

BritishRedCross



# Home to the unknown

Getting hospital  
discharge right

Policy, Research  
and Advocacy



# Contents

<b>Foreword by the British Red Cross</b>	<b>4</b>
<b>Acknowledgements</b>	<b>5</b>
<b>Introduction</b>	<b>7</b>
<b>Objectives for this research</b>	<b>9</b>
<b>1. What happens when people go home from hospital?</b>	<b>10</b>
<b>Coming home from hospital</b>	<b>12</b>
Difficulty getting home	12
Coming back to unsuitable housing	12
Reliance on informal, sometimes inadequate, care	13
Unclear expectations of support after hospital	14
Lack of clarity about the value of professional support	15
Delayed or unsuitable care	16
Coping with the emotional toll	17
Struggling with money	17
<b>Independence factors: what influences recovery once people get home?</b>	<b>20</b>
Independence at home	20
Phillip	22
Flora	24
Audrey	26
Alastair	28
Beth	30
<b>2. What happens in hospital?</b>	<b>32</b>
<b>People's experiences of being in hospital and of being discharged</b>	<b>34</b>
Motivation to return home and regain independence	34
Taking an active role in recovery	35
Social life of the ward	35
Lack of clarity about what is driving discharge decisions	36
Not thinking about long-term recovery	37
Don't know what support is available	38
Don't want to be a burden	39
<b>A systems perspective</b>	<b>41</b>
Who is in charge of the hospital discharge process?	42
Challenges in co-ordination between teams	43
Accessing social care packages and wider support	45
Initiative fatigue	46
Short-term pressures vs long-term goals	47
Role of patients/families in patients' own recovery	48
A note on emergency readmissions data	49
<b>3. Conclusions</b>	<b>52</b>
What outcomes should everyone be aiming for?	54
<b>British Red Cross recommendations</b>	<b>56</b>
<b>4. Appendix – Methodology</b>	<b>58</b>
Expert interviews and scoping	59
Understanding local ecosystems	59
<b>About the hospitals</b>	<b>60</b>
<b>Interviews with families</b>	<b>62</b>
Recruitment	64
Interview approach	64

# Foreword

by the British Red Cross

The British Red Cross has a long and proud history of working in partnership with the NHS in health and social care. Day in and day out, our frontline staff and volunteers support patients in hospital emergency departments, provide ambulance support, help people get home from hospital, carry out home assessments and support older and vulnerable people to live independently at home.

Through this work we see some of the strains the NHS and care systems are facing and the impact this can have on vulnerable individuals. This report focuses on our research findings around the way that patients are discharged from hospital and their transition from hospital to home.

We believe that safe, well-planned discharge can make all the difference to an individual's recovery – as well as preventing readmission, improving the flow of patients through the system and reducing costs.

The findings in this report reveal that, despite a wealth of guidance on 'ideal' hospital discharge and examples of excellence and good practice, problems persist. Discharge processes vary considerably, not just between nations but within even local areas. Our research suggests that while patients might appear to be medically fit for discharge, their wider, non-clinical needs can go unmet.

This research builds on our 2018 report *In and Out of Hospital*, which highlighted concerns that some patients can face a cycle of avoidable hospital readmissions, due to inadequate support when they are sent home from hospital.

Hospital stays are costly for the health and social care system and can have negative consequences for patients. There is widespread agreement among policy-makers and frontline staff alike that hospital is not a good place for people to spend long periods of time.

It is essential that we get the transition from home to hospital right. The simple recommendations we have developed build on existing theory and practice of good patient discharge, on operational insights and our growing evidence base. They aim to ensure that patients are set up to make the best possible recovery once they leave hospital.

We hope that this report will make a useful contribution at this critical time where there are genuine opportunities to work together across sectors for a truly personalised approach to health and care, in line with the vision set out by the NHS Long Term Plan and the ambitions of the forthcoming social care and prevention green papers.

# Acknowledgements

## Special thanks to:

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- Voluntary sector, health and social care staff from across England, Scotland, Wales and Northern Ireland who generously agreed to be interviewed, shadowed and observed during their busy working days - and who introduced us to patients and their families.
- The four hospitals we visited – Eastbourne District General Hospital, Royal Infirmary of Edinburgh, Bronglais Hospital and Ulster Hospital.
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- Finally, to the diligent research team at Revealing Reality who carried out the research with sensitivity and thoroughness and wrote this report - and to the team at Together Creative who designed it.



# Introduction

“

*When you come out of hospital, you get back to your flat and you're different. Mentally, you're different because your life has changed, so you've got to do things in a different way.*

”

“

*The care was first-class on the ward but when we we're leaving the hospital that's when it started to go downhill – no one told us what to expect when I got home or whether we'd be able to cope.*

”

**For those working in hospital, sending someone home is usually viewed positively: the patient has been successfully treated and now their bed is free for the next patient who badly needs it.**

But it's rare for healthcare professionals to see what happens next. A patient's discharge can be seen as a single event, rather than just one moment amid a much longer transition from hospital to home, and from illness or injury to recovery.

This report, and the research that underpins it, reveals what happens before and after a patient walks – or is wheeled – out of the hospital doors when there is no formal support or care. It describes what it feels like to return home after an unplanned visit

to hospital when there is no professional involvement to support the transition.

The research provides qualitative evidence to inform health and social care policy at a national and local level. It also makes recommendations for practical steps to be applied in acute and community health settings, by social care providers and by voluntary and community organisations including the British Red Cross – individually and in multidisciplinary teams.

The recommendations follow the ambitions of the NHS Long Term Plan and the Delivery Plan for Personalised care<sup>1</sup>, published in January 2019<sup>2</sup>, and the forthcoming social care and prevention green papers. These highlight the opportunities to work across sectors for a truly personalised approach to health and care.

As the British Red Cross 2018 report *In and Out of Hospital*<sup>3</sup> illustrated, well managed discharge from hospital is integral to people's recovery as well as essential to 'patient flow' in acute settings.

Building on that report and the wider evidence base, this research explores from the patient's perspective the experience of returning home from hospital. It is based on ethnographic-style interviews at home with 28 people across the United Kingdom who had recently been discharged after an unplanned stay in hospital without social care, as well as conversations with their carers.

1 – <https://www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/>

2 – <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

3 – <https://www.redcross.org.uk/-/media/documents/about-us/research-publications/health-social-care-and-support/in-and-out-of-hospital-report.pdf>

Policy discussions and research have often focused on delayed transfers of care, on people who are not discharged as soon as they could or should be. But less attention has been paid to those who are sent home without feeling adequately prepared or without appropriate support.

As the real-life stories in this research show, a poor transition home can have long-lasting effects on the patients who experience it.

To consider the whole picture, the researchers also interviewed 13 policy and operational experts, and interviewed approximately 40 staff and observed systems in one hospital in each of the four nations: Bronglais Hospital, Ulster Hospital, Royal Infirmary of Edinburgh and Eastbourne District General, spending a full day in each.

Comprehensive UK data is lacking, but according to a 2018 National Audit Office report, overall emergency readmissions continue to rise in England. Healthwatch England reported a 22 per cent rise in emergency readmissions between 2013/14 and 2017/18<sup>4</sup>. Even less is known about readmissions in the other nations, where data is less readily available. As of March 2019, NHS Digital has announced that they will publish emergency readmissions data for CCGs<sup>5</sup>. This data was not available at time of writing.

The evidence in this report brings home the direct impact that a person's experience in hospital and their preparation for discharge can have on their short-term and longer-term recovery, rehabilitation and wellbeing.

These experiences can not only affect someone's physical recovery, but their confidence, independence and outlook – all of which have a direct impact on their ongoing health and happiness.

Being clearer about the relationship between what happens in hospital and what happens when people go home – seeing through patients' eyes how it feels when they walk back through their front door – can only help patients and professionals alike.

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4 – [https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20181114%20Emergency%20readmissions\\_0.pdf](https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20181114%20Emergency%20readmissions_0.pdf)

5 – <https://files.digital.nhs.uk/FD/458CEE/Emergency%20Readmissions%20Summary%20Position%20Paper%201.pdf>



# Objectives for this research

This research explored patients' unplanned stays in hospital and what it was like for them after they had returned home.

More specifically, the research sought to reveal:

- Patients' experiences of being discharged from hospital
- Hospital systems and healthcare professionals' experiences and perceptions of the discharge process
- What it was like for people returning home from hospital feeling more or less prepared.

As a result, it aimed to explore the impact of discharge on recovery and wellbeing and to identify opportunities to improve systems, communication and support.

This qualitative research has sought to bring the human experience of hospital discharge to discussions, getting beyond the predominantly quantitative data to help describe what an unexpected admission to hospital looks and feels like for people and their families. The people included in the work met a number of criteria:

- They were ineligible for social care support – or turned down this support
- They were admitted to hospital unexpectedly – no planned admissions for surgery or other treatment
- They had a range of different reasons for hospital admission, including illness and injury.

The sample was made up of:

- Mostly older people, although the sample has a spread of ages
- Some people who were supported by services provided by the British Red Cross.

This research covered all four UK nations, deliberately including a higher than representative proportion of respondents from Scotland, Wales and Northern Ireland.

More detail on the sample and methodology can be found in the appendix.

**1**

**What  
happens  
when  
people go  
home from  
hospital?**

“

***The transfer from laying in bed then walking through the front door back home needs more forethought. They've no idea what goes off. Once you leave hospital, that's it.***

”

The impact that a person's experience in hospital and their preparation for discharge can have on their short-term and longer-term recovery, rehabilitation and wellbeing cannot be underestimated.

For some, returning home from hospital can lead directly to an improvement in health or a significant step in recovery after illness or injury. For others, however, returning home can be a complex and difficult process. In some cases, people are left vulnerable to a risk of readmission to hospital.


As this research demonstrates, once people are discharged from hospital, their experiences of being at home – both upon immediate return and in the longer term – are largely out of sight of healthcare professionals, certainly those in acute settings. This means healthcare professionals rarely see the longer-term consequences of their actions or patients' experiences beyond the hospital doors. This issue was observed across all four UK nations, regardless of national language around health and social care integration.

Unless specific support has been arranged from services such as the British Red Cross Home from Hospital, the moment patients return home is often witnessed only by family or carers. Some people are alone.

This chapter explores people's experiences of coming home from hospital, describing and reflecting on the transition from hospital to home – the arrangements and support put in place, and the communication in hospital and afterwards.

The last part of the chapter considers the factors that appear to affect people's independence and recovery positively or negatively.

# Coming home from hospital



The participants in this research had a wide range of experiences of returning home from hospital but there were several recurring themes.

## Difficulty getting home

For some people, the experience of getting home from hospital had as much of an impact on their recovery and independence as their hospital stay itself. Many people found leaving hospital daunting. Their journey home and the days that followed often directly affected their confidence and their outlook on their recovery.

**Colleen**, 79, broke her ankle when she fell while playing golf. Colleen and her husband, John, said that nothing was discussed as part of her discharge about how to get home.

When Colleen left hospital, she and her husband, who is in his 80s, struggled to get her into the car to get home. She had to keep her ankle raised, and he was not as strong as he used to be. Getting her out of the hospital wheelchair and into the car was really difficult. A family friend had given John a tip: lay bin bags on the seat to help Colleen slide in. Nonetheless John struggled to get Colleen into the car and home – the journey left them both “completely exhausted”. Once home, he had to create a makeshift ramp to help Colleen into the house. Luckily, he had borrowed a wheelchair from a friend to help her around the house.

“

**He was traumatised, and I was traumatised – it was not a good experience.**

” Colleen (79, Northern Ireland)

The uncertainty and confusion that some patients experienced at this point could set up negative feelings or fear. Colleen had not anticipated that getting home would be so challenging and she was left feeling overwhelmed by what other unforeseen difficulties her recovery might entail.

Many patients described feeling in limbo when they were discharged – at the end of their clinical care but without support to get home.

## Coming back to unsuitable housing

Some people came home to houses that had not been prepared for their return, with no hot water or heating on.

Others returned to homes that were unsuitable or inappropriate for their recovery and their changed or changing needs. This ranged from struggling with a single step up to a front door, to feeling unable to get upstairs to the toilet.

Reduced mobility – either as a direct result of illness or injury and/or as a consequence of time they’d spent immobile in hospital – was often the greatest challenge people faced when they got home. People struggled to get around their houses and to do everyday tasks such as washing, cleaning or cooking.

Even before **Graham's** (64, Northern Ireland) most recent cardiac arrest, his home was not suitable. Graham had muscle wastage from radiotherapy to treat prostate cancer and found it difficult to move around and to use the toilet. He had recently had a walk-in shower installed at his own expense as he couldn't get in and out of the bath. He no longer cooked any of his meals because he couldn't stand long enough. Graham has been in and out of hospital many times – he has had inoperable prostate cancer for 12 years and has had three cardiac arrests.

Some had felt comfortable and independent in their homes before they went into hospital but on their return found it difficult to move around or to maintain them – or they lacked the confidence to try.

Others had found it hard to move around at home easily even before their hospital stay. When they returned they found their homes even less suitable.

**Theresa** (65, Northern Ireland) had been admitted to hospital several times over the past three years following falls at home. She had been referred to an occupational therapist who explored options to establish safer mobility around her house. But Theresa had turned down the recommended construction of a lift in her house as the lift shaft would have “been right in the middle of my living room”.

Following her most recent visit to hospital with bronchitis, Theresa had been struggling even more with the stairs in her house and had resorted to sleeping downstairs in her chair on nights she felt unable to make it up to her bedroom. She had also begun to restrict her intake of food and drink to limit the number of times she had to visit the upstairs toilet.

**Alastair** (68, Scotland) was given information by the British Red Cross about supported housing. He didn't feel ready to move yet, but knew he needed to be realistic about his changing health. He was glad that he was now aware of the options should his health continue to decline and felt more confident about his future.

Despite the enormous impact housing support can have on a person's health and overall wellbeing, it was cited as being often overlooked.

“

***Especially if someone went into hospital because of a fall, maybe if we came in and did a home assessment it could be fixing that piece of carpet before they trip over it again – something small that could prevent them from going into hospital.***

” Catherine Glenn  
(Belfast Central Mission)

## Reliance on informal, sometimes inadequate, care

People often relied heavily on informal care from relatives, friends or neighbours from the moment they left hospital. Without this kind of help it was not always clear they would have had any support at all.

Many had engaged, loving and proactive people around them who were able to make adjustments to their own lives to help look after them.

However, in many cases this care was not as informed or thorough as care from a professional could have been, or the carers didn't fully understand the person's needs.

Despite best intentions, the care provided by family or friends sometimes undermined the confidence or independence of the person they were caring for. Some families or friends worried about people hurting themselves or making themselves more ill after hospital. This meant they would do everything that the person needed to be done, rather than encouraging people to gradually do more things for themselves. This could hinder their recovery or cause problems when the initial level of support was no longer available. A minority of people in the sample had families and friends whose approach was proactively seeking to empower the person.

**Audrey** (87, Wales) received support from Laura, the warden of her supported housing. Laura went above and beyond her contractual responsibilities, visiting Audrey daily and ensuring she had all the relevant adaptations to her home. Laura also arranged Meals on Wheels, a gardener, and private carers for Audrey. It was Laura who noticed Audrey had contracted an infection and accompanied her to hospital on the second of her recent visits.

“

**She saved my life, did that girl.**

”

**Audrey  
(87, Wales)**

However, Laura had since been promoted and was no longer working within Audrey's accommodation. While her replacement was making every effort to provide similar support, Audrey was apprehensive about how she would manage because she had relied so heavily on Laura in relation to her health and day-to-day living.

Providing support could also place family members or friends under a lot of physical and emotional pressure.

**Flora** (59, Scotland) found that her relationship with her husband became strained following her hip surgery as she relied so heavily on his help to move around and complete basic tasks. While their relationship is now back to normal, Flora's husband had to take more than three weeks off work to help care for her. They found this time so difficult that they had discussed whether he should take early retirement.

## Unclear expectations of support after hospital

Coming home from hospital was made difficult for many people when their expectations of what would happen, when, and who was responsible for it were unclear or not well managed.

Most people had little or no concept of the differences between acute, primary and community care in relation to their own recovery. They did not understand the relationships between them and how they overlapped in terms of the services they provided or what they could expect of them. This was observed among patients and families across all four UK nations.

Patients were often confused about how 'the system' shared information about their situation, assuming that all data was passed from the hospital to any community healthcare automatically. Many people were unclear what their discharge notes meant, who they were intended for and who else had been – or should be – given a copy.

When **Arif's** (56, Scotland) wife was taking him home from hospital, she was handed her husband's discharge note in the midst of organising transport and his medication. This note detailed his experience of a fall and the diagnosis of diabetes he received in hospital. At this point, her understanding was that this was a copy for her and Arif to keep, while another would be sent to his GP.

On his return home, Arif waited, increasingly frustrated, for a follow-up appointment with his GP. He felt he had been "left to fend for myself". After a few days, he called to ask after his appointment and it became apparent the GP had not received the discharge note and had no knowledge of his hospital stay. It was only at this point that it was explained that the intention was for his wife to hand over the note.

In instances such as these, the transfer of care from healthcare professionals presented a breakdown in communication with patients and their families. Arif was proactive in contacting his GP, which uncovered the fact his GP hadn't received his discharge note, but in other cases this kind of gap in communication may go unchecked, with implications for recovery.

After hospital, **James** (61, England) did not receive any follow up from any of the healthcare professionals he was already in contact with – for example his liver transplant doctor, diabetes nurse or his GP. He had been admitted to hospital following a bout of cellulitis, which he had suffered from before, and he was confused about why he'd been admitted to hospital this time when previously he'd been treated at home.

“

**Once you leave the hospital, that's it. They've done their bit.**

”

**Caroline, James's wife**

Confusion about which parts of the health and social care system were responsible for what and how they communicated left people confused about what to do or who to speak to while they recovered at home. This could undermine their agency, desire and ability to proactively seek help or take control of their own health and wellbeing.

**Flora** (59, Scotland) found her post-hospital experience with her GP surgery extremely upsetting. During an appointment to remove the clips following her hip replacement ten days after she got home, Flora asked for a repeat of her painkiller prescription. The nurse said there weren't any notes about this from the hospital, even though Flora's husband had taken a paper version into the practice himself the day Flora left hospital. The nurse said only the doctor could prescribe the painkillers and offered her co-codamol, which Flora is allergic to. The nurse said she could get the doctor to fax the chemist for the tablets and told Flora to go there to pick them up. However, the chemist told Flora she couldn't be prescribed painkillers without a paper prescription.

“  
**That's when I broke down. I felt like I'd been left out in the cold. They made me feel like I was asking for something that I wasn't entitled to. I was so worried about the pain.**

” Flora (59, Scotland)

Eventually, Flora's husband took her home and went to the GP to complain. He got the medication from the GP there and then.

## Lack of clarity about the value of professional support

When **Sinead** (75, Northern Ireland) was in hospital with pneumonia, she was visited by a social worker who asked her about her home situation.

“  
**She was asking me if I had support at home. I knew exactly what she was getting at, so I said: 'I'm going to stop you there and tell you not to worry, I've got plenty of people around and there are other people here that need your help more than I do.'**

” Sinead (75, Northern Ireland)

After her return home, Sinead's daughter visited daily after work, helping Sinead cook dinner or keep up with the household chores. However, Sinead admitted that she worried how much of her daughter's time

she was taking up and felt guilty about her daughter coming to visit so frequently.

Informal care was prevalent among the research respondents for several reasons. The sample was recruited specifically to explore the experiences of patients and their families who did not receive social care packages, either because they were ineligible or because they did not want them.

Among the people who were ineligible for social care, many of them had no options for additional support, especially if they weren't signposted to voluntary sector support. Some people were offered professional support but decided not to accept it for a range of reasons. Often, they were not sure what the support they were offered entailed, turning it down because they didn't fully understand how it may have helped them. Others weren't clear on the longer-term impacts of their ill-health or injury and so didn't think they would need much support. A number of people were also reluctant to put more pressure on the NHS or social care system, feeling other people needed help more than they did. In many cases, it was a combination of these factors.

**Elizabeth** (84, Wales) lived in a remote hamlet and had been in hospital with a leg injury. She had also been admitted a few months earlier for a knee operation, and had a ruptured gall bladder and contracted sepsis during her stay. Elizabeth had found the care she had received after her first hospital visit disruptive. She wasn't sure whether she'd been formally offered care after her most recent admission, but she was adamant she didn't want it anyway.

“  
**I was sort of [offered care] – but it was never really very constructive, it was never very certain. It's difficult, I didn't want to have carers this time – I'm very independent as you probably realise. I want to get up and washed when I choose to get up and washed.**

” Elizabeth (84, Wales)

Instead, Elizabeth was heavily reliant on help from a neighbour in the local village who brought her ready meals, shopping, and helped her with breakfast. Elizabeth was still cooking for and washing herself, meaning

she had to stand for long periods of time. This was painful, and she wasn't sure if this was helping or hindering her recovery. As Elizabeth had been readmitted to hospital in the space of a few months, an assessment of her home to identify any equipment could have alleviated some of her difficulty and prevented her feeling she was losing her independence.

A strong desire to retain their independence and a perception that support services would undermine it was felt by many of the participants in this research. Alastair (68, Scotland) saw receiving care as somehow 'giving in' to his condition and forgoing independence and recovery.

## Delayed or unsuitable care

**Beth** (36, England) remembers very little of the three days she spent in hospital following an overdose. After her discharge, her husband Richard received a letter of recommendation to contact the "post-release mental health team". He called the next day and, after telling them about her support network of himself and some close family nearby, he was informed that Beth wouldn't be referred on to other services.

Beth then contacted the counselling service she had used prior to her overdose which told her that, because she'd had a mental health crisis, she was no longer eligible for their services. When her husband pointed out that this meant she was now not receiving any support, he was told that she could be re-referred for counselling but this would take around ten weeks.

“**They were both saying they couldn't take me but clearly I had to fit somewhere. It's not just a case of 'Go home, job done,' which is kind of what it felt like.**

” **Beth (36, England)**

Unsuitable or delayed care could be a traumatising experience. Rather than providing people transitioning home with the tools to begin regaining their independence, it could hinder their confidence and recovery.





Communication breakdowns and lack of clarity were most evident when post-hospital care was delayed. This could leave people without the care they needed, lacking information as to why the delays had occurred or knowledge of when the care would arrive. In addition, care that was provided was sometimes not suitable. This left many respondents feeling as though they were not being adequately informed, listened to or respected.

After **Jane** (47, Scotland) spent four days in hospital following a stroke, she was told she would be contacted by a member of the stroke support team within a couple of days to discuss next steps and put her in contact with a physiotherapist. Jane and her partner waited two weeks before they had contact with a professional, during which time their concerns over her health and the subsequent impact it would have on their financial situation mounted. Jane described feeling “left completely in the dark” and “almost giving up hope” that they would get any help at all.

## Coping with the emotional toll

Coming home from hospital was often an emotional experience. Despite the feeling of happiness and relief when discharged, the first days at home were often filled with apprehension, anxiety and loneliness. These feelings often stemmed from:

- Worries about how best to manage new health conditions and medications
- Nervousness about ongoing symptoms and what might be an indication of worsening health
- Loneliness from having fewer people around than in hospital
- Anxiety and embarrassment about being a burden for family members.

**Sinead's** (75, Northern Ireland) treatment for pneumonia was the first time she had stayed in hospital. After losing her husband to lung cancer, she said as soon as she heard there was a problem with her lungs she thought: “That’s it, I’ve got what he had.” Since coming out of hospital she had been feeling “anxious” about her health in a way that she had not done before.

“

**It worries me. I think about it a lot more now. I’m concerned about what will happen with my family once I’m gone.**

”

**Sinead (75, Northern Ireland)**

Despite getting practical help from her daughter and neighbours, Sinead had not spoken anyone around her about her worries. She felt she needed to keep up appearances as a strong mother and important member of her community.

**Flora** (59, Scotland) found coming home after an unplanned hip replacement surgery extremely emotionally difficult. Her first interaction with her in-home physiotherapist was an awkward one. Flora was feeling emotional and told her physiotherapist, “I’m sorry but I might cry today,” to which her physiotherapist responded, “That’s because you’ve lost your life.”

Flora found this insensitive and said it made her reflect on how she was indeed unable to do the three things in her life which gave her the most joy: looking after her grand-daughter, taking her dogs for walks and going to choir.

For many, these emotions extended beyond the first few days, particularly for those people who had to adapt to a compromised health situation and develop new routines to cope. Many respondents had a need for emotional support, in particular in the early days, to help start their recovery with a clear plan in place. However, few respondents mentioned looking for specific help in this respect, often instead assuming they would find ways of coping, or unclear where they could turn.

## Struggling with money

Emotional strain was often compounded by financial difficulties. People were concerned about the impact their hospital stay and ill-health would have on their financial situation.



**Phillip and Anna** (81 and 84, England) decided not to look for a place in a care or nursing home when Phillip was leaving hospital. As they fell above the financial threshold for a social care package, they were required to pay for private care four times a day.

“

**They cost a fortune – about £1,000 a week unless you're on benefits. If you've got more than £23,500 I think, which is not a lot, then you pay the lot until it's gone and then they take a lien on your house. This is a cruel system in a way.**

” **Anna (84, England)**

Phillip found that, despite the large amount of money they were paying for care, it provided limited help. Due to the fact that the private carers required three days' notice to changes in their schedule, Anna was unable to visit the GP at short notice – something that was essential for dealing with her MS. They are in the process of applying for Carer's and Attendance allowances, but this will amount to around £80 per week should it be granted. Phillip's recovery is likely to take several more months and the financial burden of this places a continued strain on Anna and Phillip's life.

The financial pressure of paying for private services could also heighten the conditions that caused a person's admittance to hospital.

**Beth's** (36, England) depression was exacerbated by her family's difficult financial situation and she attributes her mental health issues to finances and the pressures of managing her own business. In the absence of any other support when she came home from hospital following her overdose, she was paying for private psychiatric treatment, but she was struggling to afford it and the cost was resulting in greater financial pressure.

**Shona** (45, Scotland) was admitted to hospital in Edinburgh for stomach abscesses. She stayed seven days and had an operation and a stoma fitted. Though her GP signed her off to go back to work as a chef, subsequently there were several push-backs to the date from her work-place occupational therapist. Shona was set to return to work at the time of the interview, but her HR department had called to say they were still concerned about how to support her with the more manual aspects of her job and requested they receive further medical assessment before returning to work. Shona had had over three months off work and was reaching the end of her sick pay quota. She was worried and annoyed about what impact a follow up operation in winter would have on her finances, when she would then be required to be on half pay.

# **Independence factors: what influences recovery once people get home?**

1

People's experiences of 'ill health' do not 'finish' when they are discharged from hospital. Most are on a trajectory of recovery that continues well into the future. In fact, for some, this is where longer-term challenges begin, especially if they must come to terms with temporary or lasting adjustments to their health or wellbeing.

Most people who were ineligible for a social care package were deemed clinically fit to leave hospital but sent home without adequate consideration of their non-clinical needs and their longer-term trajectory. This meant opportunities were frequently missed to give them the greatest chance of returning to good health and an independent life after hospital and to minimise the chance of them being readmitted to hospital.

It is helpful to think of people's likelihood to make a full recovery after an unplanned stay in hospital – to thrive rather than merely to cope – in terms of several 'independence factors' that contribute to overall wellbeing. The combination of these factors indicates how independent someone is overall – a key determinant of their recovery.

Unplanned hospital stays are inevitably disruptive to a person's wellbeing. But the experience someone has during their stay, the ways they are prepared for discharge, and the extent to which the trajectory of their long-term recovery is actively considered all affect the strength and relative balance of their independence factors, and therefore their ability to thrive once they return home.

Active consideration by health and social care professionals during all patient interactions of how they can help boost these independence factors and avoid undermining

them could significantly alter people's long-term health and wellbeing trajectory.

## **Independence at home**

Encouraging good health and preventing readmission should be the ultimate goal of the discharge process. A primary consideration in this should be the control a person has over their trajectory through their independence. Building independence helps to build confidence and practical skills necessary for people to return to – or reach beyond – their wellness prior to their hospital visit. This is a key factor in minimising the risk of readmission.

This does not yet seem to be a central focus of the discharge process on the ground, as will be demonstrated in the next chapter. Supporting independence allows people to thrive and take control of their own recovery. People need to be encouraged to live independently and well for longer.

A person's independence can be positively or negatively changed by the experience, interactions and interventions patients have in hospital and when leaving hospital. Staff and the healthcare system can encourage recovery, building patients' confidence and desire to be autonomous, but they can also reduce patients' confidence, motivation and agency.

In some cases what happens to a person in hospital, during discharge and once they get home can hinder their long-term recovery.

This research has identified five categories of independence factors. These can be assessed – and compared – before, during and after someone's stay in hospital.

These are not all equally important for each person, but they illustrate the importance of considering how the wider context of a person's life – beyond their immediate, clinical needs – needs to be accounted for in planning for their discharge.

They independence factors can broadly be defined as follows:

- **Physical independence** – physical capability and mobility and how this affects a person's daily routine and domestic tasks, such as washing and dressing. It also covers the general physical health of a person and the effects of medication.
- **Social independence** – whether the person is at risk of loneliness or unwanted social isolation. The meaningful connections and support network someone has in place, including who they live with, the relationships they have with friends and family and how regularly they have social contact with loved ones. It can also involve interaction with carers or paid-for support, and how positively or negatively these seem to impact on a person's life.
- **Psychological independence** – individuals' ability to cope, e.g. dealing with the stress associated with injury/illness and the effect on their overall mood and wellbeing, including the exacerbation of previous issues. This could also relate to how positively a person views an experience and the impact this could have on their personal confidence and trust in interventions.
- **Practical independence** – how well adapted a person's environment and surroundings are to their needs. This would include their home environment as well as whether they live in a rural or urban setting. It would also include how practically able a person is to carry out their normal routine, for instance if they can drive, how often and easily they are able to access local amenities, or how capable they are of making and attending appointments.
- **Financial independence** – the ability to cope with any financial stresses or burdens.

These factors are often inter-related. A rise or fall in one factor will often be reflected by a similar effect in another. For example, a lack of environmental adaptations may lead to people being less able to be physically active and independent in their own home. This may also cause frustration and a lack of confidence or motivation to drive their own recovery.

The people within the sample who coped best after their hospital stay tended to have experienced:

- A drive to recover and be independent – motivation, inspiration, trying to do things for themselves
- A strong, active support network – people who were able to look after them and encourage social activities
- Tailored advice given at the right time
- Good understanding of how long recovery would take, what the next steps in recovery were and what they could do/need to do in order to manage their health
- Knowledge of who they could get in touch with if they are unsure about something, e.g. the right information about who can help with health/housing/finances
- A suitable home environment and a means of getting around
- Physical aids and adaptations to help with mobility and physical recovery.

The following case studies illustrate the changes to people's independence during their hospital stay, the discharge process and their return home.



## Phillip, 81

### Stroke, four months in hospital

Phillip<sup>6</sup> and his wife Anna lived in a 2 bed, semi-detached house in England. Before he fell ill, Phillip worked as an engineer for most of his career. Anna, his wife, 84, lives with multiple sclerosis.

Anna felt that no consideration was given in hospital to the long-term impact of Phillip's stroke when he got home, or how he and his wife would cope with this change. Both have struggled to manage the dramatic shift in his life and his experiences in hospital and the way he feels about them have affected his recovery.

Phillip's physical independence was severely affected by having a stroke and made worse by a lack of regular physiotherapy support during his four-month hospital stay. He was confined to his bed all weekend in hospital and was rarely encouraged to move. His wife Anna felt this delayed his recovery and left the couple feeling abandoned.

Anna and Phillip also felt completely in the dark about what his recovery would be like. They were anxious and concerned about the future, worried about when they could expect him to walk again. This has placed increasing strain on the couple.

When he was discharged from hospital, they said there was no clear, obvious plan for his transition home. The couple were not told what to expect when they got home and have struggled to buy the constant supply of cleaning products, such as wet wipes, that Phillip now requires. This has had practical impacts on his life. Since his stroke, Phillip can no longer get upstairs and has a bed in the living room so he can be moved to his chair more easily. He needs a lot of equipment at home and Anna, who has multiple sclerosis, has tripped over it and found it difficult to manoeuvre around.

Phillip and Anna were above the financial threshold to receive a care support package, so they have paid for private carers, costing around £1000 per week. Anna has applied

for some financial assistance, which only amounts to £80 per week, but has found the forms lengthy and complicated. Anna was starting to think about taking a loan against their house to cover his care.

Phillip's hospital experience also took a toll on his mental and emotional health. Phillip described his time in hospital as distressing, feeling that resources were overstretched and struggling emotionally with his reduced mobility. Anna didn't think he was motivated enough to start moving and helping himself to recover well while he was in hospital. Small details such as the hospital staff not returning Phillip's glasses after his stay have also added challenges, because Phillip was unable to get to the opticians to get a new pair for several months.

These challenges have been compounded by his problematic discharge. After he travelled home, he was immediately readmitted because the ambulance team didn't think he had the correct guard rails on his bed at home. He was readmitted onto a general ward for five days; a ward that didn't have specialist stroke support. Phillip was discharged for a second time after being told that he did actually have the right guard rails on his bed. This ordeal had a huge impact on Phillip's confidence in both his own recovery and the support he could expect from the system.

The British Red Cross have been sitting with Phillip for several hours a week to give his wife the time to get to her own healthcare appointments for her MS. Anna noted that there are many charitable organisations whose services are very helpful, but the fragmented nature means it often takes a considerable amount of time to find and access the details of the help they can provide – something that is in short supply now she is a full-time carer.

<sup>6</sup> – The case studies included here have not all been to the four hospitals we visited as part of this research.



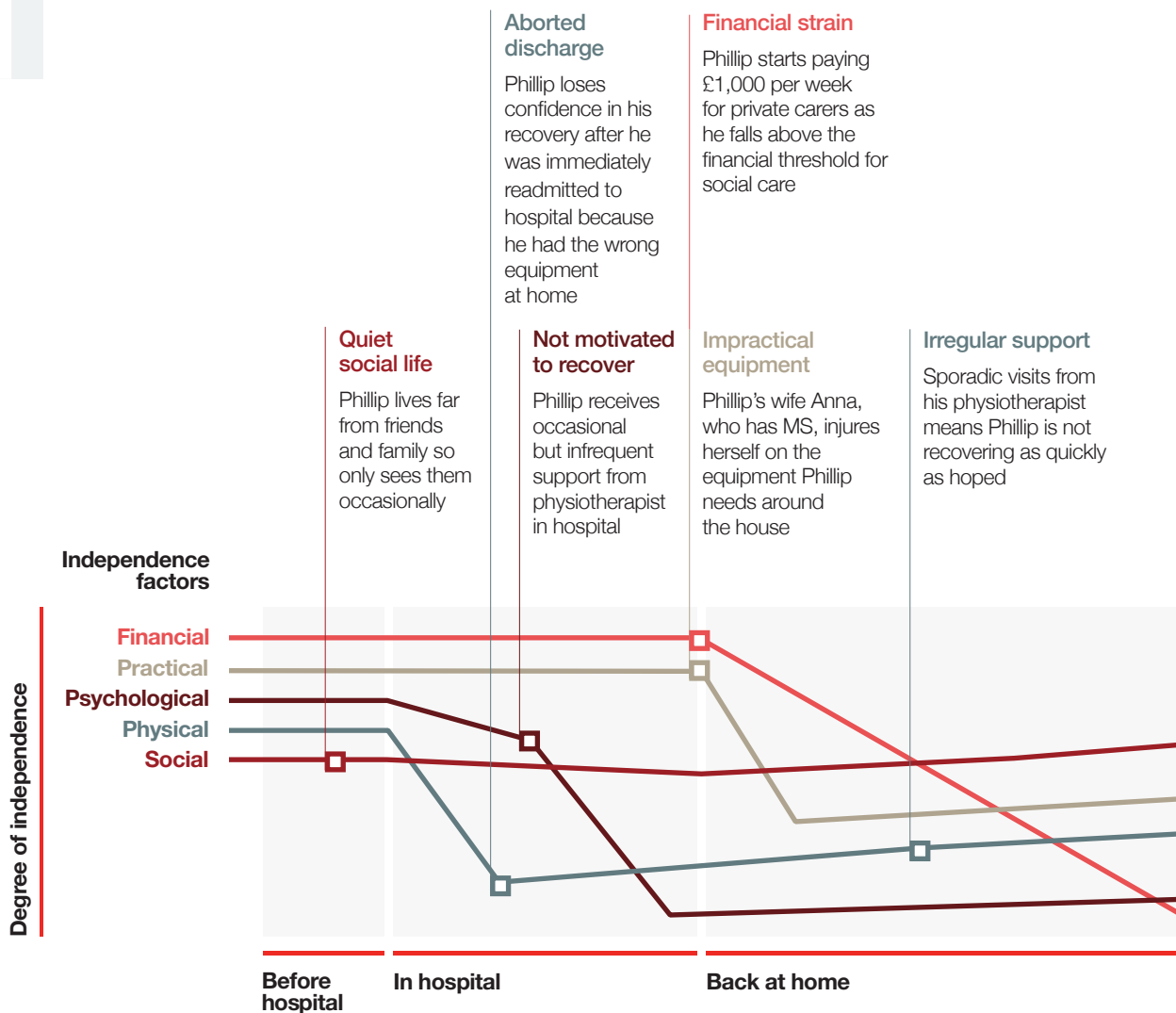
“ Really he was partly bed-blocker and partly they didn't know what else to do with him. There was very little proactive intervention due to lack of staff.

” Anna (84, England)

“ Yes, they were very busy.

” Phillip

## Phillip's journey





## Flora, 59

### Unplanned hip replacement surgery, eight nights in hospital

After a nasty fall in her garden, Flora was rushed to hospital in an ambulance. Her hip had broken in two places and she needed hip replacement surgery. The information she received while in hospital had a significant impact on her recovery at home.

Flora's physical independence reduced drastically from her injury and the marked shift in her mobility. While in hospital, Flora's physiotherapist "drummed" three golden rules into her: don't cross your legs; don't bend more than 90 degrees; don't twist. Flora stuck to these carefully, but when she had a new in-home physiotherapist several weeks after being discharged, she was told that these rules had been limiting her recovery and sense of independence.

Flora had an active social life prior to her hospital visit, but her mobility placed a strain on her ability to socialise. Before hospital, Flora attended the local choir and looked after her granddaughter most evenings – things she really enjoyed doing each week. After hospital she was unable to leave her house for several weeks, which limited interaction with her granddaughter and friends. It also placed a strain on her relationship with her husband as both struggled to come to terms with her limited mobility. This has, however, now improved and Flora noted that her relationship with her daughter has been positive throughout this time, possibly even enhanced, as she has come to cheer her up regularly. Despite this, Flora's social interactions continue to remain limited in comparison to her time before hospital.

Changes in practical independence for Flora have been largely as a result of her mobility and pain. Following Flora's fall, there was some concern about how she would manage around her house once discharged. Her occupational therapist arranged for a range of adaptations to be fitted in her house prior to her discharge and Flora was impressed with how well this was organised.

Flora was forced to buy a new car, an automatic one instead of her old manual, so that she could drive more easily. This was a difficult financial decision, but one that has meant she can drive herself to choir each week again. She still needs to plan every journey and consider how she will get about.

Perhaps one of the biggest impacts of Flora's hospital stay was on her psychological independence. There were two major factors that affected this; unclear information about what to expect after hospital in the long-term, and interactions with health care professionals she described as difficult. Flora felt the staff in the hospital didn't properly prepare her for the full impact of her injury on her life at home. It was only at a GP appointment, three months after being discharged, that she was told her pain could last a year and that she may never fully recover. Flora continued to struggle to come to terms with this.

“

***It was the first time I'd heard this. I'd been expecting to be pain-free at this point. Nobody at the hospital had explained to me how I was an unusual case or how long-term my recovery could be. It was all so quick in the hospital – they just treated it like another surgery case. I was so disappointed.***

” Flora

Flora also described her hospital experience as “traumatising” after being put on a ward with very ill patients. She cried every morning of her stay.

This was compounded by a consultant who, close to her discharged, warned her that the next few weeks would be “sheer hell”.

Upon leaving, she struggled with the fact that she could no longer do the things that brought her the most joy, namely looking after her granddaughter, walking her dogs, gardening, and attending choir.

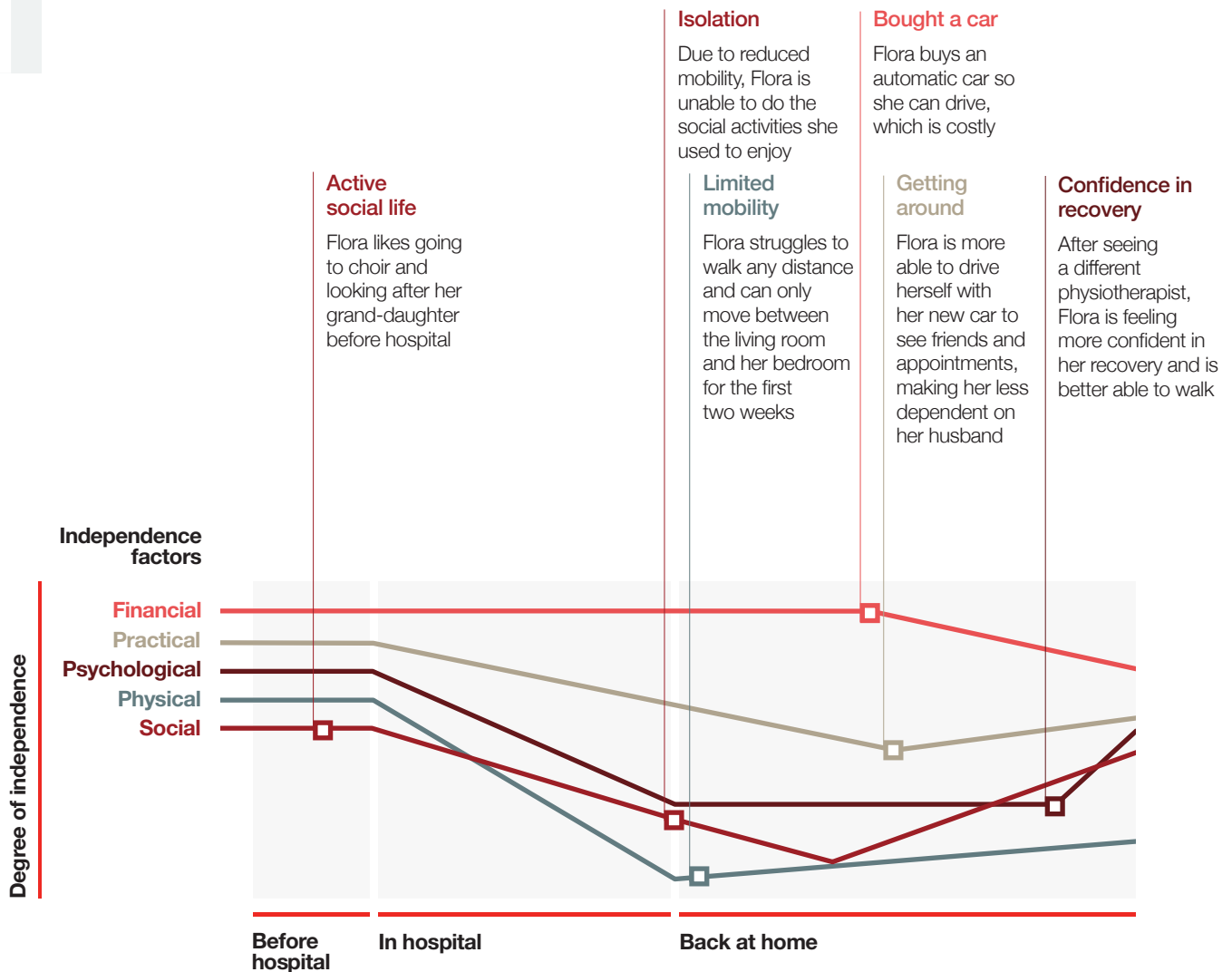
Flora's case shows the interrelation of different independence factors, and how the information and experience of hospital could severely impact recovery and independence at home.





“  
*The new physio was excellent. He noticed that I had no confidence and that I was just dragging my leg along. I had been restricting myself with the three golden rules, I was so cautious about hurting myself. He told me those rules are not well-researched and that he was going to work on building my confidence up again.*  
 ” Flora

## Flora's journey





## Audrey, 87

### Breathlessness, leg infection, bladder infection, sepsis (three visits), two weeks in hospital

Audrey, 87, has lived in supported housing in a coastal Welsh town for the last five years. Prior to this, she travelled the country breeding and showing guinea pigs until her health began to decline. She gets on well with the wardens of her housing, who check on her most days, and often goes on outings with local social groups.

Audrey went in and out of hospital three times in 2018, sometimes with short gaps between visits. On one occasion, she was discharged and readmitted with 24 hours. The timings of her visits have meant that the details of each are unclear for Audrey, and she continues to be unsure of the exact nature of her illnesses.

Audrey's physical independence has diminished after her multiple hospital visits, meaning the once avid gardener now struggles to walk between her living room and kitchen. After her first visit, Audrey received support from the British Red Cross Positive Steps scheme. Just as she had built the confidence to walk again, Audrey was readmitted to hospital, which set her back. Audrey continues to get help from the British Red Cross but is still physically weak.

Audrey was part of several local groups prior to her hospital visits and was hoping to attend a Christmas meal at the local school. Her illness has meant she had to miss the occasion and other meetings, significantly limiting her social life and connection with her community. Audrey does not have family close by, so these relationships had meant a lot to her.

Her difficulty getting around her small, cosy bungalow has had wider practical implications. She decided she needed to employ a cleaner and receives Meals on Wheels because she has struggled to stand for long enough to cook a simple meal.

The need for these services has affected her finances, but she felt she could afford to do this. The British Red Cross have also helped her with shopping and given her a trolley to use around the house to carry her tea. The adaptations around Audrey's house have gone some way to reduce the practical impact of hospital. The wardens in her accommodation have also helped her get rails and a commode to help her move around.

Following her first time in hospital, Audrey remained resilient and was confident in her own recovery after she saw positive progress in her mobility. Since being readmitted, however, she now doubts her recovery process and cannot see herself making a full recovery. This has taken a psychological toll. During her second visit, Audrey felt doctors were "cagey" about the details of her illness, and she still feels unsure about what had been wrong.

There had been little dedicated conversation about the long-term effects of Audrey's hospital visits. She felt she didn't really understand the implications of being ill and what it would be like when she got home. She was shocked by how ill she had been and the lasting effect this would have on her time at home.

**“ They just said it was an infection, they didn't say how it was going to affect me or anything like that.**

**” Audrey**

She's also frustrated that she's been unable to fill her time with the things she loves doing, namely gardening and building model houses. The emotional toll that Audrey's various readmittances has taken on her has meant that she is less motivated to push herself to recover as she's scared that she will be hospitalised again.

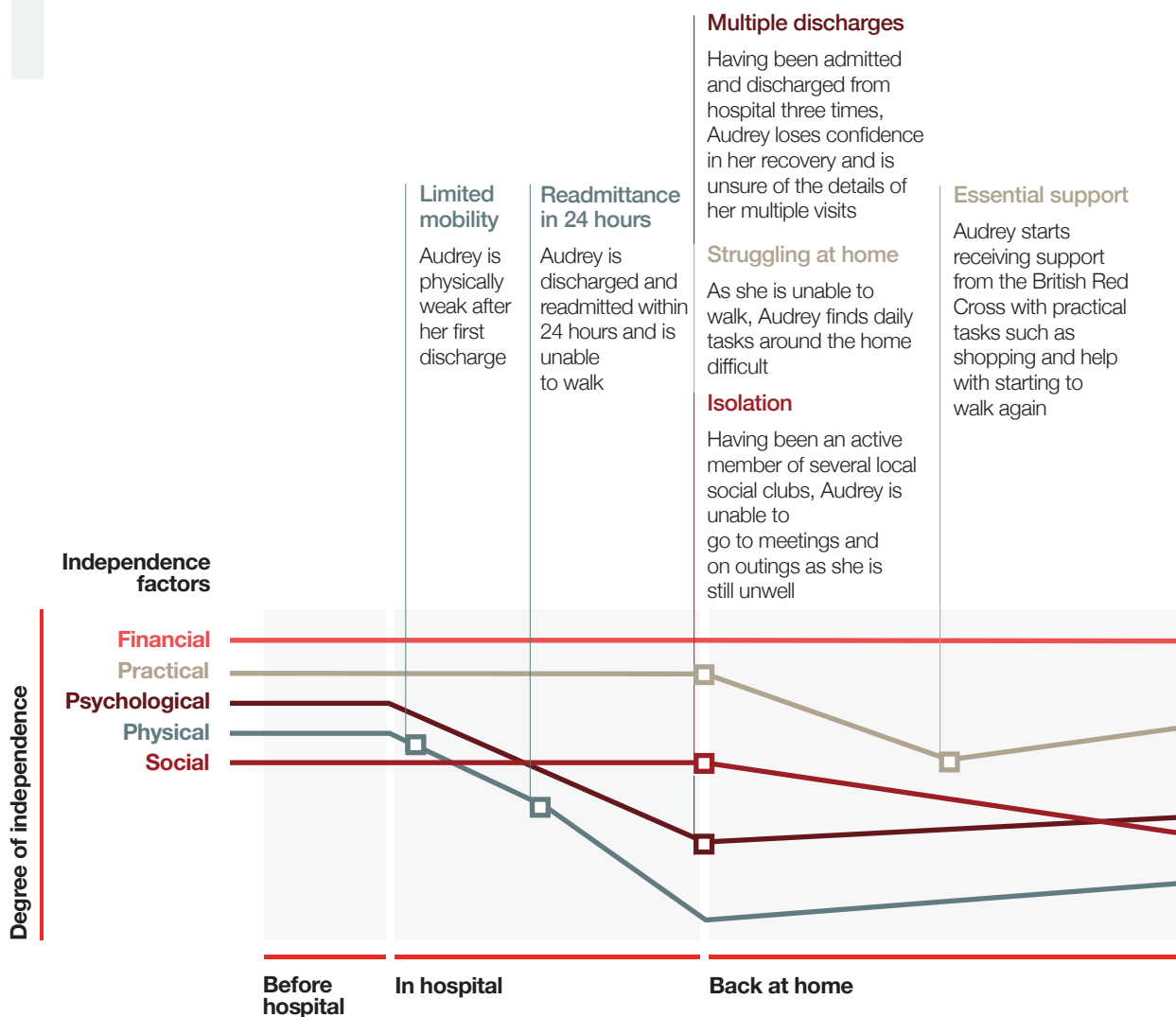
Audrey's readmissions have been a disruptive experience for her and left her anxious and concerned about the future.



“ I got fed up asking questions because I wasn't getting any answers.

” Audrey

## Audrey's journey





# Alastair, 68

## Breathlessness, four days in hospital

Alastair lives alone in a semi-detached bungalow in rural Scotland. He is very independent and spends much of his days browsing eBay – he has a particular love of “unusual watches”. Alastair suffers from Chronic Obstructive Pulmonary Disease (COPD) and had noticed he was starting to feel worse and worse throughout the year. Alastair believes he is not someone who is ever going to be in fully good health.

Alastair went to hospital when he was having trouble breathing in late 2018. It got to the point where he couldn't walk very far without becoming short of breath. He admitted that his most recent hospital visit had been a bit of a wake-up call for him.

He has seen his physical abilities decline since his hospital visit, particularly in terms of breathlessness, which he felt had been happening more and more since his hospital stay. He has felt increasingly wary of exerting himself and has started to limit his own movement. He often drives round the car park of the local supermarket until a space near the door becomes available.

Practically, Alastair has been struggling to maintain his home. Maintaining his independence is a real concern for Alastair, and he feels that he is a naturally strong and independent character. He does not want to be a burden and believes that accessing support could undermine this independence rather than improve it. When there was a mix up with the syringes for his medication, he simply ordered some more himself from eBay.

He was given some contact details for organisations while in hospital but has not been keen to contact them for help.

Despite this, the day after Alastair returned home the British Red Cross visited his house to check on him. Alastair believes they had been in touch in the hospital but couldn't remember the meeting well. They continued the visits for the next few days, providing Alastair with information about

housing options he might want to access in the future.

Even though Alastair didn't take up all the help that was offered to him, he was thankful for the information he'd received about what he can get when he feels ready to access the services:

“**When I got the information, I was glad I had it, that I could fall back on it.**

” Alastair

After a few days, Alastair felt he didn't need their support anymore. He was feeling a lot better and didn't want to be using up their time.

“**After about three days, I was feeling quite well enough to do without them and you feel like you're maybe a drag on their time.**

” Alastair

This support had positive psychological benefits for Alastair. He felt reassured now he had someone he could get in touch with if something were to go wrong. In the past year, as his health has continued to decline, he has been increasingly worried about his future and the precautions he may need to take. The information about support that may be available to him, provided by the British Red Cross, has given Alastair more confidence in his future and his capacity to manage his health should it worsen.

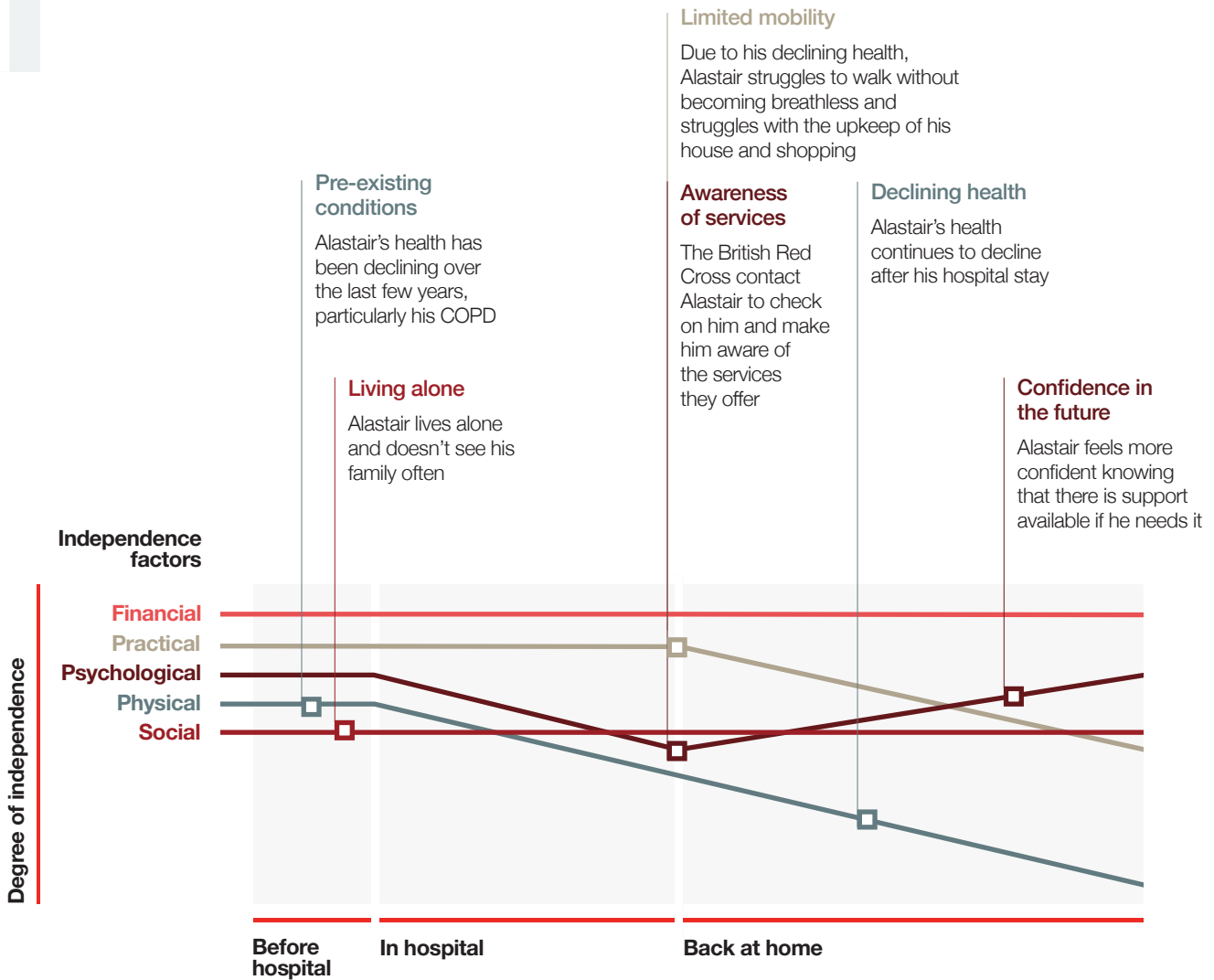
Even if patients do not want to engage with services, it is essential that they are still made aware of what is available and what they entail to encourage living independently and well at home.



“  
It seems like giving in to your condition rather than trying to work through your condition.  
”

Alastair

# Alastair's journey





## Beth, 36

### Mental health crisis and drug overdose, four days in hospital

Beth lives with her daughter and husband in a three bedroom house in a suburban town. She also has a son who recently moved away for university, but who she has visited several times.

Beth was admitted to hospital in the summer of 2018 after taking an overdose. She has struggled with mental health issues for several years, beginning with postnatal depression after her first child and developing anxiety and depression in the last few years. The lack of support and services offered to her and her family following her discharge has made an already difficult transition increasingly hard to manage.

The biggest impact of Beth's hospital stay has been on her psychological wellbeing. Aside from the implications of the overdose she took, she has had a problematic transition to home. Following the overdose, Beth's husband was told it was a 12 hour wait for an ambulance and it was only when she began having serious seizures that one was sent to the house.

Beth was discharged on her third day in hospital and has almost no recollection of the process due to the impacts of the medication and the overdose. She wondered why they chose to discuss discharge and her recovery at the point as she was unable to remember or absorb any of the information she was given. Later at home, Beth was repeating the same questions every thirty minutes. Her husband took her back to A&E, because he worried she wasn't well enough to be home. She was told she had global amnesia and was sent home again.

**“ I felt like something had been missed. I think they discharged me too early.**

**” Beth**

Beth's husband has spent a lot of time looking after and supporting her at home and she has relied heavily on his help rather than

formal services. This reliance has reduced her social network as he's one of the few people who knows the details of what has happened. He said she's also become increasingly practically dependent on him and felt unable to be left alone.

When she was admitted to hospital, Beth had just started receiving counselling from a local support service. After her overdose and hospital stay, she called the service to get some ongoing support but was informed that, because she had been through a mental health crisis, she was no longer eligible for their service. Her husband contacted a crisis suicide service, but he was informed that as the crisis had already past they were also unable to help Beth. This left Beth in limbo, receiving no formal support for her mental health issues. She was offered a re-referral for a counselling service, but this could take up to ten weeks.

**“ There just didn't seem to be anywhere to go for support.**

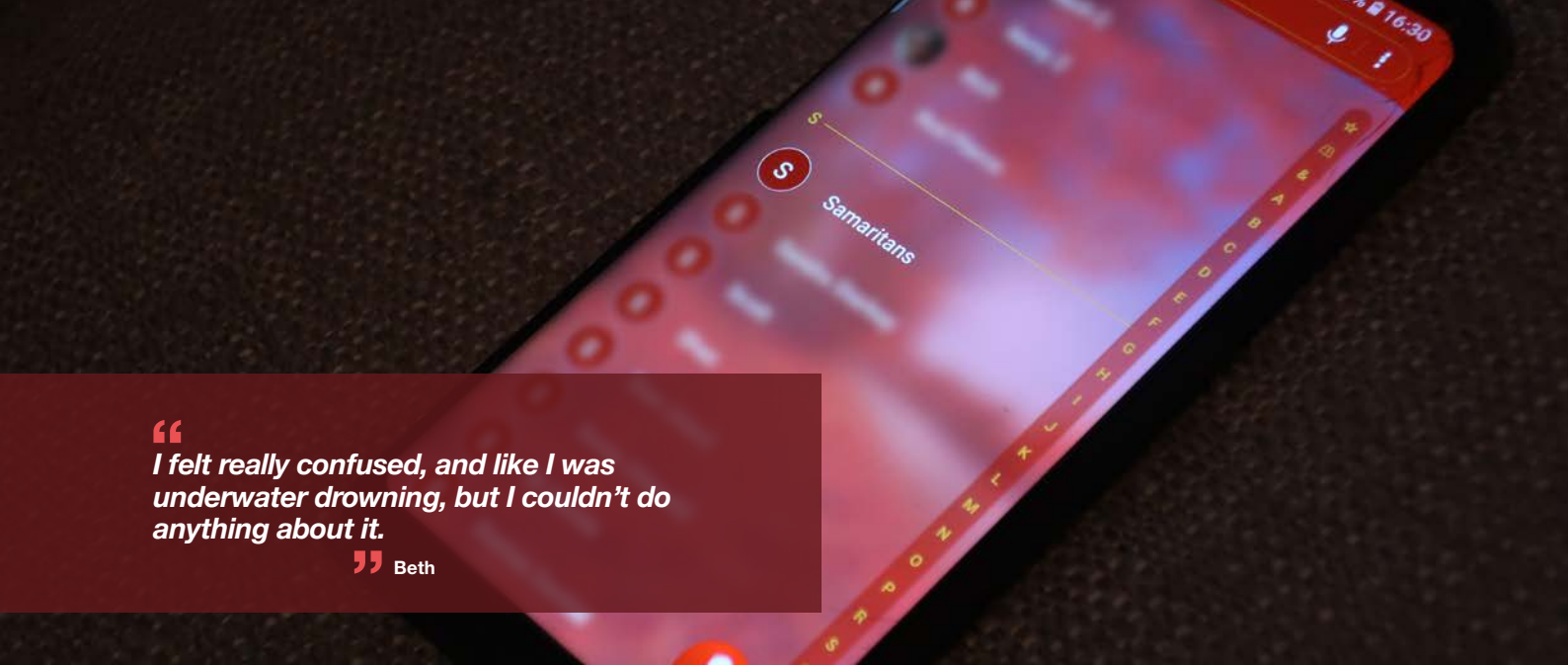
**” Beth**

Both Beth and her husband now regularly call the Samaritans for support. She thinks she's called about 40 times since leaving hospital. She's also now seeing a private therapist weekly at a cost of £50 per session. Financial pressure was one of the triggers for Beth's original diagnosis of anxiety and depression, and this additional cost has placed the family under growing financial strain.

The lack of mental health support has had a serious impact on her recovery. Beth feels abandoned.

She feels fortunate to have her husband to navigate this difficult situation at a time when she was overwhelmed and struggling to understand what was going on.

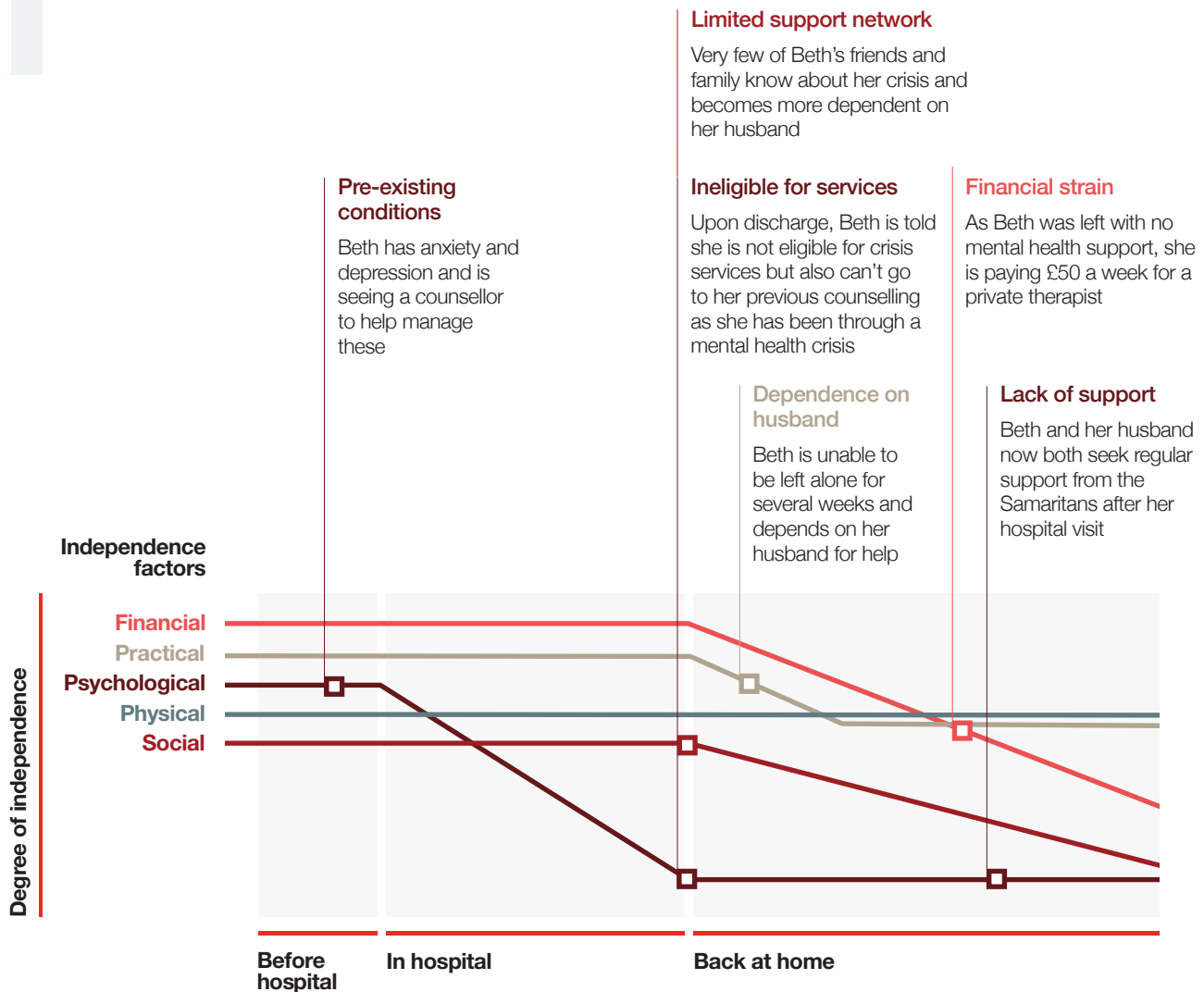
There was no plan or discussion of expectations in the transition to home when she was in hospital, or any clear referrals or signposting to valuable mental health support.



“  
I felt really confused, and like I was underwater drowning, but I couldn't do anything about it.  
”

Beth

## Beth's journey



# 2 What happens in hospital?



For those working in hospital, sending someone home is usually viewed positively: the patient has been successfully treated and now their bed is free for the next patient who badly needs it.

But it's rare for healthcare professionals to see what happens next. A patient's 'discharge' can too often be seen as an event, rather than just one moment amid a much longer transition from hospital to home, and from illness or injury to recovery.

As the previous chapter demonstrated, the reality is that sometimes people coming home from hospital are left with unsuitable, informal care and without the proper knowledge and tools to enable a good recovery.

The British Red Cross 2018 report *In and Out of Hospital*<sup>7</sup> illustrated how safe discharge from hospital is integral to people's recovery as well as essential to 'patient flow' in acute settings.

As this chapter will describe, while professionals are focused on patient flow, processes and clinical fitness, patients and their families have different priorities for their hospital stay and discharge experience. Despite incorporating many of the same events and elements, the professionals' discharge pathway and the patient experience are often poles apart

in terms of the way they are experienced. This disconnect often leads to problems in communication and can affect the patient's understanding and control over their own hospital experience.

The service journey was characterised by technical language, which was often used when describing the discharge process. It also focused heavily on handovers between professionals and between different but similar-looking departments. Emphasis lay on 'clinical fitness' to return home, which can be determined by timelines dictated by doctors, test results and prescriptions, although there were also sometimes unacknowledged emotional elements in decisions around discharge. Together, these dictated the way in which patients were discharged and the way that medical professionals and departments perceived the discharge process.

In contrast, the patient's journey focuses on emotional and social experiences of hospital, professionals and discharge. It is often defined by trauma and uncertainty and characterised by a loss of control and a heavy reliance on others. Recovery and discharge were not thought of in terms of medical fitness but defined relative to 'normality' and a return to baseline wellness situated at home.

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<sup>7</sup> – <https://www.redcross.org.uk/-/media/documents/about-us/research-publications/health-social-care-and-support/in-and-out-of-hospital-report.pdf>

# People's experiences of being in hospital and of being discharged

The patients' and their families' experiences can be described under several headings.

## Motivation to return home and regain independence

During their hospital stay, many respondents spoke about their desire to return home, to what they hoped would be normality and comfort. For some respondents, the desire to return home was on their mind but they left decisions about leaving hospital totally in the hands of the professionals caring for them.

Others, however, were more proactively thinking about what they needed to do to get home and proactively spoke to staff about when they could be discharged.

**Kev** (63, Scotland) had a stroke and was admitted to his local hospital. He spent his first few days in an acute ward, but after "a while" he was moved to the rehabilitative stroke ward. While initially the staff would rush to give him a hand each time he got out of bed, on the stroke ward he was encouraged to do more things to help his recovery. Kev was keen to get home and said the staff encouraged him in trying to be independent.

**“**  
*I was quite keen to go home as quickly as possible, so I worked hard at my physiotherapy and I set myself a goal and that was to be home in time for the World Cup. One of the challenges was to be able to manage stairs – I have a flat with two flights of stairs... so I worked hard for two weeks.*

**”** Kev (63, Scotland)

Several respondents, in different situations, praised the hospital staff's encouragement of developing their independence during their stay as a means of getting home sooner and in better health. When it was encouraged and supported by staff, it tended to be focused on practical and physical independence such as washing, making a cup of tea or getting dressed. People generally perceived these as positive first steps to recovery. Though it was clear during interviews with researchers that other factors of independence (mental, emotional, environmental and financial, for example) were not usually addressed and discussed during life on the ward.

**“**  
*The last day I was there I knew I couldn't get up and shower because I was so ill. I asked one of the girls, 'Could you please wash my hair, it's so greasy?'. They said, 'We're a bit busy now, but we'll come back later.' And of course, they didn't so I had to do it myself. I don't know whether they said all that to make me do it because the next day, when I was home, I was better able.*

**”** Annabel (77, England)

## Taking an active role in recovery

While many patients were keen to get home, not everyone was encouraged and supported to take an active role in their recovery while in hospital. Those who saw themselves as more tenacious and driven, or more confident in talking to the staff, recognised that not everyone would be in a similar position. Some of the respondents were much more likely to let hospital staff do things for them, either because of how they felt at that moment or because of their temperament generally.

Several people felt it was beneficial to have professionals in charge of their care who were responsible for making sure they were okay. This was more common among people who became accustomed to being able to request things from staff, as well as staff doing things for them, and had less encouragement to take steps towards recovery. As a result, they often didn't feel confident about going home to recover or look after themselves.

**Elizabeth** (84, Wales) suffers from insomnia as a result of previously diagnosed PTSD. Due to the clear routine enforced on the ward, she was given her insomnia medication at 8.30pm, however it is only effective for four hours meaning she slept very little during her time in hospital. Elizabeth equally had problems with bed sores and her hearing aid, and due to her reduced mobility was often anxious as staff were unable to help her for 20 minutes.

Although she felt irritated that staff weren't available to help her when she couldn't move to the toilet, Elizabeth also felt she wasn't encouraged to recover and do anything other than lay in bed. Elizabeth might require further surgery on her leg to help her walk if it doesn't heal, however she is reluctant to go back into hospital after her most recent experience.

“

**I don't want to go back into hospital, I just don't like it. I can't be myself in hospital, it's just miserable for me. I'm not like the old dears who just see their days away in bed, I like to be sitting up and doing something.**

” Elizabeth (84, Wales)

In contrast, after **Colleen** (79, Northern Ireland) had an operation on her broken foot, she was asked how she felt about returning home the next day. She felt she had received 'first class' treatment in the hospital and felt comfortable with the staff. She requested to stay in hospital at least another day so that she had staff there to look after her and ensure she made a good recovery.

“

**They were not speaking to me as if they were some kind of demi-god at the end of my bed. It was, 'Colleen, how do you feel? Colleen this, Colleen that.' It was lovely.**

” Colleen (79, Northern Ireland)

## Social life of the ward

Regardless of how long people were in hospital, many people became used to the routine of being on the ward such as meal-times and other daily patterns such as visiting hours and bedtimes. In particular, when comparing life at home with life on the ward, many reflected on how social it can be. For some, this made it a positive place to be and sometimes this meant they didn't want to leave.

“

**I felt a certain amount of...deflation when I got home. No camaraderie or chat anymore, like in the hospital. Just... get on with it.**

” Kate (65, Wales)

Many of the respondents also had lots of people who came to visit them in hospital, spending extended time with grown-up children and friends.

But some respondents felt excluded from the hospital socialisation while they were on the wards.

**Arif** (56, Scotland) was allocated his own room in hospital. While he said that most of the hospital was designed this way, he worried there was a more sinister reason he was kept in a single room that he hadn't been told about. He thought the lack of communal wards in the hospital was a shame and he felt quite isolated.

Some respondents found the 'communal' nature of the hospital problematic and disruptive, further driving their desire to return home.

After hip replacement surgery **Flora** (59, Scotland) was put in a recovery ward with three other patients, one of whom had severe dementia. This patient kept wandering around after her surgery with her new hip, getting totally undressed and scratching at her wound. Flora kept ringing the bell for the nurse because she was so worried about the patient's safety and recovery. Flora felt the nurses were annoyed with her for ringing the bell. This patient prevented Flora from sleeping well the whole time she was in the ward; she cried out of exhaustion every morning. After seven nights on this ward, Flora's daughter told the nurses that her mother had to be moved somewhere quieter.

“  
**I don't know if this was the right thing to do or not or I had any right, I've never been to hospital, but I was so happy when they moved me.**

” **Flora**  
(59, Scotland)

## Lack of clarity about what is driving discharge decisions

For many of the respondents, there was a lot of confusion about why things happened when they did, during their care in hospital and their discharge experience. While most people admitted their time in hospital was hazy, because of illness or medication, few people could remember discussing a specific discharge date or a discharge plan. More often than not, their impending discharge was mentioned the day before or the morning of the day they were going home.

“  
**She texted me after a couple of days there to say she could come home. I was a bit shocked, but to be honest, it was a relief. It was what I wanted to hear, so I didn't really ask any questions.**

” **Richard, Beth's husband** (36, England)

Some respondents weren't clear what was wrong with their health during their whole hospital experience and discharge. This lack of understanding meant that they often weren't sure what the next steps were, how to best help their own recovery, or why decisions about them were being made in hospital.

**Angela** (78, Wales) was admitted to hospital after feeling nauseous and registering a blood sugar level of over 30 units. During her time on the clinical decision unit, she felt the staff involved in her care weren't clear when describing the decision made about her health. She received little information about what was wrong with her and the information she was given was different from different staff members. She wasn't sure which person was ultimately responsible and whose opinion she should trust.

“  
**They told me first of all it was a urinary infection, then it was a kidney infection, then it wasn't, so I don't know what it was.**

” **Angela** (78, Wales)

Three weeks after her stay, Angela still wasn't sure why she was admitted to hospital, nor who was responsible for her care once she was discharged. She was unsure about what the next steps for her recovery were, particularly after receiving a letter from the hospital which she found very difficult to understand. She didn't know who to contact when she got home.

**Cat** (84, Northern Ireland) was also confused about the cause of her stomach ulcers that had necessitated her hospital visit. Jill, her daughter, only realised during the interview with the researchers that her mother's ulcers had been caused by an allergic reaction to her medication. Not understanding the cause of her illness when she was in hospital meant Cat was unable to be instrumental in her own recovery.

When patients had a good understanding of the reason for their admittance they were better able to take ownership of their own recovery process and generally found the hospital process more positive.

**Carina**, for example, (67, England) was admitted to hospital after experiencing sustained dizziness and passing blood. These symptoms were the result of a stomach ulcer caused by overconsumption of ibuprofen. During her time in hospital, Carina spoke with her doctors daily and continually asked about her progress and when she could expect to be discharged.

“**I needed to know what was going on and they did get to the bottom of it.**

” **Carina (67, England)**

Fully understanding her diagnosis allowed Carina to take proactive steps towards furthering her own recovery at home. Since coming home, on the advice from medical professionals, she has improved her diet (specifically researching food and teas that will not further damage her stomach lining) and has stopped drinking alcohol.

## Not thinking about long-term recovery

Perhaps due to the emotional stress of hospital admittance or a general lack of understanding of their condition, people were not often actively asking about or trying to plan for longer-term recovery. People prioritised short-term goals for recovery, for example, simply getting home. For some, family and friends could help plan for shorter-term tasks, such as the heating the house or filling the fridge with food, but for those living alone these considerations could easily be missed prior to discharge.

When combined with a lack of conversation by hospital staff around these needs, some patients were left with no clear idea of what life would be like after hospital.

**Phillip** (81, England) had greatly reduced mobility following his stroke. Following the distress of being in hospital for over four months, Phillip and his wife's main focus

was getting him home. However, once home, his wife Anna realised the huge financial, physical, and emotional strain that Phillip's care would now place on their life – something she had not been prepared for while he was in hospital:

“**I wouldn't say there was any real plan at all, there was nothing I can remember – you're just kind of dumped in it. You're quite glad to have somebody home, but you just expect to get on with it somehow.**

” **Anna (84, England)**

**Anna** felt that small details about the care that Phillip would require, such as the amount of washing or the large number of wet wipes she needed to buy, were not communicated to her.

For others, a lack of understanding about their illness, symptoms and medication caused similar challenges to long-term recovery.

**Sharon** (76, Northern Ireland) was admitted to hospital after a heart attack and she was informed she also had pneumonia. Upon leaving hospital, Sharon was told there was a “query” about whether she really had had a heart attack. She also did not know how she had contracted pneumonia. After she went home, she was unsure about whether she should go back to life as normal. She stopped going out in the cold and wind and stopped using her exercise bike because she had been exercising at the time she fell ill.

She was also not sure whether she should continue taking her blood pressure medication.

“**I found that confusing about whether I should take those tablets and the ones I already had at home.**

” **Sharon (76, Northern Ireland)**



*She rang her chemist who told her to continue only with her new medication. Clearly, taking medication when the purpose is not clear or not knowing whether to continue taking existing medication could lead to problems.*

The focus by professionals and patients on short-term milestones as opposed to long-term planning meant that some people were less instrumental in their own recovery than they could have been, or that the shock of coping at home has been emotionally strenuous.

## **Don't know what support is available**

People didn't always know what support there was available to help them prepare for recovery at home. This was compounded by difficulty understanding distinctions between secondary, primary and community care.

“  
*I've never even thought of it until you said it but yes I suppose it would have been nice if someone popped in the day after I got back and just asked if I was getting on okay. I don't know what help's available.*

” **Graham (64, Northern Ireland)**

For **Alastair**, an extremely independent man who has lived alone for the majority of his life, being told by British Red Cross staff what options were available to him was reassuring. In the past year, his COPD has been getting increasingly worse, resulting in two hospital trips, which has made him start thinking about his future, although he's not ready to make big changes yet.

“  
*I have been worrying about not having anyone if something went wrong. It's just nice to know what you can get.*

” **Alastair (68, Scotland)**

People were sometimes unsure where to turn for extra information about the services they had been signposted to. Simply being signposted in hospital (especially when still unwell) or by post/leaflet was not always effective and, in some cases, people required extra emotional support to attend a service in the community, or, practically, transport to get there.

**Natasha** was recently admitted to hospital following alcohol-induced seizures. Natasha was signposted to several services when she visited the GP after being discharged from hospital, but felt her primary need was emotional support:

“  
**It’s all very well having all these services, I know all about them, I just can’t make it there when I’m not feeling good.**

” **Natasha (52, Scotland)**

In some cases, there is poor take-up of support services because of unclear information or misunderstandings.

As the manager for an older people’s voluntary service in the Lothians, **Jenny** has worked hard to engage the healthcare staff she works with, whom she believes don’t always view the community-based hospital service she offers as a “concrete” option. She believes the service is misperceived as one that helps people with odd jobs – rather than a form of practical support that addresses the emotional side of regaining independence.

Confusion about voluntary services or lack of awareness might have meant that opportunities to signpost those who were not eligible for social care were missed.

## Don’t want to be a burden

Patients’ references to the strain the NHS is under were heard across the sample and, in some cases, had influenced the extent to which people asked for help. This pre-conceived knowledge of NHS pressure was sometimes articulated alongside pride or the desire to ‘not make a fuss’ resulting in a tendency to believe ‘I can do without’.

Not wanting to be a burden often led to people understating their need or not being open with health professionals.

When **Graham** (64, Northern Ireland) last went to hospital because of a cardiac arrest, they treated him for that, and he went on his way. But Graham also had prostate cancer and difficulties at home. He was reluctant to admit anything was wrong because of his pride, combined with guilt about using up scarce resources.

“  
**I’m sure I’ve been asked whether I’ll be okay at home. I always just say yes. Because I am alright. When I have said, nothing ever comes of it. I think it gets lost in the paperwork. I think there’s too much to do.**

” **Graham (64, Northern Ireland)**

Some people did not ask for more information about their condition, their medication or what to expect from their recovery because they felt guilty about the idea of ‘bothering’ the hospital staff. In some cases, this meant people were going without basic items that could have improved their experience in hospital.

**Agnes** (82, Scotland) did not want to ask the nurses for extra clothes which she didn’t have with her when she’d been admitted. **Elizabeth** (84, Wales) similarly, was given a gown that didn’t close properly and found herself shuffling around the ward with her back exposed “because you don’t want to make a fuss”.

Sometimes, however, the narrative around NHS pressure could have a more serious impact on patient experiences.

After a fall, **Annabel** (77, England) was admitted to hospital for a week where she was diagnosed with sepsis. She was aware of the media narrative around elderly people using up NHS resources and being in hospital for long periods of time.

“  
**We’re constantly told we’re blocking beds!**

” **Annabel (77, England)**

When Annabel was starting to get better she joked with her doctor, saying “I told the young guy, really you need my bed”. While this comment wasn’t necessarily taken seriously by anyone in the hospital, Annabel was discharged when she still felt fairly weak. Fortunately, her family were able to look after her at home.

When **Sinead**, a retired nurse, (65, Northern Ireland) felt unwell, she went to her GP – it turned out she had pneumonia. They offered to call her an ambulance then and there, but she decided to drive herself – knowing “how much pressure they [the NHS] are under”. Similarly, in hospital, a social worker asked Sinead about her home situation – with a view, according to Sinead, to seeing if she needed to set up social care. Sinead told the social worker she had lots of people to look out for her, effectively denying care before it was properly offered. She reasoned it was best that they focused their efforts elsewhere.

This desire to not be a burden to staff or family and friends could be problematic for longer-term recovery. People who turned down care packages or failed to fully understand their illness and recovery because they didn’t want to be a bother could find they were unable to fully understand their illness or required more support than they’d anticipated later in their recovery.





# A systems perspective

## 2

While there is substantial documentation from a range of organisations (including NICE, NHSE, NHS Improvement, individual trusts and think tanks such as the King's Fund) that could be considered confusing, most of the ideas around what the process should involve are clear.

- Single point of responsibility – a professional in any role whose responsibility is to ensure the smooth discharge of the patient (e.g. a discharge co-ordinator)
- Involve carers/family – they often know the most about a person's lifestyle and needs and so should be involved
- Multidisciplinary teams<sup>8</sup> to organise and manage discharge
- A discharge plan – this should be shared with the patient and their family<sup>9</sup>
- All patients have an expected discharge date<sup>10</sup>
- Use Discharge to Assess approach – don't over-assess people in hospital, focus on getting people 'home first'<sup>11</sup>
- Establish and utilise a trusted assessor to reduce delays of transfer of care between hospital and home<sup>12</sup>
- Senior review before midday – ensuring a clinician able to make discharge decisions reviews a person's care and clinical fitness for discharge early in the day
- Early discharge – aiming to get a third of people home by midday<sup>13</sup>
- Automatic home assessments triggered for people who have come in and out of hospital several times within a few months<sup>14</sup>
- People who live alone, have poor mobility and have been in and out of hospital due to falls should automatically have their home assessed for falls hazards before they are discharged<sup>15</sup>
- At a minimum, transport home from hospital should be offered to all those who live alone, who are leaving hospital alone and who have poor mobility.<sup>16</sup>

As ever, the challenge is implementation – ensuring organisational cultures,

**8** – A multidisciplinary team (MDT) is a group of health care workers who are members of different disciplines (professions e.g. Psychiatrists, Social Workers, etc.), each providing specific services to the patient. The team members independently treat various issues a patient may have, focusing on the issues in which they specialise: <https://www.hse.ie/eng/services/list/4/mental-health-services/dsc/communityservices/multidisciplinaryteam.html>

They operate in hospitals and, increasingly, in the community. The NHS wants to create fully integrated community-based health care supported through the ongoing training and development of MDTs in primary and community hubs: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf> p.15

**9** – These 5 points stem from <https://www.nice.org.uk/guidance/ng27> and <https://www.nice.org.uk/guidance/qs136>

**10** – <https://improvement.nhs.uk/resources/safer-patient-flow-bundle-implementation/>

**11** – <https://www.nhs.uk/NHSEngland/keogh-review/Documents/quick-guides/Quick-Guide-discharge-to-access.pdf>

**12** – <https://improvement.nhs.uk/resources/developing-trusted-assessment-schemes-essential-elements/>

**13** – These 2 points come from <https://improvement.nhs.uk/resources/safer-patient-flow-bundle-implementation/>

**14** – <https://www.redcross.org.uk/-/media/documents/about-us/research-publications/health-social-care-and-support/in-and-out-of-hospital-report.pdf>

**15** – Ibid

**16** – Ibid

collaboration and systems facilitate the delivery of these goals.

Implementation is arguably made harder by the lack of data about how often these ideals are delivered, what the outcomes are for patients when they are, and what outcomes patients experience when they are not. Data generally about discharge processes and outcomes is sparse, with significant gaps and huge variation in what is collected across the four nations. As of March 2019, NHS Digital has announced it will publish emergency readmissions data for Clinical Commissioning Groups (CCGs)<sup>17</sup>. At the time of fieldwork and writing, the most useful data that seem to be used and collected are emergency readmission data collected by Healthwatch England (not covering the other nations) and delayed transfer of care data used by NHS trusts.

However, this data was sporadically collected. As a result, it has been hard for staff at a hospital level to see the case for changes in their culture and practices around discharge as the effects are hard to measure.

This section explores what hospital discharge looks like on the ground across the hospitals visited, in comparison to what is understood as a good process, to try to understand how challenges in hospital discharge may lead to some of the problems described in the preceding parts of the report. It describes hospital culture, communications between staff and with patients and the systems and processes that shape the discharge experience for staff, patients and their families.

## Who is in charge of the hospital discharge process?

NICE guidelines<sup>18</sup> outline the need for a person or people to act as a central point of contact around someone's discharge from hospital, for health and social care professionals and family.

In the hospitals visited, the 'discharge co-ordinator' was often based in the discharge lounges or hubs, rather than a member of staff specific to a patient. Discharge planning was frequently tacked on to the patient journey at the end. In one hospital, a sister observed how especially junior doctors tended to leave any planning for discharging patients to the nurses they worked alongside. This set-up sometimes meant discharge planning was not integrated into the thinking of all staff who had responsibility for the care of, and clinical decisions concerning, a patient.

The discharge planning that these teams did was sometimes sporadic and characterised more by the decision-making of individual staff, than reflective of a system and clear processes. For example, in one hospital, discharge dates were made up and based on a member of the team's upcoming birthday for the sake of putting something, rather than being based on a proper assessment of need. In those cases, the impact on patients directly and the ability to plan for their support must have been hindered. In another instance, the expected discharge date for a patient who was dying was changed to avoid others in the system 'boarding'<sup>19</sup> him (i.e. by moving him to an outpatient ward to free up his bed on his specialist ward) because they could see on the system that his expected discharge date was drawing close.

Professionals also struggled to admit that their emotional attachment to certain patients and wanting them around the wards could impact their reflections on discharge. Some staff had patients that were frequently readmitted that they described as people they liked having around. It was much rarer for them to reflect on whether those same patients needed something different to happen in their discharge experience to reduce readmission.

There was inconsistent awareness of Discharge to Assess/Home First<sup>20</sup> and other initiatives (including Red2Green and

17 – <https://files.digital.nhs.uk/FD/458CEE/Emergency%20Re-admissions%20Summary%20Position%20Paper%201.pdf>

18 – <https://www.nice.org.uk/guidance/ng27>

19 – A patient who occupies a borrowed bed is described as boarding <http://www.acutemedicine.org.uk/wp-content/uploads/2014/11/Plenary-5-1030-Wrong-Place-Anytime-Why-Boarding-is-Bad-for-Patients-Hospitals-and-Healthcare-Systems.pdf>

20 – <https://www.nhs.uk/NHSEngland/keogh-review/Documents/quick-guides/Quick-Guide-discharge-to-access.pdf>



the SAFER discharge process), aimed at reducing the time people spent in hospital, among health and social care professionals across this work. During the fieldwork with patients and their families and with health and social care professionals, the research team found limited evidence of Discharge to Assess or trusted assessor initiatives being delivered in practice. The clearest example was in one hospital that had step down beds available, used for people who were deemed clinically fit for discharge but had rehabilitative and/or social care needs before they were able to cope at home. This hospital was also trying to deliver Red2Green days, which had indicated that wait periods for Occupational Therapy (OT) assessments was causing delays in helping people to go home. The team said that they had hired more OTs as a result of this data. The team had some challenges supporting reablement. They tried to get teapots for their patients to make their own tea and coffee, but were told they were not allowed due to health and safety.

Many of the professionals' decisions about discharge were in the context of hospital-wide patient flow or were based on purely clinical assessments, rather than on holistic assessments including non-clinical needs essential to prepare patients for leaving hospital. In one hospital, clinicians mentioned that they would try to disconnect themselves emotionally and physically from their patients and their needs as a coping mechanism. Researchers were told that clinicians worked in specialist teams and rarely strayed out of what they consider to be their bounded professional role. This could result in a short-term focus in terms of the assessment and their understanding of their patient's life. This view has been extensively written about by Scotland's chief medical officer in the *Realistic Medicine Series*<sup>21</sup>.

## Challenges in co-ordination between teams

In one hospital a patient was taken home without all their belongings from the ward or their medication because the ward team and discharge lounge had different information about the patient. In other situations, patients were waiting until the end of the day for review by doctors to be discharged, leaving families worried about getting equipment in time to have it at home overnight.

Many of these challenges stemmed from the clinical handoff, with the communication of patient needs between ward staff to those working in discharge lounges. Paperwork that was shared between wards and the discharge lounge – and then often onto social care – were discussed by many across the hospitals as being completed inconsistently by staff across the wards. According to a hospital social worker: “Ninety per cent of the time I ignore what they've written and just go and speak to them.” Transferring information was made more difficult by outdated technology. In one hospital, there was one paper form to organise transport for those leaving the hospital and during the research site visit, the form was being transported on foot by the nurse since the fax machine that would have usually done the job was not working.

The second challenge of co-ordination came in the communication between health and social care. Despite the different types and degrees of integration of health and social care in each of the four nations<sup>22</sup>, challenges in information sharing, engagement in each others' work and clashing priorities for budgets continue to exist in all four nations. In one hospital, an adult social worker embedded at the hospital explained how social care delays can sometimes

21 – <https://www.gov.scot/publications/chief-medical-officer-scotland-annual-report-2015-16-realising-realistic-9781786526731/>

22 – In England, health and social care teams are on a journey to working more collaboratively since the 2012 Health and Social Care Act introduced a number of changes designed to promote the closer integration of services. Health and wellbeing boards were created and were tasked with assessing their local population's needs, developing a joint health and wellbeing strategy, and promoting greater integration of health and care services. The Care Act 2014 also placed a duty on local authorities to promote the integration of care and support services with health services.

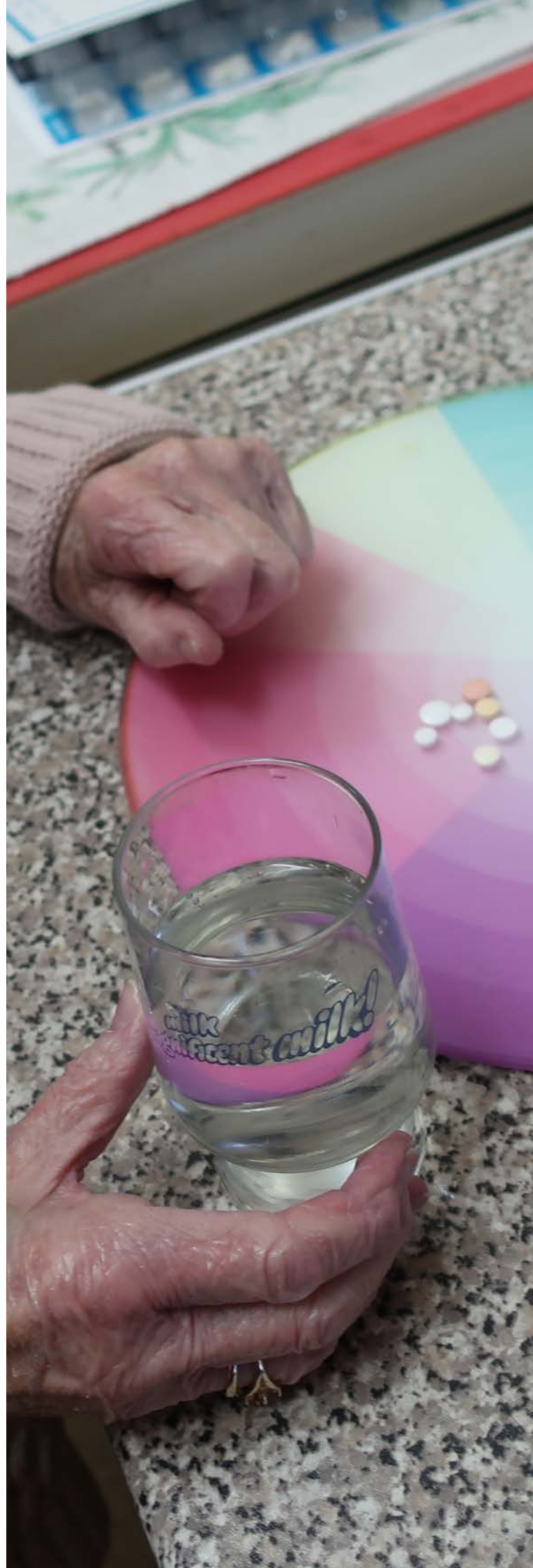
Wales is also trying to move towards integration, set out in 'A Healthier Wales' from the Welsh Government in 2018. Local Health Boards and Local Authorities have a statutory requirement to work together to address the well-being of the population.

In Scotland, health and social care have been legislated to be integrated since 2016. 31 Integration Authorities exist to ensure providers of health and social care are responsive to the needs of the population.

Health and social care in Northern Ireland has been structurally integrated since 1973. In 2009 the Health and Social Care reform act created a large single commissioning body (Health and Social Care Board, or HSCB) for health and social care services.

be preventable because they originate from miscommunication or the absence of long-term thinking among healthcare staff. An ongoing challenge for this social worker was when clinicians made assumptions about patients needing a care home before the patient has been assessed, or when healthcare professionals sent referrals from people who are ineligible for support. There were also cases where healthcare professionals have requested a package of care as their next step, but the social care team feel that with a few more days rehabilitating in hospital, the package of care can be shorter with the patient going back to being independent more successfully.

Where health and social care teams were not co-located, the physical distance between them could be a challenge too. Health professionals across multiple locations suggested that their local social care colleagues were difficult to get hold of and, as a perceived result of the physical distance between them, they had weak personal relationships with specific members of staff. Word of mouth, the power of soft skills and reliance on personal relationships were in lieu of universal agreement on effective collaborative strategy. In one hospital, a discharge liaison spoke proudly of having accrued the email addresses of the local social workers over her tenure. She did not, however, have all of their direct phone numbers. She was due to retire soon. When staff members had previously worked in co-located health/social care teams, they reported seeing more effective care. A nurse in the discharge lounge in one hospital had previously worked in an integrated orthopaedics team for patients who had hip and knee replacements with physiotherapists and occupational therapists, as well as doctors.





The team had been successful in reducing delays for transfers of care; she attributed its success to a more flexible way of working when organising care schedules, because of the ability to have face-to-face relationships with her social care counterparts. There were some examples of efforts being made to make better use of the voluntary and community sector to support those being discharged from hospital. In Ceredigion, the British Red Cross, Care & Repair, Citizens Advice and Age Cymru have been running a Third Sector Community Resource project, funded through the Welsh Government. People were referred through to the service at the point of hospital discharge. Since October 2016, when the project started, they have supported around 450+ clients. Throughout the project, the voluntary care partners have had several sessions with statutory partners to identify issues around the discharge process – what was potentially unsafe, what wasn't done well, what was done well and how to learn from mistakes. They are also investigating opportunities for earlier third sector intervention via attendance at multi-disciplinary team meetings where cases and discharge are being discussed. However, a lot of room for progress remains.

**“  
We are on a journey to convince the statutory partners that these services are necessary and beneficial. There is still work to do.**

**” Simon Wright, Age Cymru Ceredigion**

## Accessing social care packages and wider support

Healthcare professionals within acute settings across the four nations continue to have strong narratives about the problems inherent in social care. This seemed to be regardless of national language around health and social care integration. Especially persistent was a narrative about a shortage of carers causing delays in hospital discharge. Many healthcare professionals, across the UK, had stories about patients who were getting worse waiting on the wards for a care package.

**“  
Social care is definitely the main issue. If I try to get a patient on their radar as needing social care support, there's no flexibility from social care. They just say 'they need an OT assessment' and then there's nothing more.**

**” Ward and discharge lounge nurse**

Some health professionals, across the four nations, were aware of the nuances in the system around the eligibility and availability of care packages, and as a result tried to find the best time to register someone for help. In more than one hospital, care packages have to be reapplied for and restarted if someone comes back into hospital or have to extend their hospital stay so staff try to keep people in until they feel confident they'll be able to cope better. They then try to make applications and get people discharged within as quick a possible time, to reduce the amount of potential delay in receiving the package and preventing them coming back.

The impact of budget constraints in social care and the ongoing challenges in accessing care became apparent during the research. For example, Occupational Therapists in each hospital were some of the hardest people for the research team to reach. For some, the team waited for several months for a response and in others the response never came. Many talked about their workload and issues around time for supporting each person being reduced.

In another hospital, the patient flow liaison, linking people within the hospital to social care and support from the voluntary sector, had recently had their remit reduced. While they used to deliver support to people across two counties, this had been reduced to one. Every morning the liaison walked around the hospital and tried to identify people who lived in the specified county to understand what's happening with their social care, if they have a case worker and make the appropriate referrals if they need them.

One of the remaining challenges, within this context, was that clinical staff, and some social care staff, were unclear about where to signpost people who didn't qualify for social care support. Few knew what organisations provided different types of help for patients and few seemed to be directing

patients towards other types of help. In one hospital where British Red Cross's assisted discharge service had a team based on site, the team had to walk around the hospital every single day to raise awareness of their presence and try to find patients who could benefit from their support. While some staff did signpost patients on, and patient liaison were aware of their presence, it felt to them that clinicians continued to forget that they could help.

“  
***They need a constant reminder that we're here.***

” **Assisted discharge service**

In some hospitals, there were specific teams or services to better connect patients with support (such as signposting teams, liaison officers, care navigators). However, these didn't always have capacity to reach all the patients that might have different support needs. For instance, voluntary care workers in one hospital who offered a hospital-to-home service were in high demand though short-staffed, with lots of wards wanting to use their services but only one volunteer per day of the week on site.

## Initiative fatigue

The implementation of initiatives and strategies to achieve an ideal discharge was inconsistent, and this was sometimes compounded by changing senior staff and related shifts in priority and direction. A change of management in one hospital meant various work streams had been put on hold, causing uncertainty around ongoing discharge initiatives amongst staff.

Researchers also found examples where the initiative lost momentum in delivery within each of the hospitals visited. For instance, though there were physical signs of either one or both the Red2Green and End PJ Paralysis posters and leaflets, for most, these posters didn't equal action. The commitment to these initiatives as a means of improving patient flow and hospital discharge experiences was sometimes limited.

“  
***We have daily meetings to talk about our Red2Greens. It's like with anything new, though, people run with it at first, then they drop it.***

” **Discharge manager**

Where discharge lounges existed, the extent to and way in which they were used also varied, often ward-by-ward. In one hospital, the discharge lounge was effectively used as a waiting space or transport service. The staff in the lounge frequently booked transport home for patients, which meant patients were not asked about their living conditions or financial situation. Despite trying to convince doctors and nurses of the value of utilising the discharge lounge, some days the lounge did not fill up. Researchers were shown how discharge lounge staff would send text messages to ward staff to tell them of spaces in the lounge to try and increase uptake.

In another hospital where a discharge lounge was being trialled to improve patient flow, it was described as a “daily grind” for senior managers to promote it. Paradoxically, despite these efforts, some lounge staff felt that other colleagues didn't think they were pulling their weight, when they walked by and saw the lounge empty. The staff in the lounge suggested that it was underused because once a patient was sent to the lounge, the empty bed on the ward was perceived as more work for ward staff, in terms admitting a new patient, changing beds and getting to know their new needs.

Discharge checklists were used to varying degrees across the nations. Both health and social care staff commented on the difficulties when they were not used effectively or inconsistently filled out. Some discharge checklists shown to the researchers only contained clinical information rather than wider information significant to patients' recovery. Patients spoken to within the sample also did not recall having a systematic conversation about discharge or anything they would consider similar to planning for their discharge.

Multidisciplinary teams (MDT) within hospitals that span health and social care are also a recommended part of the guidance around discharge<sup>23</sup>. In one hospital visited, daily MDT meetings saw staff discuss patients on the ward before their discharge to enable a holistic approach to discharge, but this was not consistently utilised across all wards.

## Short-term pressures vs long-term goals

Patient flow and the ideal discharge process sometimes felt in conflict. Within this research, short-term goals, such as the need for beds, meant reducing delays and promptly discharging people from hospital were a focus. Less attention seemed to be given to consideration of the patients' future trajectory at the point of discharge to help them stay out of hospital. As a result, some people seemed to be sent home underprepared.

A nurse who had been nursing for thirty years perceived a cultural change where the drive for efficiency had affected nurses' resources to rehabilitate patients:

“*I've asked other nurses why they are walking their patients to the toilet and they respond “It's just quicker.” Sometimes nurses help their patients too much, but it's not my place to tell other matrons how to run their wards.*”

” Discharge lounge nurse

In other cases, healthcare professionals, across hospitals, were so worried about patients injuring themselves, they tried to limit their movement around the ward, even if it would be beneficial for their recovery and life after discharge, and potentially the likelihood of their readmittance. In one hospital a patient was classed as a 'wanderer' if they got up to go to the loo and stretch their legs by walking around. Members of the medicine for the elderly ward team encouraged one elderly, visually impaired, but mobile, woman to stay in bed

because they worried she would have a fall. They did not discuss how she should cope when she got home, where she would be staying on her own. They also did not consider the fact that this patient was visually impaired before she came to hospital and had managed on her own until then.

“*We do a lot for them, so a lot of them don't want to go home.*”

” Ward clerk, medicine of the elderly ward

Processes were often characterised by short-term fixes or proxies that eased the day-to-day management of the hospital. In at least one hospital, some expected discharge dates were arbitrary. Keeping track of the patients in the hospital sometimes meant running around 'counting people', with a lot of duplication of data. This information was easy to lose and doesn't really give a sense of the human needs within the system. In one hospital, in the absence of clear data, hospital managers tried to keep a handle on patient flow by comparing the people who came in to the ED (ins) with the prescriptions written in the pharmacy (outs).

Decisions were also directed by the need to reach certain targets. In one hospital, there is a pre-12pm target for discharging patients. Staff told researchers that this was because the patient transport service has two windows for slots between 8am–12pm and 12pm–8pm. They didn't explicitly link this to the SAFER patient flow bundle<sup>24</sup>, but the intention seemed to chime with E – early discharge. As a result of this policy, the discharge lounge at this hospital saw a rush of patients needing to be discharged around 11.30am, meaning the discharge of some patients was under significant time pressure.

What happens during hospital and at the point of discharge is key for patient recovery in the long-term but sometimes the immediate patient flow issues or other measures taken for efficiency take precedence over these considerations.

23 – <https://www.nice.org.uk/guidance/ng27/chapter/recommendations>

24 – <https://improvement.nhs.uk/resources/safer-patient-flow-bundle-implementation/>



## Role of patients/families in patients' own recovery

Despite a commitment to a smooth and well thought-through discharge process, professionals sometimes felt the health and social care system didn't always encourage patients and their families to help achieve this ideal.

Researchers were told how patients, for example, aren't always open or forthcoming with their own information. This could be for several reasons, including misunderstanding what was needed, the impacts of medication, poor memory generally, the desire to get home quickly or concerns about losing their independence if they suggest that they cannot cope at home. Among the patients within our sample, it was often a combination of these factors. In one hospital, occupational therapists did not always have time to verify what they are told by patients regarding, for instance, their social support, finances or fitness of home. GP district nurses were sometimes able to help verify the information given if they knew the patient (but it meant having to ring them up to ask).

“

**People say anything to get out of hospital.**

” Catherine Glenn, Belfast Central Mission

There was also a perception that the focus on short-term pressures, as mentioned previously, and therefore the style of treatment of patients in hospital could shape patients' expectations of support and recovery. From observation within the four hospitals and from the patients and their families included in this work, the data showed that hospital care led to people getting used to staff doing things for them. This could have implications for decisions made by the patients and their families throughout their recovery. The nurse in charge of the step-down unit in one hospital saw these impacts playing out in her care, expressing frustration with some patients who she saw as unwilling to take action with their own recovery when they could.





For example, some were refusing to do their physiotherapy exercises on the days when the physiotherapist didn't come to visit.

Sometimes family members of patients also had a negative impact on the discharge process according to hospital staff. A staff member in the discharge lounge believed that while almost all families want to be contacted with updates, when it comes to caring for the patient at home families are reluctant, worried or fearful to take on this responsibility. A discharge lounge manager told researchers that sometimes families who were able practically, were unwilling or anxious to be responsible for the care of elderly mothers/fathers etc. before their package of care came in to place.

Families could find caring for older relatives very challenging and were unable both practically and emotionally to cope with all aspects of the care, as the research has shown. Jeff Hawkins, CEO of Age Connect Wales said family issues can be a challenge to smooth discharges and the staff in his charity frequently act as a go-between for hospital staff and families.

## A note on emergency readmissions data

The ways the ideal discharge process affects readmissions would be informed by relevant data, but there are significant gaps. This makes it hard to draw conclusions, present a solid evidence base for targeted improvement or to measure the effectiveness of current initiatives. As of March 2019, readmissions data will be mandatory and published for CCGs, as announced by NHS Digital in January 2019<sup>25</sup>.

As reported by the National Audit Office (NAO), readmissions data 'can serve as a warning indicator that local practices may not be providing the required quality of acute care and discharge planning'.<sup>26</sup> According to Healthwatch, however, systemic collection of data around readmissions does not exist.

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***It's not enough for the individual clinician on the ward to understand what has gone wrong when someone gets readmitted but actually the whole system has to be learning about what is going wrong.***

” **Jacob Lant, Healthwatch**

On top of this, “collecting this [type of] data is simply not a priority. At the end of the day, it's still another form that needs to be filled in” (*King's Fund*). Pressures on trusts and hospitals mean that time dedicated to learning from the available data is limited.

In one hospital, there was a coding office where the staff accessed the system to retrieve a list of people who had been discharged but whose data hadn't yet been processed. They print off the list and walked around the hospital with a trolley to collect patients' paper files. They then used two large reference books to find the codes for diagnoses and procedures and input them for each patient. Depending on the length of their hospital stay, this could take up to one hour for each patient. Records from various visits were joined up, though this was mainly to make sure procedures didn't get mixed up, for example, when someone had a surgery too soon after a previous surgery. While the coders believed that the information fed into a national database to help inform statistics (for example, to learn how much each patient costs the NHS), they could not say how and if the senior management were using the data to learn about admissions.

Where data was collected (at the time of fieldwork), it was on a service-by-service basis. What happened to patients as they moved between services across health, social and community care was not captured<sup>27</sup>. The transition between services in the handover of care can be a vulnerable point in time when problems are likely to arise. In addition, services are not yet sharing data systematically between themselves. The Welsh government and local authorities receive data they provide to the Local Health

25 – <https://files.digital.nhs.uk/FD/458CEE/Emergency%20Re-admissions%20Summary%20Position%20Paper%201.pdf>

26 – <https://www.nao.org.uk/wp-content/uploads/2018/02/Reducing-emergency-admissions.pdf>

27 – However, see CQC's 2018 'local system's review' on the ways in which older people move through the health and social care system [https://www.cqc.org.uk/sites/default/files/20180702\\_beyond\\_barriers.pdf](https://www.cqc.org.uk/sites/default/files/20180702_beyond_barriers.pdf)

Boards, but it is not in the public domain nor passed onto charities. Data on frequent attendees has been published and available on the Information Services Division Scotland but it is sparse. Data on admissions rates has also been published monthly but relies on the good will of local boards to pass it on directly (*Unscheduled Care, Scotland*).

Different services across health care also used different definitions and measurements which meant data may not be comparable and could be unreliable. The term ‘medically fit for discharge’ may mean something different in two different hospitals. Other discrepancies could include whether planned discharge dates are captured in the first place.

Data may also indicate the wrong things or provide findings that offer little real insight, for example, even where there is solid delayed transfer of care data, it doesn’t necessarily tell us much about the patient experience. The 2018 CQC report expresses the need for a new way of measuring the performance of service-providers with a data metric that is focused on measuring patient outcomes.

The current data deficit can mean that case studies from voluntary services such as the British Red Cross are taken as anecdotal by the health care system. Additionally, data can’t ‘see’ people bending rules – staff may be taking ‘shortcuts’ which might result in anomalies. The *Unscheduled Care Director* for NHS Scotland told researchers that data on ‘boarding’ 28 within the hospital is used as a measure of how well the hospital is managing flow. A high boarding rate is a sign of poor patient flow management. But researchers were also told in one hospital that sometimes staff members change a patient’s discharge dates to stop the patient being boarded.

There are also significant limitations to how much data can improve patient experience. Data may be able to tell us how many care packages are being bought but data collection is not good at capturing the ‘softer’ elements, both for the trusts and for the patients. Some effort is made to better understand patient experiences, for example, in 2017 the CQC conducted an adult inpatient survey. It found patients’ perceptions of the quality of preparation and information for leaving hospital, among other things, had become less positive or had not improved over time. National surveys can only tell us so much, however; while they can tell us that something is happening, they can not necessarily tell us why.

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28 – A patient who occupies a borrowed bed is described as “boarding” <http://www.acutemedicine.org.uk/wp-content/uploads/2014/11/Plenary-5-1030-Wrong-Place-Anytime-Why-Boarding-is-Bad-for-Patients-Hospitals-and-Healthcare-Systems.pdf>



# 3

# Conclusions

Healthcare professionals rarely see what happens after patients leave hospital. But for some people, it's when they get home that longer-term challenges begin, especially if they must come to terms with temporary or lasting adjustments to their health or wellbeing.

This research explored the patient experience of discharge across the UK. While health and social care systems focus primarily on clinical outcomes and patient flow, the priorities for patients' and their families tend to be about their wellbeing, independence and feeling in control and informed about their health.

It was common for patients and their families in this research not to have a clear understanding of what was wrong with their health or why they were in hospital at all – either while they were there or afterwards. In these situations, feeling in control of the decision-making about their health, care or wellbeing and understanding the processes that were driving these decisions was almost impossible.

Across all four nations, frontline clinical staff did not appear to be consistently considering the longer-term implications of the experience in hospital and getting home. This research also found people across all four nations who were leaving hospital without any support from clinicians or support services focused on ensuring they, and their family, could cope and rebuild their lives after hospital.

As a result, our research showed that people across the UK were leaving hospital underprepared for their recovery or for life after their illness or injury.

Many of them experienced problems once they got home – often finding it an unsuitable place to return to, but worried about the prospect of being anywhere else. Many were heavily reliant on informal care networks, but this type of support wasn't always available, or as reliable or thorough as they needed.

Few patients and their families knew what to expect in terms of information, guidance or more practical support from the system on returning home. Some were waiting for calls from professionals with information on next steps and only a minority felt confident in what their recovery would look like in real terms, and who they could call upon to help if they found themselves struggling at home.

It is helpful to think of people's likelihood to make a full recovery after an unplanned stay in hospital – to thrive rather than merely to cope – in terms of several 'independence factors' that contribute to overall wellbeing. The combination of these factors indicates how independent someone is overall – a key determinant of their recovery.

This research has identified five categories of independence factors (physical, social, psychological, practical, financial). These can be assessed – and compared – before, during and after someone's stay in hospital.



## What outcomes should everyone be aiming for?

Focusing on outcomes for patients that everyone can agree on is not just desirable but inarguably helps to frame and develop specific recommendations. Below are the outcomes this research suggests professionals, patients and their families should aim for.

### 1 Experience in hospital

**Outcome: At every interaction a patient has with a professional during their hospital stay, and every decision that is made about their care, active consideration is given to the implications of that interaction/decision for the patient's long-term recovery as well as their immediate health and care needs.**

Health and social care professionals need to recognise the patient's wider needs as well as their immediate and clinical ones, ensuring communication in both directions is as strong as possible.

Patients in hospital need to understand what is happening to them in the moment, and to be clear what will or might happen to them next. They need clear information often at multiple points in time.

They should be encouraged and empowered to share their views, have a say in their treatment where possible and be given multiple opportunities to ask questions.

It should also be recognised that empowerment has its limits: some patients may be unable to articulate their needs or know which questions to ask. They may also be unclear, or even mistaken, about what treatment, care and information they are entitled to – now or during their recovery.

The onus must be on health and social care professionals not to assume 'everything is ok' just because the patient has not told them they're having problems or feeling uncertain.

## 2 After hospital discharge

**Outcome: Every patient is helped to thrive after they leave hospital, rather than just cope.**

This outcome is underpinned by the principle that people leaving hospital must not only be able to cope in the immediate term, but that they have the conditions in place to enable them to thrive in the medium to longer term.

The health and social care system needs to better consider the environment and circumstances that the person leaving hospital is returning to as well as the factors that are likely to influence the trajectory of their recovery over the long-term.

This means proactively taking into account the physical and practical living conditions of their home and the support that will be available to them – both informal/family and professional.

It also means setting an expectation that a person's hospital experience does not 'end' at the moment they are discharged. Instead, we need to recognise that they have a trajectory beyond this point which has implications for both the individual and the health and social care system.

If this outcome is met, fewer patients will return to hospital with a subsequent unplanned admission or return as soon as they might otherwise.

## 3 Preventing admission and readmission

**Outcome: People are better able to take a proactive role in self-care and self-management of health.**

This outcome is underpinned by the possibility of preventing or reducing hospital admissions altogether.

While certain elements of decline are unavoidable, encouraging people to reflect on and take action in regard to their changing and growing health needs, especially as they grow older, is necessary.

The health, social care and voluntary sectors must encourage activities that could help prevent a person's health decline, going

beyond the medical aspects to consider wider physical, emotional and practical actions.

There must be enough options for people to make decisions about when and where to receive health care before hospital admittance becomes a necessity. This is in recognition of the wide range of negative impacts a hospital stay can have on a person's independence that could be prevented by other health or social care delivery models.

3

# British Red Cross recommendations

## How to improve the transition through hospital and home again

Our research showed that, unless well planned and managed at every stage, being admitted to hospital can be a confusing and even distressing experience, which does not necessarily create the foundations for a return to recovery.

Our recommendations draw on insight from this research and build on our previous report *In and Out of Hospital*. Our proposals reflect the need to prioritise the implementation of a personalised approach to a person's journey through hospital and home again together with opportunities to relieve the pressure from hard working NHS and care staff.

We believe there need to be clearer lines of accountability for ensuring a recovery-focused patient journey through hospital and home again, and that people's non-clinical needs should have parity of esteem with their clinical needs.

### 1

There is a **substantial opportunity for commissioners and providers to harness the power of non-clinical support, including the voluntary and community sector (VCS)**, to relieve the pressure on the NHS and to create better outcomes for people and improved patient flow within and between health and social care providers. We recommend the following options should be explored:

- Supporting transition and recovery by having a **named non-clinical person to provide support throughout a person's journey** through hospital and the transition home again<sup>29</sup>, including as the critical link with community teams;
- **Facilitating more frequent in-person discussions with patients, their families and carers**, about their holistic clinical and non-clinical needs, in order to improve patient experience and better communication flows;
- Tackling 'initiative fatigue' by providing greater support from the VCS for clinical teams, including to deliver existing good-practice programmes to support recovery, such as End PJ Paralysis.

### 2

Every point of hand-off between clinical teams in hospital and from the hospital to the community is a potential point of success or failure for patient recovery. We recommend that there is a **clinical responsibility to ensure the effective management of these transitions, so that there is continuity of care and patients don't fall through the gaps between teams**. Hand-offs between teams should be informed by the patient's own outcomes-focused goals, ideally developed through regularly-reviewed, simple, personalised care and support planning<sup>30</sup>.

<sup>29</sup> – his support along the whole patient journey would be in addition and complementary to the named clinical consultant each patient will have, ensuring that a genuinely holistic approach is taken, as well as providing support and assurance to the busy clinical lead.

<sup>30</sup> – The British Red Cross uses a bespoke methodology to ensure service users receive person-centred care and are supported to make meaningful decisions about their own care. Our 'What Matters to Me' approach supports service users to identify the things that matter to them, and monitors outcomes against those self-defined goals. Among other benefits, this allows us to better understand the impact our services are having on people from their own perspective.



### 3

A significant proportion of people are likely to be discharged from hospital following a partial assessment based primarily on their medical fitness or with a small number of other factors. Discharge dates can also be arbitrary, making it hard to plan for going home.

We recommend that a **five-part 'independence check' should be completed as part of an improved approach to patient discharge** – prior to discharge or within 72 hours of going home. This would help to inform the setting of a realistic discharge date and would include assessing:

- Practical independence (e.g. suitable home environment and adaptations);
- Social independence (e.g. risk of loneliness and social isolation; if they have meaningful connections and support networks);
- Psychological independence (e.g. how they are feeling about going home; dealing with stress associated with injury);
- Physical independence (e.g. washing, getting dressed, making tea) and mobility (e.g. need for a short-term wheelchair loan) and;
- Financial independence (e.g. ability to cope with financial burdens).



# 4 Appendix Methodology

This research was qualitative in nature, to explore in detail the systems and experiences of hospital discharge from a range of perspectives. The ambition was to see what professionals and patients see, to empathise with how it feels and to use this detailed understanding to reflect on how decisions are made along the discharge journey and how this impacts someone's preparedness for returning home.

The research used an ethnographic approach, meaning the team collected different types of data from interviews, observation of processes and interactions, written documentation and photography. By understanding professionals' and patients' experiences in detail, spending time in hospitals and in people's homes, the research can explore the tensions, contradictions and decision points that impact their journey and outcomes.

## Expert interviews and scoping

13 expert interviews with professionals across health and social care, including policy makers, professionals responsible for operational delivery and stakeholders working at the British Red Cross.

These included:

- Healthwatch England
- NHS Improvement
- Age Connect Wales
- King's Fund
- Scottish Government

## Understanding local ecosystems

Site visits and telephone interviews with clinical and social care teams working in four NHS Trusts across the UK. Interviews with professionals across these sites included consultants, ward nurses, discharge lounge managers, occupational therapists, social workers, charity support staff, physiotherapists and operational teams (e.g. data management) among others.

The hospitals were selected to provide valuable, illustrative evidence on both the system and staff in these local areas:

- East Sussex Healthcare – incl. Eastbourne District General Hospital
- Ceredigion and Mid Wales NHS Trust – incl. Bronglais General Hospital
- NHS Lothian – incl. Royal Infirmary of Edinburgh
- South Eastern Health and Social Care Trust – incl. Ulster hospital

The hospitals selected were in a mixture of both urban and rural locations across the four nations. Visits to the rural sites were able to shed light on challenges in accessing and travelling to services, such as in rural Wales. In other locations, there were local economy factors that impacted on care and presented an interesting comparison, such as in Northern Ireland where carers were said to be moving across the border to work in Ireland where the wage is higher. One of the sites has an embedded British Red Cross assisted discharge service, but we have kept this out of reporting to maintain some anonymity in the strengths and challenges that were observed in practices across these sites.

It should be noted that this research was not intended to offer a meaningful comparative study across the United Kingdom, focused as it is on only four Trusts. It is noteworthy that there are cross-country observations to be made throughout this research.

# About the hospitals



## Eastbourne District General Hospital

Eastbourne DGH is set on the outskirts of town, just under 2 miles from the town centre and train station. The hospital has 14 wards with approximately 380 beds, offering medical and surgical wards and specialist units as well as a 24-hour Emergency department and a range of diagnostic services such as MRI and CT imaging.

The hospital is in a quiet, residential area and staff emphasised how this helps to provide a calming environment for patients, with features such as a therapeutic garden available for use. The main areas of the hospital were busier at certain periods of the day, but this was generally formed of older patients. Beds ready to be used were lined along the walls. Staff defined being busy not by the number of beds that were in use, but whether they had sufficient the resource available on the ward to deal with current patients.

A range of support services had posters and leaflets available across the hospital. There were posters in the main entrances of the hospital for the “Let’s Get You Home” campaign from NHS across East Sussex, designed to encourage people to return home quickly and safely. A gateway social worker and a Hospital Intervention team were pro-active at the front end to treat patients and encourage early discharge.

The discharge team are based in a small office in the south east area of the hospital. The discharge lounge was located next to the pharmacy, with colourful pictures on the wall and separate male and female discharge bays. Not every patient discharged went through this lounge. While 50–60 patients a day were discharged overall, the lounge saw about 15–20 patients a day pass through. Staff in the lounge were primarily responsible for booking travel for patients and arranging risk assessments.



## Royal Infirmary of Edinburgh

Royal Infirmary of Edinburgh is a major, acute teaching hospital set around 4 miles from Edinburgh’s town centre. With over 900 beds, it is a large hospital and has a general feeling of being light and open, with skylights in many of the main areas of the hospital. These areas tend to be bustling but didn’t feel overly busy or overcrowded at the time of visiting on an August morning during the week.

The discharge lounge itself had 12 chairs, and on average has around six patients in there at any one time. It has been in use for the last 15 years but never tends to be completely full. Due to space restrictions, patients with requirements such as oxygen and stretchers are not able to use the lounge. The busiest period in here tends to be around 11.30am, as the hospital has a pre-12 target for patient discharge.

During the discharge process, the discharge team will generally receive a call from the ward to say a patient is ready to be transferred to the lounge. The lounge staff will collect the patient from the parent ward. The ward staff are responsible for booking transport for the patient through the flow centre, who can then approve this request and attach it to the patient record in Trak, the hospital tracking system. The discharge lounge will then print this booking form, so they have a list of the patients due to be discharged. Once the patients who are being discharged via the lounge have arrived, the discharge team record their location in the lounge and their mode of transport.

Delays can be caused by pharmacy waits for medication, but there are some instances where the hospital will discharge the patient and deliver their medication to the house. Two to six volunteers along with two staff members are responsible for managing the 30–40 people that come through the lounge each day.



## Ulster Hospital

The Ulster Hospital is one of the busiest in Northern Ireland and the major acute hospital for the South Eastern Health and Social Care Trust. On the outskirts of Belfast, the hospital itself has around 98,000 attendees per year through Accident & Emergency and this is continually rising. A considerable number of patients also attend the hospital from outside the Trust area. As a result of this, the Ulster Hospital is experiencing a bed shortage, being 68 short at the time of visiting in August (this number was expected to rise to 100 for the busy Winter period.)

The hospital has a Discharge Hub, Transition Unit and Discharge Lounge. The Discharge Hub is made up of a multidisciplinary team including a Band 7 Nurse, Physiotherapist/Occupational Therapist (OT) and Social Workers. Control meetings are held three times a day and are led by the Unscheduled Care Lead and involve all service leads. These meetings focus on patient safety and patient flow with information being gathered in respect of available beds and targeted discharge processes to address demand.

The Transition Unit focuses on the social and physical rehabilitation of patients. The unit focuses on individualised care with an aim of finding the most appropriate pathway of care for the patient in the long term. Patients will have ongoing therapy goals and the unit also provides the patient and family with ownership of care.

The discharge lounge is an area with easy chairs and privacy curtains. Nurses are often responsible for arranging discharge, which involves forward planning by the staff.



## Bronglais Hospital

Situated in Aberystwyth and administered by the Hywel dda University health board, Bronglais Hospital has around 125 beds. The hospital itself is quite new, founded in 1966 with a new A&E department and new day case theatres opened in 2013. The rural nature of the area this hospital serves has a big impact on the services it provides, particularly regarding discharge transport.

All wards in the hospital deal with discharge at Bronglais including A&E – and Y Banwy ('step down' unit). Y Banwy is designed largely for those who are medically fit but may have social/rehabilitation needs that mean they're not quite ready for discharge. There is no longer a dedicated discharge team within Bronglais, but a community resource team closely liaises with hospital staff to support with discharge. The community hospitals in the local area are also available, but these tend to be very full so staff are wary of discharging patients to these.

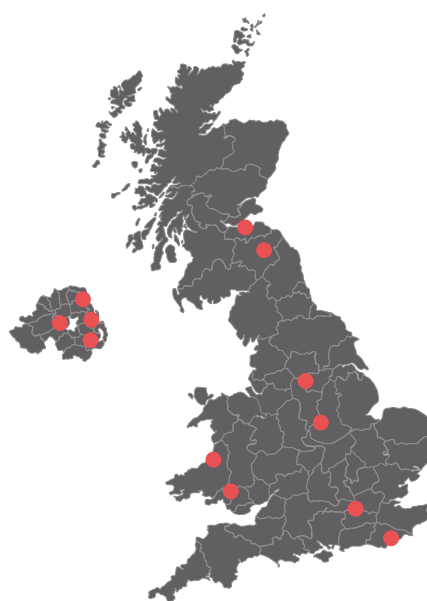
# Interviews with families

4

Across the 28 depth interviews, we included a diverse range of experiences of hospital, discharge and after-care. The sample was focused on people who had not received social care support, either because they were ineligible, because they were unaware of its availability or because they turned it down.

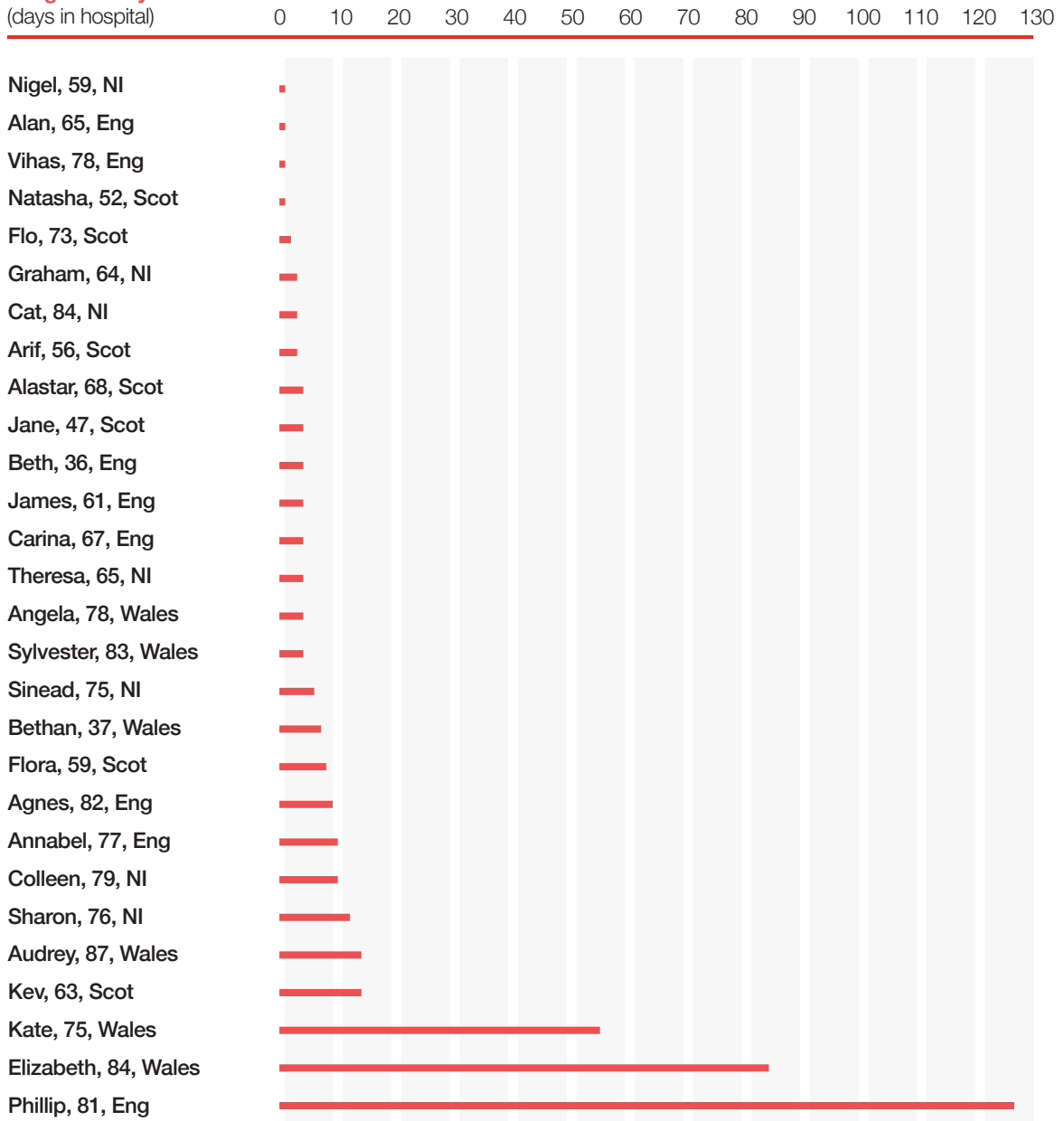
Our sample included:

- All respondents had an emergency hospital admission – we didn't include people who had planned procedures or operations
- All respondents were discharged from hospital within the last six months
- Respondents were in hospital for various length of stay, from one day to 120 days, with an average of four days
- Mostly older adults – but with a spread of ages:
  - Three respondents aged under 50
  - 12 respondents aged 51–70
  - 13 respondents aged 71+
- Spread of genders across the patients and their loved ones
- Range of ethnic backgrounds, including white British, black British, British Asian
- Several reasons for emergency hospital admittance (covering injury and illness), including: sepsis, broken bones, attempted suicide, complications from operations, infections, stroke and heart attacks
- Users of British Red Cross services, including five respondents who have used British Red Cross support around their hospital discharge



- Respondents were living across the UK, ensuring we had a range of people in each nation:

**Length of stay**  
(days in hospital)



4

## Recruitment

Recruitment for this project was incredibly challenging due to the ill health of our potential participants and the stress experienced by family and friends who are caring for them. Our ambition was to ensure that people who took part felt comfortable and able to participate and that their participation would not cause any undue harm or stress. A number of the people who participated were taken ill during the course of the recruitment, fieldwork and follow-up contact, and some re-admitted to hospital.

We used a mixed method approach to recruitment, working with multiple free-find recruitment partners alongside professional intermediaries delivering health and social care across the four nations. In total the research team contacted nearly 100 professionals to support the recruitment process.

The research had significant interest from people and their families who had recently experienced hospital discharge. More than 75 people came forward to be interviewed and enquired about participation. However, the project had a significant drop-out rate, often as a result of respondents being taken ill and/or being readmitted to hospital. For some of our respondents who did take part, a number of months passed between initial contact and our interview as we allowed them time to recover from their readmission and feel comfortable once again with being interviewed.

## Interview approach

When people agreed and felt able to participate, our research team conducted a two to three-hours longW interview in their home, often with a loved one or family member in attendance.

Conducting the interview within their homes helped our research team understand and explore the environment they returned to after hospital and see first-hand some of the challenges they faced there. A number of our respondents had been admitted to hospitals we had visited as part of the early fieldwork, meaning researchers could more accurately piece together their discharge experience.

Respondents were asked to discuss their life prior to hospital, the details of their time in hospital, and their experience of the transition from hospital to home, as they remembered it. Following this, the interview explored their experience since leaving hospital and their experience of recovery.

Family and loved ones who were involved in people's discharge often filled in gaps, especially when someone had been particularly poorly. Some of the data from friends and family was captured during the initial interview, which often happened in pairs. For a subset of respondents, wider telephone interviews were conducted with people involved in their discharge, including wider family, friends and neighbours and in some instances, professionals involved in their care.

4







The British Red Cross has been working between home and hospital since before the NHS was established. Today our health and social care services help over 200,000 people across the country continue to live safely and independently. Our services have a simple idea at their heart: preventing health problems from escalating into personal crises.

**44 Moorfields  
London  
EC2Y 9AL  
[redcross.org.uk](https://www.redcross.org.uk)**

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