

IMPACT Evidence Review: Supporting older people coming out of hospital

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What is the issue?

Hospital discharge is a really difficult area of policy and practice for a range of reasons (see below for further discussion) – but it tends to hit the headlines because of the impact in has on the **health service**, rather than the impact it has on **older people and families**. In practice, both are important – but we need to make sure that we're focusing on outcomes that matter to people and that we don't only see adult social care through the lens of the NHS.

Before exploring these issues further, it is important to be clear on key terms – which are very contested (see Box 1). In practice, anything we can do, individually and collectively, to avoid the term 'bed blocking' is basically a step in the right direction.

We also need to recognise that this is an **international issue** (affecting lots of different health and social care systems around the world). As but one example, a review of good practice in trying to tackle these issues found relevant studies from different parts of the UK, the US, Australia, New Zealand, Italy, Lebanon, Singapore, the Netherlands, Pakistan and India (Cadel *et al.*, 2021).

These are also very **longstanding issues** (see Glasby, 2003 for some of this history). In the UK, for example, the first government guidance on this issue was published in 1963, and concerns about people becoming delayed go back to the very beginning of the NHS (and even further back). Thus, during the Second World War, there were concerns that the rest centres set up to support people whose houses had been damaged by the bombing would become 'blocked' by frail older people who came into the service due to an emergency housing need, but who might be unable to leave due to ongoing health and social care needs (the so-called 'un-billetables').

Box 1: The importance of terminology

Historically, people have talked about this in terms of 'bed blocking' (with people stuck in hospital described as 'bed blockers'). This is still the case in the media – and sometimes from a health professional – but most people see this as an offensive and unhelpful term, effectively blaming the victim (i.e. as if it's the person's fault they are still in a bed – when they're almost certainly desperate to get home and only there because the system can't organise itself to get the person out).

A more neutral term is 'hospital discharge' or 'delayed discharges' (used here). However, the use of the word 'discharge' runs the risk of encouraging hospital services to see their role as finished when the person leaves (i.e. their responsibilities end when they 'discharge' the person from their care, rather than playing an active part in a planned transition from one setting to another, with responsibilities to achieve a smooth transition shared).



Probably most accurate, therefore, is the term 'delayed transfer of care' – which captures this sense of a transfer rather than one set of responsibilities abruptly ending. However, it tends not to slip off the tongue, and policy tends to abbreviate it to 'DTOCS' (which sounds horrible and impenetrable).

The impact on health services (often the media and policy focus)

Current policy and practice is very focused on tackling the huge **backlogs** which built up in the NHS during **COVID** – and freeing up beds by tackling delayed transfers of care is a key part of getting the waiting list back under control.

Hospital beds are an expensive and (compared to a number of other health systems internationally) scarce resource, for which demand frequently outstrips supply. There is therefore significant pressure on health service colleagues to ensure rapid throughput – and delays in people leaving hospital when they no longer need the services provided there are a major source of frustration.

This has sometimes been likened to the motorway on a bank holiday, when there is just too much traffic for our road network to cope. It only needs a minor change – too many cars joining at a junction, a piece of debris on the road, a really minor shunt, some minor roadworks – and the whole thing can ground to a halt.

Another parallel is a bath filled to the brim. If even a small glass of water is poured in, the entire contents of the glass spills out onto the floor, because there is literally nowhere else for it to go.

However, there is a danger that pressures on the health service come to dominate other priorities – and that we end up interpreting what social care does through the eyes of the impact it has on health partners, rather than valuing the contribution it makes in its own right. Certainly this is a risk in the media and in some policy circles. Just to put this in context, about half the adult social care budget is spent on people of working age (not on older people at all), and supporting discharge from hospital represents a fairly small amount of what adult social care does at any one time.

Moreover, although waiting for various forms of social care can lead to significant delays (and the number of social care-related delays has been increasing) – it often accounts for less than half of delays. Prior to the pandemic, for example, social care accounted for about 40% of delays (either social care delays or joint health and social care delays). While significant, the NHS was solely responsible for the other 60% (Cavallaro *et al.*, 2023).

The impact on older people and families

While delays leaving hospital have a significant impact on the NHS, they are also problematic for patients and families. Hospitals are busy, stressful environments, and most people want to get home as quickly as they can. Staying for longer than you need can also put you at risk of a hospital-acquired infection, and being in bed all day can reduce people's



independence and functional ability. People with learning disabilities or with dementia might also find hospital really confusing and disorientating, making it even harder to keep independent.

Beyond the issue of delays, moreover, there is a longstanding literature on hospital discharge, with **common themes** emerging time and again over decades (at least as far back as research in the 1960s and 1970s – see Glasby, 2003 for a summary). These include:

- Poor communication between hospital and community
- Poor planning in situations where people are likely to have ongoing needs after they leave hospital
- Inadequate notice of discharge
- Inadequate engagement and consultation with patients and their carers
- Over-reliance on unpaid carers at the point of discharge (when someone might have particularly significant needs) and lack of (or slow) statutory service provision
- Inattention to the needs of groups who might need even more support (such as people with dementia, homeless people)

What stands out from this literature – particularly from studies which have talked to older people and to families – is how distressing it can be to be on the receiving end of all this (see Box 2 for some practical examples from Age UK's advice line). People describe being at their wits end and feeling completely helpless, with no ability to influence what happens to them, and with families feeling completely taken for granted and left without adequate support. This latter issue was brilliantly but heart-breakingly captured over 20 years ago by IMPACT's Emily Holzhausen in the title a national report for Carers UK: 'You can take him home now.'



Box 2: Negative experiences of hospital discharge (case studies from the Age UK [2016] helpline)

Mary: Paul's wife Mary, 85 years old, is in hospital. She has lost her mobility during her hospital stay. Yesterday the hospital told him Mary was ready for discharge today and she can't occupy a hospital bed anymore. Nobody has assessed what she will need to help her recover at home, whether she can regain her mobility, or what adaptations are available to help them manage. Paul was able to delay the discharge for a day by getting the Patient Advice and Liaison Service involved but he still wasn't given any information about her rights, or about how they are going to manage at home.

Phil: Phil is in hospital and nearing the end of his life. The hospital says they can't do any more for him and want to discharge him. Phil lived in a care home with nursing prior to going into hospital, but this home is now unsuitable. Social services have identified a couple of alternative care homes, but his daughter Susan and her family have refused them because they are too far away for the family to visit him regularly. The family have found what they consider to be a suitable home nearer to them but there aren't any vacancies. They've asked the GP to refer Phil to a hospice, but the GP has refused because Phil's diagnosis doesn't say he has a specified time to live.

Alfred: Alfred is in hospital following a series of strokes and is due to be discharged in the next two weeks. It is being recommended that Alfred now goes to a care home. Alfred lacks mental capacity to make decisions about his care arrangements but his son has a registered Enduring Power of Attorney for Alfred's property and financial affairs. The hospital social worker is advising the family that social services will choose the care home and that it will need to be some way away to meet local authority cost limits. The family is unhappy about this because they think he needs to be closer to them so they can visit regularly.

Bob: Hannah's father Bob has a range of health problems, including dementia. At a discharge planning meeting two weeks ago the consensus was that Bob should return to his sheltered accommodation unit with a care package in place. However, the housing association that manages the sheltered accommodation says they do not want him to return because he is no longer well enough to manage, while Social Services are saying that sheltered housing is his best option at the moment as he does not yet meet the criteria for specialist residential dementia care. Hannah feels that they are now at an impasse and that she is going to be forced to agree to something she doesn't believe to be the best option for Bob.

Rachel: Janet's mother Rachel is in hospital for the second time in 10 days. Rachel lives in her own home. Janet feels she shouldn't have been discharged home on the first occasion and intends to complain. Before her readmission the Intermediate Care Team agreed that she wasn't safe at home. Now that Rachel is back in hospital Janet fears the same thing will happen again. She's trying to find someone who can help them find out what the options are and wonders what the responsibilities of the hospital social worker are and who, if anyone, joins everything up.



Putting these issues in a broader policy context

Taking a step back, therefore, some of the biggest issues aren't about delays in isolation. Instead, there are a series of broader challenges and dilemmas:

- While there is significant focus on delayed discharges, there can be just as much of an issue with premature discharge (when someone feels pressured to leave hospital before they feel ready to be back in the community) and/or poorly co-ordinated discharge (where all the focus is on getting the person out of hospital, not on enabling a smooth transfer to community services).
- When pressures increase on hospitals, there can be pressure to get people out at almost any cost and this can lead to premature admissions to care homes, rather than taking the time to help people return to their own homes. Even if a care home placement is intended to be short-term, the risk is that under-staffing and lack of access to rehabilitation can turn a short-term admission into a permanent one, prematurely 'writing people off' as unable to be at home. Lots of people would argue that no one should be admitted straight to a care home from hospital, unless they were living in a care home before they were admitted (a 'home first' approach).
- Hospital is a really bad place to make fundamental, long-term decisions. You might be scared, in pain, disorientated – and just not yourself. Wherever possible, people are usually desperate to get home, so that they can take stock, start to recover and get support to be the best that they can be, before taking any longer-term decisions about their care and support.
- Various policy initiatives have tried to create new services that people can go to for additional support and rehabilitation after hospital. However, if an underlying issue is that there isn't enough capacity in the system, then these services can quickly fill up, becoming just as 'blocked' as the hospital beds they were designing to free up. There are some fantastic services that provide really tailored care and support, build people's confidence and help them return home but there's also a danger that we just shift a problem somewhere else, so that it's 'out of sight and out of mind'. The risk of this usually increases when we do something under significant pressure/quickly, when we don't consult partners first and, above all, when we don't engage with older people and families to design services.
- While all the policy focus tends to be on discharging people from hospital, it's just as important to work in a more preventive way to help people stay as healthy and independent as possible, thus reducing the number of people admitted to hospital in the first place. Indeed, a former national body (the Audit Commission) helpfully identified a 'vicious cycle' where there is insufficient prevention and rehabilitation, leading to too many people being admitted to hospital and discharged to permanent care homes places, meaning there is even less money available to spend on prevention/rehabilitation thus leading to even more hospital admissions and discharges to care homes. Instead, they proposed investing strategically in prevention and rehabilitation as a way of breaking out of this vicious cycle.



Some important gaps in our knowledge

Although these issues have been widely debated and frequently researched over the years, there are still a number of key gaps in our knowledge – both of which are important for this IMPACT Network to take into account:

- 1. Most previous research into the extent of delays has tended to be conducted by medical/clinical researchers, reviewing the case notes of patients in hospital (either based on professional opinion or using a structured tool to decide who is delayed in hospital and who still needs to be there). However, there have been surprisingly few meaningful attempts to involve older people, families and front-line social staff in this research and these debates. The risk here is that any solutions put forward may fail to draw sufficiently on this lived experience and practice knowledge, thereby failing to solve the issues at stake. In contrast, IMPACT argues that people are experts in their own experience, they often know what works for them and they are the only people who have an overview of their journey through services (with many of the professionals involved in their care and support often only knowing them at a particular moment in time) (Glasby et al., 2004a-b, 2006; see also Glasby et al., 2016 for a similar discussion around debates about 'inappropriate'/preventable admissions to hospital).
- 2. Some research is so focused on counting delays and on identifying risk factors and characteristics of patients who experience delays, that it **fails to consider possible solutions**. To counter this, an international review by Cadel *et al* (2021) looks at international good practice examples, in an attempt to be more solutions-focused (see Box 3). However, numerous problems remain not least the facts that most studies are focused on quantitative outcomes rather than the perspectives of patients, families and staff; that sustainability of new initiatives is rarely considered; and there is a lot of contextual information missing from accounts of perceived good practice.

What needs to happen next?

In one sense, there are no real solutions – as suggested earlier, this has been an issue since before the NHS came into existence, in all four nations of the UK and in lots of different countries around the world. Although often associated with older people (which is the focus here), it's also an issue for other groups of people, including people with learning disabilities (Ince *et al.*, 2022) and people with mental health problems (see, for example, Glasby and Lester, 2004; Poole *et al.*, 2014).

One of the reasons why no one has solved this issue is that it involves <u>competing notions of good practice</u>. Although it is a vast oversimplification, hospitals tend to be focused on/rewarded for <u>efficiency</u> and <u>'throughout'</u> (getting someone in, treating them, getting them out again and using the bed for someone else), while social care tends to be focused on <u>empowerment</u> (looking at outcomes that matter to the person, and helping them make very difficult and potentially life-changing decisions about their long-term destination and needs). It's not that one of these is right and the other is wrong – they're just different (and



arguably incompatible at this particular fault line in the system) (see Glasby, 2003; Heenan, 2023 for further discussion).

Box 3: Initiatives for improving delayed hospitals discharge: an international scoping review (Cadel et al., 2021)

This international scoping review argued that most of the current literature focuses on the risks of being delayed and the groups of people most likely to be delayed (i.e. some of the 'problems' to be solved) — not on practical solutions. In contrast, they reviewed initiatives that seek to tackle delays in order to identify best practice.

Their article is free to read (https://bmjopen.bmj.com/content/bmjopen/11/2/e044291.full.pdf), but summarises a number of practice changes, tools and guidelines, approaches to information sharing, and projects around infrastructure and finance that have been attempted in different parts of the world.

A number (but not all) of these seemed to have some positive results – albeit the research to date tends to focus more on system outcomes than on the experiences of older people/families. There is also a lack of data over time (to see how sustainable any changes were) and a lack of information about the local context (making it difficult to share learning with others).

It was also unclear whether some initiatives simply moved problems from one sector to another, rather than genuinely solving the problem.

Overall, the review identified some potentially promising approaches, but also concluded that:

"This highlights the need to shift to a more patient-centred approach that focuses on improving outcomes and experiences, rather than system and hospital outcomes (i.e. length of stay and hospital occupancy) alone. Despite the number of unique initiatives aimed at addressing delayed discharges, current strategies may not be getting at the root of the problem... and there is a need for solutions to this problem that have a long-term and sustainable impact" (p.26).

Even if we recognise that there are unlikely to be any 'magic answers', we might still be able to make progress by doing things such as:

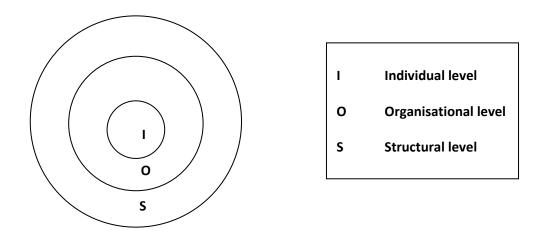
- Focusing on doing what we can to go beyond the confines of our role/organisation/ profession in order to ensure that support is as joined up as possible. Rather than passing the buck off on others and getting frustrated with partner agencies, we need



- to acknowledge that this is often no one's fault and spend more time looking for answers than blaming each other
- Local organisations establishing **good relationships** with each other and finding practical ways to smooth over some of the tensions and fault lines that get in the way of effective joint working. As but one example of the way in which partners can work together to better understand and respond to these issues, the report 'Why not home? Why not today? sets out some practical suggestions and advice which may be of interest to local Networks (Better Care Fund/Newton, 2017).
- National policy makers trying to avoid the dangers of focusing solely on discharge at
 the expense of other issues and of viewing adult social care through an NHS lens.
 There may also scope for more work nationally in order to remove some of the
 administrative, legal and financial barriers that get in the way of joint working, and
 better align different health and social care incentives so that joint working happens
 because of the system rather than in spite of it.

Interestingly, this suggests action at three different but inter-linked levels: individual, organisational and structural (the 'IOS' model - see Figure 1). Thus, the contribution of individual workers, although significant, takes place within an organisational context, which itself is influenced by structural barriers to improved joint working. Similarly, structural barriers derive at least in part from certain organisational features associated with particular types of health and social care agency and, ultimately, from the individual practitioners working within the organisations concerned. As a result, co-ordinated action might be needed at all three levels if we are to make significant progress.

Figure 1: The 'IOS' model of hospital discharge (Glasby, 2003)



Box 4: Focusing on things that matter to older people – insights from the Fife User Panels project



Although nearly 30 years old, an interesting example comes from work undertaken by the 'Fife User Panels' project. While there was a growing emphasis on involvement and engagement, many examples at the time focused on people of working age; it was much less common to seek to engage groups of frail older people in sharing experiences and exploring opportunities to improve care and support. Once they started meeting each other, the group quickly realised that they all had personal (and often negative) experience of hospital discharge. This included:

- "Being given no advance warning and being told during a relative's visit that they could go home immediately
- Being packed and ready to go but having to wait hours until an ambulance service was available
- Returning to cold and empty houses with no services available until the following day" (Barnes and Cormie, 1995, pp. 30-31).

In response, they developed a practical guide to good hospital discharge – examples included:

- The heating should be turned on in the house from the morning of discharge. The bed should be made up and warm for the patient
- There should be fresh staple goods (such as milk, tea, eggs and butter) in the house
- One meal should be ready for the person coming home
- The home carer should be in the house awaiting the patient's arrival if no friends or relatives are available or if requested by the patient
- Adequate notice of discharge should be given to family members (remembering that this person in turn will have to make their own domestic arrangements)
- Discharge times should be given within reasonable parameters (for example, whether discharge will take place in the morning, afternoon or early evening). People should not be kept waiting for hours
- At least 24 to 48 hours' notice of discharge should be given
- Services should be in place on the day of discharge, not the day after
- Services following discharge should be available 7 days per week, including public holidays

This advice has since been built into senior NHS leadership development programmes in England, as part of an exercise to think about the insights provided by different types of evidence. In addition to a systematic review, a randomised controlled trial, professional guidelines and a national survey of carers, participants were given this good practice guide and asked which of the sources was the most valid/reliable, and which was the most helpful in terms of helping to tackle the issues at stake. Participants always felt that this material was really powerful (because it drew on lived experience) and very hard to argue with – we may or may not have a research study that 'proves' if it matters if someone's heating is on in advance, but not many people would disagree that an older person coming out of hospital in the middle of winter and late at night should come back to a warm house. Ironically, the advice given by the Panel is also fully consistent with all the research published on this topic over the last few decades (Glasby, 2003).



Box 5: Focusing on things that matter to older people – insights from SCIE's systematic review

In 2006, the Social Care Institute for Excellence (SCIE) sought to develop approaches to reviewing evidence that were rigorous and transparent, but which could include people's lived experience in a way that was less common in more medically-orientated research (which often focused on quantitative research about effectiveness) (Fisher *et al.*, 2006). They chose to focus on hospital discharge - a topic which they felt had recently been subject to "a conventional, high-quality systematic review, but which lacks attention to the views of older people about what they value in terms of both process and outcomes."

By asking a different kind of question – focusing on older people's experiences, rather than on issues of effectiveness – they were able to prove that such approaches to reviewing evidence could be feasible and productive, producing different answers to reviews that adopted more traditional methods. In particular, they found that professionals often see discharge a discrete event and on focus on risk, safety and functional independence. In contrast, older people saw their hospital stay and discharge as part of a broader process of coming to terms with the impact of illness on their lives and future plans, and were often anxious about the implications for their self-sufficiency and the control they had over their own lives. They therefore really valued things such as education, training and continuity of staff to help them regain control and reduce uncertainty and anxiety.

Overall (p.48):

"The synthesis shows that, while health staff may know more about the physical effects of illness and its likely impact on daily life, they know much less about what this means for older people and their life plans. Older people know their own life plan, and what they fear might be the impact of the illness, but need carefully delivered information, and carefully constructed opportunities, to review their life plan in the light of their illness and to make their own plans accordingly. They also need the recognition that discharge might involve far more important issues (to them) than safety per se, and far more than being expected to accept passively any limitations consequent on illness. The synthesis shows that, in older people's eyes, coming to terms was not a passive process of acceptance but an active process of working out how to manage, and how to preserve control over the most important things while accepting what must be given up.

Thus the value of this qualitative synthesis for the topic of older people and hospital discharge is that it reveals some of the mechanisms underpinning successful interventions to support older people after discharge, and that it points to a lifeplanning framework for understanding the impact of illness, admission and discharge. This life-planning framework is completely missing from the original review, and yet it has the capacity to change profoundly the construction of interventions to support older people through their experience of illness and hospital."

Thus, the review produced practical learning for health and social services – but did so in a way which valued and built on people's lived experience.



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