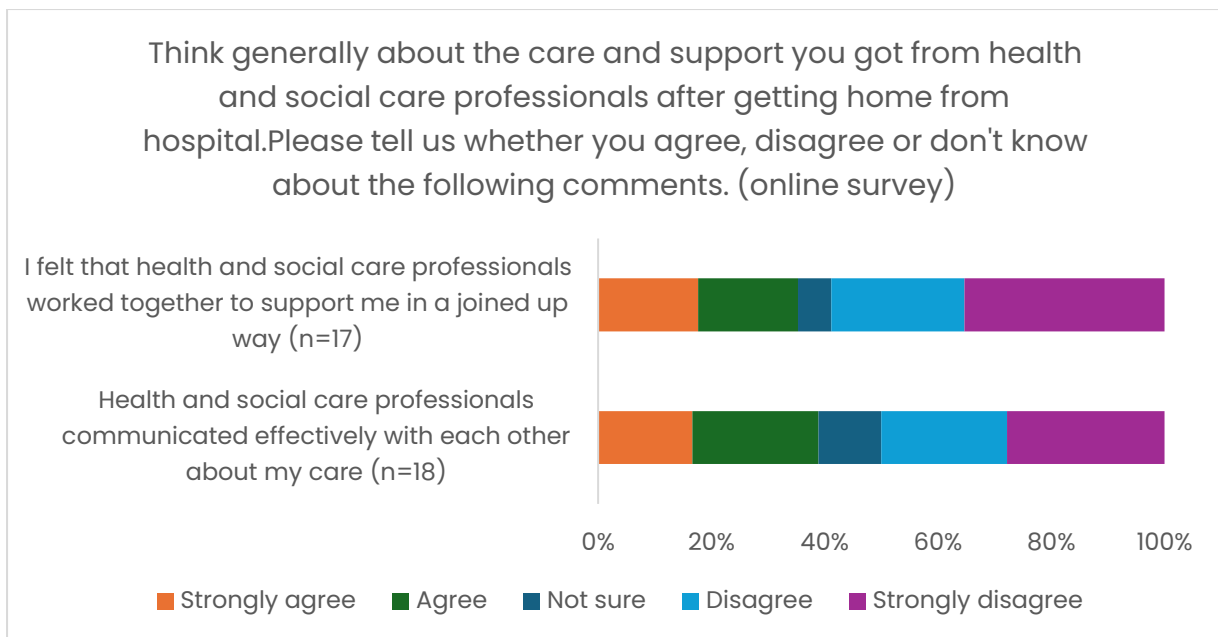
There were no clear differences in people's experiences between different hospitals or when they were discharged. However, we did hear how **health inequalities could be exacerbated** by issues around **accessible communication** and the **cost of transport** (for example to attend follow-up appointments). We also heard several instances where people **felt they had to pay for care** – a rehab bed, physiotherapy, or carers – to get the level of support they needed.

## **Joined-up working**

Effective collaboration between different departments and services is fundamental to providing a good patient experience of a process like leaving hospital, which involves multiple organisations. We heard from patients who received additional care and support at home after leaving hospital that, from their perspective, joined-up working and communication was not always happening.

*“Communication was terrible and appeared to be no interdepartmental cooperation – dreadful!”* (D2A patient, online survey, Horton, since Apr 2024)

Half of online survey respondents who received care at home said they disagreed or strongly disagreed that health and social care professionals communicated effectively with each other about their care, and more than half (10 out of 17, 59%) disagreed or strongly disagreed with the statement 'I felt that health and social care professionals worked together to support me in a joined up way.'



**Figure 14:** Graph showing responses to online survey question about patient and carers’ perceptions of how well health and social care professionals communicated and worked together to support the patient in a joined up way.

**Health and social care professionals’ views on joined up working**

In our survey for health and social care professionals, we heard from 87 people about what is enabling joined-up working and what makes it challenging, as well as suggestions for how things could be improved.

**What is working well?**

Health and social care professionals told us that multidisciplinary teams and the Transfer of Care Hub are working well, and expressed appreciation for colleagues doing good work across the system.

*“Think that MDTs within OUH are effective and that TOC has sped things up. Lots of excellent staff.”* (Acute care professional, online survey)

*“The TOC process is generally working well and has reduced some inappropriate referrals to community hospitals.”* (Community care professional, online survey)

Healthwatch Oxfordshire attended two Transfer of Care ‘huddle’ meetings as an observer, and saw in action the positive communication and teamwork that is possible when different services are able to come together. These vital meetings enable the different services to share insights and work together to best develop joined-up support around an individual’s care.

Staff also praised the Trusted Assessor scheme (a collaboration between the Oxfordshire Association of Care Providers, OUH and OCC<sup>19</sup>), and the 'out of hospital' support provided by Age UK Oxfordshire.

*"Age UK support on the ward has been critical for patients who do not have family/friends support for discharge planning."* (Community care professional, online survey)

People told us they valued being able to have verbal handovers with colleagues about a patient's care, especially for complex cases. A GP told us they appreciated being emailed a discharge summary, reducing the potential for delays.

*"Recently I received a phone call from a junior doctor on a hospital team about a specific patient's discharge which was very helpful, but a one-off."* (Primary care professional, online survey)

### **Barriers and challenges**

Things that people told us got in the way of joined-up working and providing a good discharge experience for patients included difficulty contacting and liaising with other services, which people attributed to staff pressures, high staff turnover or rotation, and a lack of understanding about when different services operate.

*"It can be hard to get hold of care providers, social workers, GPs etc."* (Acute care professional, online survey)

*"It is often challenging to get in touch with the wards for further clarification on things."* (Community care professional, online survey)

Linked to this were barriers to sharing notes between services and the fragmentation of patient records between multiple data systems.

*"Lacking a shared notes system does not help. We are having to waste time sharing lots of basic information with the social workers and community teams because they are not able to access the hospital notes."* (Acute care professional, online survey)

*"Huge barriers, we use different systems so have no access to hospital records. Communication is hugely challenging as we are often not copied*

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<sup>19</sup> <https://www.oacp.org.uk/trusted-assessors-in-oxfordshire>

*in to planned procedures or post discharge recommendations and follow up.” (Community care professional, online survey)*

We heard that social workers and care providers are not always given key information about a person’s mobility, home situation or healthcare needs – which may be linked to this fragmentation or be due to care providers not being involved in discharge planning.

*“People are often not sent home with the right equipment. We get told people are fit and mobile and find this is not the case. They rarely know the home set up and are often surprised when told the situation. It needs proper assessments or conversations with care providers before discharge is planned.” (Home care professional, online survey)*

We also heard from home care providers and extra care housing providers who would like to be kept informed about when people they care for come home – there is currently no system for this. This can mean that residents in these settings are not as supported as well as they could be had the housing support been informed.

Health and social care professionals told us about a lack of clarity among staff and patients about the D2A process, and gaps in understanding of the support in place.

*“Unsure what to advise patients as to when they will be assessed at home. Previously told 72 hours but feedback is this isn’t happening. It would be helpful to be able to provide patients with a leaflet or documentation about D2A and contact details in case of issues.” (Community care professional, online survey)*

There can also be a lack of understanding about how other services work and what services are available, particularly in new or developing areas such as the D2A therapy service – in some cases leading to duplication of referrals into D2A and community services.

*“We don’t know what services are available or who the relevant people/teams are to talk to.” (Acute care professional, online survey)*

*“Promises made to patients on our behalf which we cannot meet. Lack of preparation for discharge i.e. teaching patient or families to give injections or medication.” (Community care professional, online survey)*

*“Patients seem to get passed around, communication between teams could be better. For example, D2A referral is made. The patient is needing therapy input but there is no space on the form for this so we have to send a separate referral. Community Therapy Services (CTS) won't take a referral for a patient if they are on the D2A pathway but often seem to see them anyway as they get passed across. This feels very bitty. I think either D2A need a better resourced therapy team that can promptly follow up and be part of the assessment process or it should be scrapped and CTS be involved as needed from discharge.”* (Community care professional, online survey)

We heard that people are frustrated by delays in other services picking up referrals.

*“Community services to respond to referrals in a timely manner to minimise risk of failed discharges.”* (Acute care professional, online survey)

We also heard that there are problems with the quality and timing of referrals to community services, particularly around District Nursing.

*“Poor referrals to District Nurses. Minimal information shared. This delays us seeing the patient.”* (Community care professional, online survey)

*“We get poor referrals and the majority of DTAs [Decision to Administer forms] for medications from the hospital are incorrect. It is then very difficult to contact the ward to get a doctor to amend it so it is useable. This is especially difficult as hospitals often discharge patients before we have accepted their referral so patients are sent home without us being able to do their care.”* (Community care professional, online survey)

*“There is a huge gap between ALL hospitals and the district nursing service. The DN's are receiving referrals when the patient has already left hospital for same day/next day appointments. It's impossible to allocate all patients these appointments, meaning patients are often calling distressed/emergency appointments (aka syringe drivers/urgent medications) are then needing to be outsourced to Hospital at Home or similar - which wastes resource. Hospitals need to be requesting visits ahead of discharge.”* (Community care professional, online survey)

People also told us about problems with quality of discharge letters (although we also heard from one primary care professional that this has recently improved) and delays in discharge letters reaching GPs.

*“Discharge letters are not clear enough, especially if the patient is being discharged from a Same Day Emergency Care unit, it can be very difficult and time consuming trying to work out in what order and what date the info relates to. Not enough information for the GP regarding next steps.”*  
(Primary care professional, online survey)

*“Poor/late/missing discharge summaries (often never receive one) and no contact when there's important/urgent info to pass on.”* (Primary care professional, online survey)

*“Relevant information is usually buried in a multiple page document, often towards the end. This makes it longer to process them, and increases risk of information being missed. [Priority information is] scattered across 3-10 pages, often buried in text formatted in a way that makes it hard to read (multiple short lines, apparently random formatting and spacing).”*  
(Primary care professional, online survey)

The bigger picture is one of significant pressures on the system. People told us that low staff morale and lack of consultation when implementing changes was affecting capacity for joined-up working. We also heard that there is sometimes a lack of trust and goodwill between services – linked to a lack of capacity and sense that work and responsibility is being ‘dumped’ on one service by another. This may be contributing to the lack of clarity for patients over who will provide follow-up care and aftercare.

*“Workload dumping on primary care – i.e. secondary care asking primary care to complete the episode by chasing results, prescribing medicines urgently, making onward referrals. Urgent meds requests that should be provided by secondary care.”* (Primary care professional, online survey)

### **Suggested improvements**

Ideas that health and social care professionals shared for improving joined-up working and the discharge process included:

- Clear, up-to-date information about the D2A process – both for staff across the system and to share with patients and families
- Amend the D2A referral form to include therapy needs
- Opportunities for handovers between teams, e.g. therapy handover between community hospital and community therapy services or D2A team



- Ensure medication changes are clearly documented and communicated to patients and unpaid carers, and continue to fund and signpost to the Medicines Information helpline for queries
- Using flag or alert systems to ensure community and acute teams liaise to support discharge of patients with specific medication and equipment needs (e.g. home oxygen, insulin, catheters)
- Continue to improve the relationship between community care services and social services – for example to make homes safe for people who are already known to social services
- A framework for primary care professionals to escalate discharge discrepancies
- Ensure all relevant staff are able to feed into discharge decisions – including those spending time with patients on the ward, and where appropriate, specialist services such as the Tobacco Dependency service
- Addressing staffing and capacity pressures.

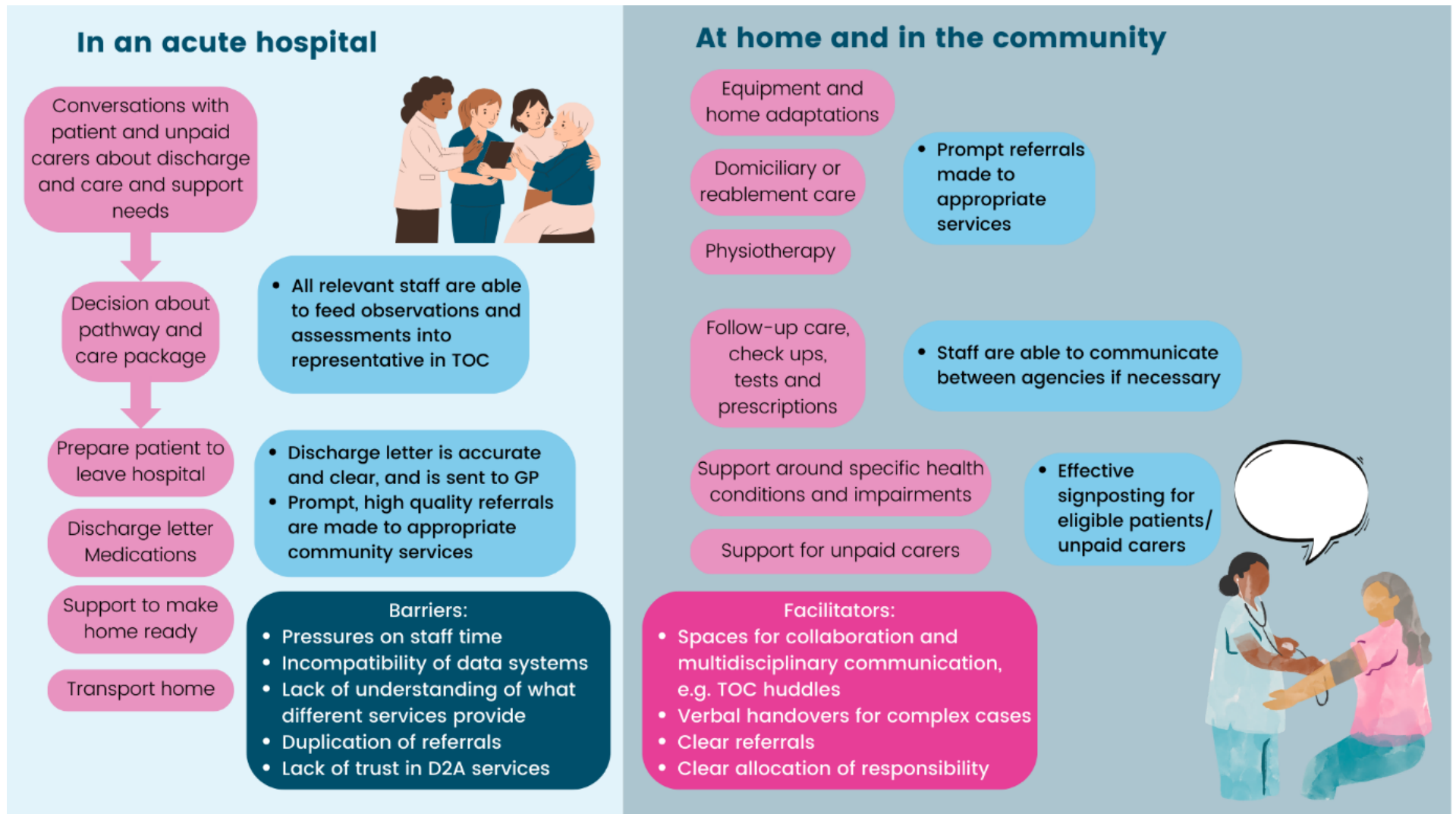


Figure 15: What would good joined-up working look like? What are the barriers and facilitators to joined-up working?

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# Acknowledgements

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Many thanks to everyone who shared their experiences and supported us with this project.

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## Useful links

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- [Carers Oxfordshire website](#)
  - [Age UK Oxfordshire website](#)
  - [Be Free Young Carers](#)
  - [Accessible Information Standard](#)
  - [National guidance](#) on hospital discharge and community support guidance
  - [LiveWell Oxfordshire](#) – directory of groups and organisations
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## Appendix 1 – Previous research

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### **Leaving hospitals with medicine, January 2023**

In 2022 we were asked to help OUH gain insight into patient experience of its Patient Medicines Helpline. The Helpline provides support – via email and phone – from a pharmacist to patients leaving hospital with medicines.

We heard from 113 people about this. Nine people kindly came forward to share their stories in depth, illustrating the journeys people took. Some of these stories are included at the end of the main report and on our website [here](#).

A key finding was that few respondents had heard of the Helpline. We also identified other themes around clear and timely communication about medicines and discharge waiting times. Based on what we heard, we made a series of recommendations to OUH, including to:

- Review communication and promotion of the Helpline

- Seek patient input into the written communication and instructions for patients about medicines taken home
- Review and improve discharge process within hospital
- Review and ensure patients have clear communication about follow up prescriptions and where to turn once left hospital

Read the full report [on our website](#).

### **How people experienced joined-up care in Oxfordshire, October 2023**

In May 2023 we conducted a survey to ask about local people's ideas and experiences of 'joined up' care.

A central theme of the NHS Long Term Plan is to develop joined up care between health and social care services. This will help patients get timely, appropriate, and holistic care based on their needs, and avoid being passed to multiple services, or having to repeat their story several times. The 2022 Health and Care Act aims to make this easier in England through the creation of Integrated Care Systems (ICSs).

This report summarises the responses of 38 completed questionnaires and follow-up interviews with five people. It captures the range of views and experiences we heard about, including people's perceptions of what joined up care looks like as well as their experiences of it.

We will share this report with health and social care providers, the Oxfordshire Health and Wellbeing Board and Oxfordshire Place Based Partnership. We hope it helps to complement and support more integrated ways of working in Oxfordshire between health, social care, and others, including voluntary sector partners, which have been emerging in the past few years. Read the report [on our website](#).

### **Healthwatch England report: leaving hospital, November 2023**

A Healthwatch England study, published in November 2023, heard that while some patients said they had an excellent hospital discharge, others had negative experiences including not being asked about whether they had transport, not being given contact information, feeling unprepared and waiting over 12 hours from being told they were ready to leave to being discharged. Read a blog about the findings on the [Healthwatch England website](#).

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