



Home to the unknown

**Getting hospital
discharge right**

A call to action

Foreword

The British Red Cross has a long and proud history of working in partnership with the NHS. 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 wellbeing and recovery – as well as improving the flow of patients through the system.

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. For example, information about whether a patient will have access to basic essentials on their return from hospital, such as food, water and heating, or if they are returning to a suitable home environment, isn't listed on many hospital discharge checklists.

This 'call to action' report brings together patient and expert interviews, hospital observations from across the UK and insights from health and social care leaders from across sectors. It 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.

Our learning

The findings and recommendations in this report are based on evidence gathered by Revealing Reality, an award-winning social research agency commissioned by the British Red Cross to undertake in-depth research into the transition from hospital to home, and the British Red Cross's own evidence-gathering over the past year. We've also included insights gathered at our health and social care leaders' summit in February 2019, where we presented our research findings.

Our evidence sources:

In-depth interviews at home with 28 individuals across the United Kingdom who had recently been discharged after an unplanned stay in hospital without social care, as well as conversations with their carers¹.

Interviews with policy experts and observations of systems and interviews with staff in hospitals in each of the four nations: Bronglais Hospital, Wales; The Ulster Hospital, Northern Ireland; Royal Infirmary of Edinburgh, Scotland and; Eastbourne District General, England².

A survey of hospital discharge checklists in England³.

This report provides a summary of the findings. A full report provides greater detail of the qualitative research.

This research provides evidence to inform health and social care policy at a national and local level. It also enables us to make 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 together, through multi-disciplinary teams.

We hope that this will help to fill a gap in existing data about how often patient discharge ideals are delivered, what the outcomes are for patients when they are and what outcomes patients experience when they are not. Data about discharge processes and outcomes is sparse, with significant gaps and variation in what is collected across the four nations.

As long as collecting these types of data around discharge and patient outcomes is not prioritised, it can be hard for staff at a hospital level to see the case for change.

¹ – In-depth interviews in people's homes with recently discharged people and key members of their support networks, such as spouses, children and friends conducted by Revealing Reality

² – Conducted by Revealing Reality

³ – More information available from the British Red Cross

Introduction

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 hospital healthcare professionals to see what happens next.

This report, and the longer research that underpins it, explores what it feels like to return home after an unplanned visit to hospital when there is no formal support or care.

The evidence 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. It would be a mistake to underestimate this.

In our day to day engagement, through our operations, we see many examples of good practice initiatives including Multi Agency Discharge Events (MADE), Discharge to Assess (D2A), Home First and hospital – or community-based hospital – multidisciplinary discharge teams. Many are working in successful partnerships with the voluntary and community sector. Across the UK, we see how these initiatives are making a real difference to the home from hospital experience.

However, although there are examples of excellence, our research findings show a lack of consistency of provision and that too many people are still falling through the gaps with unmet needs. We see a clear role for partners, particularly the voluntary sector, to collaborate with health and social care professionals to enable and support best practice examples, so that proven interventions can be taken to scale. People are entitled to expect holistic, person-centred care to support them in their transition from hospital to recovery, wherever they may live.

Some of these challenges are compounded because patients do not want to be a burden on a hard-pressed NHS or feel that there are other patients who deserve help more, so they don't always ask about what they don't know.



Key insights

A potentially significant proportion of people who are deemed clinically fit to leave hospital are sent home without adequate consideration of their non-clinical needs and their longer-term recovery trajectory.

- In-depth research by Revealing Reality, commissioned by the British Red Cross, found **people returned to homes inappropriate for their recovery**, with no hot water or heating. Others with changing mobility needs reported struggling with a step up to a front door, or felt unable to get upstairs to the toilet.
- This is supported by our survey of hospital discharge checklists in England, which found that only half include information on whether a patient will return to a suitable home environment, with basic essentials such as food, water and heating.
- Discharge planning is often tacked on at the end of the patient journey, and these issues should be much more visible in care planning to enable recovery and prevent unnecessary readmissions.

Considerable variation in discharge practices and measurement of outcomes can have an impact both on patient experience and on clinicians' ability to understand the impact of discharge on recovery.

- Most hospitals do have discharge checklists however there is considerable variation in how those are developed and what they contain. In-depth interviews from the Revealing Reality research suggest that: **discharge processes across the UK seem to vary considerably**, between nations and even within local areas.
- The Revealing Reality researchers observed a wide range of posters and other communications about initiatives to improve the discharge process. Staff reported feeling overwhelmed by the range of initiatives being delivered across hospitals, and were not always aware of new ones.

- At times, discharge planning was influenced more by individual decisions than by official systems and processes. **Discharge dates could be arbitrary**, contributing to confusion and reducing the ability of staff, patients and their carers to plan for a smooth return to home.
- **A lack of available feedback or data** meant clinicians did not see the consequences of their decisions and were not given an opportunity to consider improvements to processes or services.

Without appropriate support and communication throughout their journey through hospital and home again, people can feel unequipped and ill prepared to support their own recovery.

- The Revealing Reality researchers observed a number of examples of poor patient experience that seemed to stem from **insufficient communication and poor hand-offs between teams and individual staff**.
- Some of the patients who took part in the research **didn't know what support was available** that could help them prepare for their hospital discharge and recovery and they often didn't know who to ask.
- Many people who were interviewed for this research were **unclear about what their discharge notes meant**, who they were intended for and who else had been – or should be – given a copy.
- **Confusion about which parts of the health and social care system were responsible** for what and how they communicated left people unsure 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. 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.

Reflections and emerging solutions

In February 2019 the British Red Cross convened a Summit, bringing together over 75 leaders from across health and social care⁴ to share insights and explore collective solutions to better support the home-from-hospital experience. We shared our qualitative research and the insights and recommendations of this report and, together, we explored the critical issues at the heart of improving patient experience and supporting patient flow across the journey through hospital and in the community.

“ The NHS can’t do this alone. It’s all about collaboration with a wide range of local partners - social care, primary care, housing and critically the voluntary and community sector. ”

Miriam Deakin, Director of Policy and Strategy, NHS Providers

There was a strong emphasis throughout the day’s discussions on the need for all involved in patient care and support to commit to working together to do things differently, to focus on points of traction to put people first and to bring about change. Getting discharge right is not about a consistency of approaches – there are many examples of excellence from across the UK and smart, place-based approaches should continue to be tailored to their local context. Collectively, we need to place greater focus on the consistency of outcomes for people. We all need to commit to scale up what works, continuing to innovate for improved solutions and sharing lessons learned, in order to realise the true potential of the NHS’s proposed approach to personalised care.

“ We can always find examples of great practice. But why have various governments and agencies never cracked the problem of rolling out solutions nationwide? ”

Aileen Murphie, Director of Ministry of Housing, Communities and Local Government Value for Money at the National Audit Office

“ We need to harness the power of non-clinical support. We’re the ‘pothole fillers’. We’re here to take the pressures off the clinical staff, as well as here for the patients. ”

Matt Lewis, Community Care Navigation Lead, Wythenshawe Hospital

“ It’s about all system partners leaning in and being curious about how we work better together and transcend boundaries. ”

Mike Adamson, Chief Executive, The British Red Cross

⁴ – The Summit included representatives from frontline hospital teams from across the UK, the NHS, NHS England and arm’s length bodies, local, UK and Scottish Government, the voluntary and community sector, think tanks, policy experts, and those with direct lived experience.

Our 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 again⁵, 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 Paralysis⁶.

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 planning⁷.

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).

⁵ – This 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.

⁶ – <https://www.endpjparalysis.com/>

⁷ – 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.



Findings from the in-depth research

In hospital: Discharge planning and decision making

There is substantial documentation and advice on getting hospital discharge right, from a range of organisations including NICE, NHS England, NHS Improvement, individual trusts and think tanks such as the King's Fund. As ever, the challenge is implementation.

Our Freedom of Information request – responded to by 122 of 164 acute hospital trusts in England – revealed that 90 per cent of responding trusts reported using a discharge checklist.

However, our research by Revealing Reality with patients, carers, hospitals and health professionals highlighted that there was considerable variance between trusts and between ideals and practice.

Who is in charge?

The person or people responsible for discharge differed from one hospital to another. Often the 'discharge co-ordinator' was based in the discharge lounge, and discharge planning was frequently tacked on to the patient journey at the end, rather than integral to decision-making while a patient was on a ward.

Many of the professionals' decisions about discharge were in the context of hospital-wide patient flow or were based on purely clinical assessments, without sufficient consideration of the other factors essential to prepare patients for leaving hospital.

At times, discharge planning was influenced more by decisions taken by individual staff – albeit well-meant – than by official systems and processes. Emotional attachment to patients, particularly those who had been in hospital several times, could also hinder professional reflection on how their experience of being in and leaving hospital could affect the likelihood of subsequent readmission.

Short-term pressures can trump longer-term planning

In practice, short-term or immediate priorities about hospital beds sometimes overtook longer-term planning to help people prepare to leave hospital. Often, there were good practice initiatives or tools designed to improve the discharge process and the patient's experience of it, but these were inconsistently applied.

A lack of available feedback or data meant clinicians did not see the consequences of their decisions to consider improvements to processes or services.

Lack of co-ordination and communication

Across the areas visited in all four nations, communication and co-ordination between teams needed improvement, both within the hospital setting and between health and social care partners.

Within hospitals, a number of examples of poor patient experience were observed that seemed to stem from insufficient communication and poor hand-offs between teams and individual staff, unreliable paperwork and as a result of the ward team and discharge lounge having different information about the patient.

Clinical staff within hospitals and those working in social care frequently claimed that the other misunderstood patients' needs or made what they deemed to be incorrect assumptions about the care they required after leaving hospital.

This could leave patients in limbo, waiting for support that wasn't appropriate or available, and unclear about what would happen next.

Challenges accessing social care packages and wider support

Many patients aren't eligible for social care. Others don't want it or think they don't need it. In these cases, support may be available from voluntary sector organisations such as the British Red Cross assisted discharge service.

However, many clinical staff and some social care staff are not aware of other services. This means they often missed opportunities to signpost to other services or didn't know how to do so and people often ended up relying on informal care.

The experience of patients

While hospital managers, clinicians and nurses 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 too 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, as described below.

Planning long-term recovery

Sometimes people weren't clear why they had been in hospital or what their medical issue had been. As a result, they hadn't understood the decisions made about their treatment in hospital and they were unsure how best to manage their recovery.

This lack of understanding, combined with the emotional stress of being in hospital, often prevented people actively asking questions about their longer-term recovery. If hospital staff didn't take it upon themselves to talk to them about it, patients could be left with no clear idea of what life would be like after hospital.

Knowing what support is available

People didn't usually know what was possible or available that could help them prepare for their hospital discharge and recovery and they often didn't know who to ask. Others weren't even aware that services might be available.

Concerns over being a burden

Patients frequently and spontaneously talked of the strain the NHS is under. Many did not want to be a drain on resources or felt 'other people' warranted care or treatment more than they did. This wish not to be a burden could influence their entire hospital experience, from choosing not to call an ambulance to take them in the first place to feeling it was not appropriate to ask for anything once they were there.



Returning home: the road to recovery after discharge

Once a person is discharged, their experiences of being at home – both upon their immediate return and in the longer term – are largely hidden from healthcare professionals, particularly those in acute settings. Unless specific support has been arranged from services such as the British Red Cross home from hospital service, the moment patients return home is often witnessed only by family or carers. Some people are alone.

However, as this research demonstrates, it cannot be underestimated just how much impact a person's experience in hospital and their preparation for discharge can have on their short-term and longer-term recovery, rehabilitation and wellbeing.

Coming back to unsuitable housing

Problems often started with the journey home itself, particularly for those living in isolated places or far from the hospital. 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.





Theresa, 65

Theresa lives alone in a suburban housing development, just one street away from the house where she was born. After retiring early due to ill health, she has been in and out of hospital over the last few years because of falls. Most recently she was admitted after becoming ill with bronchitis, staying in hospital for six days.

Theresa left hospital without knowing what she had been treated for, and only realised how ill she had been after talking to her GP a week after her discharge. Prior to this, she was simply “guessing” at what her medication was for.

Theresa has an extensive support network of family and friends nearby, many of whom came to welcome her home on her return. As she settled back in, however, the visits subsided, and Theresa became heavily dependent on her son, Calvin. While Calvin is able to carry out small household tasks, his work commitments and lack of experience in health care limit the support he can offer.

Feeling weak from her hospital stay and suffering from osteoarthritis, Theresa has started to restrict her intake of food and water to avoid having to go upstairs to use the bathroom. She had spoken to an OT about her difficulties in getting around the house previously, but the solution offered involved constructing a lift shaft in the centre of her living room, a process which she felt would be too stressful and disruptive.



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.

Sometimes informal carers were unable to provide the support needed, but the person needing support would not always admit this to professionals.

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.

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.

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.





Beth, 36

Beth lives with her daughter and husband 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 after taking an overdose. Beth 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.

Having spent three days in hospital, of which Beth remembers very little, she was discharged. Her husband received a letter of recommendation to contact the “post-release MH team”, although he wasn’t quite sure of this name. Her husband called the next day and, after telling them about her support network of himself and some close family nearby, he was informed that Beth didn’t need help and that she wouldn’t be referred on to other services.

Beth was then contacted by her counselling service who acknowledged her hospital visit and told her that, because she’d had a mental health crisis, she was no longer eligible for their services. While 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 involve another 10 week wait.

At the time of interview, Beth was seeing a private psychiatrist costing around £50 per session – a sum that her family is struggling to afford. She also regularly uses the Samaritans to help manage her condition, calling around 40 times in the 2-3 months since leaving hospital.

Beth has received a lot of emotional support from her husband following her discharge. He has found this time very challenging and has admitted to having several “breakdown” points trying to cope with the aftermath of her hospital visit and discharge. They rarely talk about what happened in this period, and he relies on external and informal support services to help him manage the emotional side of supporting Beth.

Five “independence factors” to support discharge decisions

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.

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.

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

- **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 general physical health of a person and the effects of medication, for example.
- **Social independence** – whether the person is at risk of loneliness or unwanted social isolation.

- The 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 impact 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 burden.

Conclusions

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 their ability to thrive once they return home.



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.

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