



Patient Experience

When Care is Transferred

An
independent voice
for the
people of Wiltshire

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When care is transferred

Nationally, discharge from hospital is a frequent topic in the news, with concerns about people being discharged from hospital too soon, discharged without their individual needs and those of their unpaid carers being taken into account and delays when appropriate care in non -acute settings is unavailable. Local communities have concerns about discharges, and local Healthwatch organisations have examined what is happening in their areas¹.



The NHS England adult inpatient survey for 2015 identified fewer people reporting delays in being discharged compared to 2014, but that communication about possible medication side effects and signs of deterioration following discharge are areas where patient experience has deteriorated².

In 2015, Healthwatch England³ found that across the country there are five core reasons people feel their discharge did not work well for them:

1. People are experiencing delays and a lack of co-ordination between different services;
2. People are feeling left without the services and support they need after discharge;
3. People feel stigmatised and discriminated against and that they are not treated with appropriate respect because of their conditions and circumstances;
4. People feel they are not involved in decisions about their care or given the information they need;
5. People feel that their full range of needs is not considered.

¹ For example, Healthwatch Oxfordshire (2015) Improving discharges from hospital in Oxfordshire

² 2015 Adult Inpatient Survey Update, NHS England, July 2016

³ Safely home: What happens when people leave hospital and care settings? Healthwatch England Special Inquiry, July 2015

In Wiltshire, and across the country, there is an increasing emphasis on keeping people out of acute hospital if they can safely be cared for in a different setting, such as at home, a community hospital or in a nursing home. If people do need care in an acute hospital, this needs to be for as short a stay as possible, with follow up care then being provided closer to home. In Wiltshire, services to support this are being coordinated under the Wiltshire Better Care Plan⁴. The responsibility for a patient's care may be transferred backwards and forwards between different health care settings, including home, community and acute hospitals and nursing or residential homes, or other services as appropriate for the patient.

From local and national evidence, it is often at the point of discharge or when care is being transferred between services when people experience difficulties. Different health and social care services may have different systems, but need to work closely together to provide good, safe care for the patient as they move between them⁵. Patient experience of discharge is arguably a key metric for integration. Safe and timely discharge depends on various parts of the health and care system coordinating together - for example, medicines, equipment, transport and availability of suitable social care⁶.

We know that patients, unpaid carers and organisations involved in providing care in Wiltshire find discharge processes not to work as smoothly as they should. Healthwatch Wiltshire were asked to talk to local people to discover more about their experiences of discharge processes for themselves or the person that they care for.



⁴ More information about Wiltshire's Better Care Plan can be found at <https://www.yourcareyoursupportwiltshire.org.uk/health-and-social-care/better-care-plan.aspx>

⁵ Building bridges, breaking barriers: How care is integrated across health and social care and the impact on older people who use services, and their families and carers. Care Quality Commission, July 2016

⁶ NICE guidance on transition between inpatient hospital settings and community or care home settings for adults with social care needs <https://www.nice.org.uk/guidance/ng27>

What we did and who we spoke to

We heard from people whose care had been transferred between different services or settings, and from their unpaid carers.

We offered a range of ways of participating, through face to face or telephone interviews, paper or online questionnaires and discussions at community groups.



The participants who completed questionnaires or the online survey were self-selecting, which means they chose to take part. This may have been because they had a particularly good or bad experience that they wanted to share. As a result, the findings may not be representative of all Wiltshire peoples' experiences.

We tried to control for this by also going to talk to people at the point of service delivery, rather than relying only on people who chose to make contact with us. We visited the community hospital wards across the county, and care homes where intermediate care (rehabilitation) is provided. Based on our previous engagement experience, patients in acute hospitals are often too unwell to interview, so we didn't visit acute wards. We aimed to capture these patients' experiences through the wider questionnaire.

The line of questioning drew from other surveys of hospital discharge and the Wiltshire Council's research team, and used a mixture of quantitative (multiple choice answers) and qualitative (opportunity to give details) approaches. While we aimed to recruit as many participants as possible to gather a range of views, we recognise that there is value in each person's individual experiences. In line with our approach to investigating patient and carer experiences, we do not consider this to be research, more service evaluation⁷.

Up to the start of August 2016, 65 people completed questionnaires and 41 were interviewed in community hospitals or intermediate care locations, to make a total of 106 respondents. We also drew from the experiences of people who had contacted us about their discharge over the last year. The majority of the people we spoke to were people over the age of 65 (72% of those who took part).

We also spoke to professionals involved in the care and transfer of care of patients, including ward managers, therapists providing intermediate care, care home managers and staff from domiciliary care agencies. Through the Wiltshire Care Partnership, we heard from the managers of nursing and residential homes, who also shared their experiences and concerns.

⁷ More information on our approach to data collection and service evaluation can be found at <http://www.healthwatchwiltshire.co.uk/project/rationale-and-explanation-of-methods-used/>

What people told us

Planning for discharge

When we spoke to people in community hospitals and care homes, we asked about their experiences of discharge planning. We did not speak to people at the point of care in acute hospitals.

Feedback from people while they were receiving care

	Community Hospitals (18 people)	Intermediate care Locations (23 people)
felt that staff listened to them (yes or sometimes)	94%	100%
people 'very likely' or 'likely' to recommend their care	100%	81%
said someone had talked to them about arrangements for being discharged	56%	77%
knew where they were going when they were discharged	50%	66%
said they had been given an estimated date of discharge	40%	40%
had had the opportunity to ask questions about their discharge	69%	63%
had been told about other services or support organisations	60%	54%
were 'very satisfied' or 'satisfied' with the planning for their discharge	100%	77%

Once people have been discharged, from any sort of care -

- 71% of people we spoke to said they were very satisfied or satisfied with their discharge, while 20% were dissatisfied or very dissatisfied.
- 80% of people we spoke to said they were very satisfied or satisfied with their care from all the different services involved in their care, 15% were dissatisfied or very dissatisfied.
- 77% of people we spoke to said they felt ready to be discharged when they left care (16% not sure, 6% did not feel ready).
- 66% of people said they were 'definitely' or 'to some extent' involved in decisions about their discharge, (24% 'not really' and 10% 'not at all') with 48% of people reported being involved in deciding what care or support to have at home.

- 71% of people said that their family were ‘definitely’ or ‘to some extent’ involved as much as the patient wanted them to be in decisions about their care
- 63% of people reported having enough information about their diagnosis when they were discharged, and 67% said they knew enough about their medication.
- After discharge, if people needed support, there were problems arranging care at home (24% of people who needed it), medication (14%) and equipment (14%).
- 26% of people said they had not understood what care and support they would get free and what they would have to pay for when they were discharged from care.
- Over a quarter of people arrived home or at their next care location in the evening. People discharged in the morning were all satisfied with the time they got home, while 31% of those who got home in the evening were unhappy with this.

For over two-thirds of people who responded, discharges are working well. Patients and families are informed about their diagnosis and medication, involved in decision making and are satisfied with their experience. This is consistent with national research, that many people are happy with and grateful for the services that are available and tend to report high levels of satisfaction on patient surveys⁸.

However, we also know that even when their care outcomes may not have been as good as hoped, people tend to respond positively on simple measures of patient satisfaction, and that it is important to look at areas where dissatisfaction is raised⁹. Sometimes reporting satisfaction may be used as a vote of support for the NHS when it is facing difficulties¹⁰.

We looked more deeply into the things that were raised as problems. While some of these issues may not be widespread, they have considerable impact on the people they affect. This impact is not just on their satisfaction with their care, but potentially on their recovery, future care usage and on unpaid carer burden. All of which have financial costs to the health and social care system as well as the impact on the patient and their unpaid carers.

“No-one wants or deserves to be one of the unhappy or badly-served minority, no commissioner can be content with even a low proportion of services failing to achieve their intended outcomes, and no professional can rest easy knowing that some patients’ care has fallen short of what is required.”

Jane Mordue, Interim Chair, Healthwatch England

⁸ For example, see Carr-Hill, R. (1992). The measurement of patient satisfaction. *Journal of Public Health Medicine*, 14 (3) 236-249

⁹ Sitzia, J & Wood, N (1997). Patient Satisfaction: A review of issues and concepts. *Social Science and Medicine*, 45 (12) 1829-1843

¹⁰ The Kings Fund (2015) British Social Attitudes survey 2014: conclusion. <http://www.kingsfund.org.uk/projects/public-satisfaction-nhs/bsa-survey-2014/conclusion>

Waiting for care

We heard from a number of people whose discharges were delayed because of a difficulty in arranging domiciliary care, whether this was provided through Wiltshire Council's Help to Live at Home service, Direct Payments or privately arranged. Sometimes the amount of notice that a person was given did not allow for a care provider to schedule domiciliary carers immediately on discharge.

Being discharged with dignity

We heard about people who had been discharged in their nightclothes or hospital gowns, despite having their own clothes with them.

Communication

We heard from a number of people who were using intermediate care beds that they had not been involved in deciding to go to the nursing homes where the beds were located, and some didn't know where the homes were or why they were being moved there. Staff at intermediate care locations also reported intermediate care residents being unclear about why they were there and what to expect. Other people had been offered a choice of care location following a hospital stay, but then sent to somewhere other than where they had chosen.

"Nothing was explained to me about what was happening next. All I was told was that I was going somewhere else and that was it"

Intermediate Care Bed User

Inclusion of family members in decision making

While many people thought their relatives were included in decisions, we heard from family members who were not given sufficient notice that their relative was coming home. This could be problematic when family members have other commitments, and when they may have concerns about the patient's home situation (such as "turned down" heating, or an empty fridge). Decisions agreed upon with patients and families were not always followed, and some family members reported receiving mixed messages about discharge plans, making it difficult to plan to be available.

"[We] were involved [in decision making] but what was agreed didn't happen"

Patient discharged from hospital

Transport home

People relying on transport services when leaving care (rather than unpaid carers) reported difficulties, such as not being able to book community transport as they didn't have enough notice.

Some patients relying on non-emergency patient transport encountered delays as the service was unable to be booked until medication and discharge paperwork were in place. This meant that it was short notice booking so they often encountered a long wait.

Transport services were sometimes given incorrect information about the equipment available at home.



Coordination of care following discharge

We heard from people who did not know who was responsible for their care after leaving a service. Trying to find someone who would take responsibility was a challenge, and people were passed between different services.

Sometimes it was unclear that it was the patient's responsibility to arrange follow up care, such as removal of stitches or staples after surgery.

"I talked to [PALS] about the problems with my discharge - they say that it was down to my surgery to send someone [to arrange help at home]. My surgery say the hospital should have arranged this - it seems no one wants to know about this."

Patient discharged from hospital

Discharge summaries

Patients may be issued with a copy of their discharge summary when they leave care. This can be confusing to patients and relatives, who may not be familiar with the medical terminology used. We heard concerns that this paperwork is not always correct, or that it may contain information that has not been communicated to the patient or their family. Patients were also concerned whether the information on the summary was used by their GP or if it was just filed away without being actioned.

“A letter I came away with said I had a previously undiagnosed psychosis”

Patient discharged from hospital



Staff concerns

Staff from intermediate care homes, community hospitals, and domiciliary care agencies shared their experiences of care transfers, and raised the following concerns.

- Patients being discharged before they are medically fit to leave acute hospital, often leading to readmission to acute hospital
- Patients being discharged/transferred late at night and/or without the right equipment and medication
- Patients being transferred to a setting where there may not be the most appropriate staffing skills, capacity and ability to meet the patient’s needs, and to offer care to other patients, e.g. patients with very limited rehabilitation potential being transferred to a service with lots of therapy availability, patients living with dementia transferred to a location which is unable to support their needs.
- Information not being passed between different services so staff have to repeat assessments and patients have to repeatedly retell their story.
- Confusion from staff about what care is available at the different care locations, e.g. whether intermediate care homes have doctors on site
- Processes constantly changing so staff have to relearn them and be sure they pass on correct information to patients and families.

Challenges

We recognise that we have only heard from a small proportion of the people who were discharged from care in Wiltshire over the past year or so. We do not claim that these findings are representative of everyone's experience, only those whose story we have heard.

In our previous engagement we have struggled to access people at the point of service delivery, being reliant on providers to identify relevant patients and to allow us access. This has not been so much of a challenge this time, as the community hospitals and intermediate care homes have been very helpful in providing us access to their users. However, the numbers of people it is possible to talk to on each visit can be limited, as we do not want to interfere with care. There are small numbers of intermediate care beds at each of the care homes, and not everyone eligible wants to take part.



How does this fit with the national picture?

Our findings are not dissimilar to those found nationally. The high levels of reported satisfaction with care are consistent with those found in the national Adult Inpatient Survey¹¹. They also reflect what we have previously found in our engagement with people about their care under the Better Care Plan¹² and on particular schemes within the Better Care Plan, such as HomeFirst (a particular way of discharging patients)¹³. There is a lot of high quality care in the county that people are happy with, but also delays causing concerns and frustrations, and insufficient communication is at the heart of many of the issues for patients and carers.

While we did not focus on the same target populations as the Healthwatch England inquiry, we heard similar concerns about involvement, inclusion of family members, and about delays and communication difficulties between different services. While these issues are only affecting a proportion of patients, services need to consider how to make sure that every patient has a good discharge or transfer of their care.

¹¹ 2015 Adult Inpatient Survey Update, NHS England, July 2016

¹² A summary of our engagement findings can be found at <http://www.healthwatchwiltshire.co.uk/wp-content/uploads/2016/07/Update-BCP-Engagement-July-to-Dec-2015.pdf>

¹³ Our findings about Homefirst can be found at <http://www.healthwatchwiltshire.co.uk/wp-content/uploads/2016/05/Homefirst-from-the-patient-and-carers-perspective.pdf>

What next?

Over the last two years we have listened to patients and their carers about experiences of being discharged from hospital or when care is transferred between different care settings. For most people, the system is working well and they are happy with their discharge or care transfer. However, people also told us about delays, poor communication, a lack of involvement of patients and their unpaid carers, and accessing social care at home after a stay in hospital. We have shared the feedback we have gathered with the health and care partnership for Wiltshire's Better Care Plan. The partnership brings together organisations to improve 'the system' and it has welcomed the information we have shared on behalf of patients and carers. Our next aim is to produce information about discharge or transfers of care for local people so they know what they should expect.

Thanks and acknowledgements

Healthwatch Wiltshire would like to thank everyone who took the time to share their experiences of how discharge planning or their discharge worked for them. Thanks go to the providers of health and care services who have enabled us to talk to patients at the point of service delivery. Salisbury District Hospital Foundation Trust kindly sent out questionnaires to a sample of patients discharged from their care, and we will be exploring this further with other trusts. The Wiltshire Care Partnership shared their unpublished report about their experiences of discharges to their member's care. Huge thanks go to the ever-willing Healthwatch Wiltshire volunteers who have assisted with talking to patients and carers about their experiences and the data entry.



Why not get involved?

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