Hconnect

Hospital Discharge Liaison Project.

Research Report

Carers' Experiences of Hospital Discharge in Derby & Derbyshire

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1.0 Introduction

This report presents findings from the Hconnect research study, a two-phase qualitative project exploring experiences of hospital discharge in Derby & Derbyshire. The study forms part of the wider Hconnect programme led by the Derbyshire Carers Association (DCA) and aims to improve the recognition, involvement and support of unpaid Carers during the hospital discharge process.

The research adopts a phased approach to capture perspectives from both unpaid Carers and healthcare professionals involved in discharge planning. Phase 1 focuses on Carers' experiences of hospital discharge, whilst the second phase explores the views of healthcare professionals working within hospital discharge pathways. Together, the two research elements aim to provide a comprehensive understanding of the behavioural, relational, and systemic factors influencing Carer identification and involvement during discharge.

This report outlines the background to unpaid caring and hospital discharge, introduces the Hconnect project and its theoretical framework, and describes the overall research aims and methodology. Findings from Phase 1 are presented in detail, with feedback from healthcare professionals on the resulting recommendations for discharge practice. The findings from both phases were used to inform the co-production of practical resources and recommendations to support safer, more inclusive hospital discharge processes for Carers.

1.1 Caring and hospital discharge

Unpaid Carers provide care to friends or relatives needing support due to illness, disability or advanced age. The 2021 census estimated that there were approximately 5.7 million unpaid Carers in the UK[1]. Unpaid Carers can encounter a variety of challenges which may affect their well-being including chronic stress, anxiety and depression[2]. Due to the demands of their caregiving role, Carers may also neglect their own wellbeing and develop bad health and lifestyle habits[3].

Another example of a distressing experience for Carers is the hospital discharge process of the person they care for. Hospital discharge can often be a challenging and worrying time for Carers. For many, this can also be their first experience of caregiving. Carers often report feeling excluded during discharge planning which can lead to unplanned and unsafe discharges and increased probability of readmission to hospital of the cared for, or even the Carer themselves4. Another problem Carers face in hospital discharge scenarios, is that they are not identified as Carers by healthcare or other multidisciplinary professionals. Furthermore, Carers often do not recognise their own role as a Carer, they may perceive caregiving as an extension of being a friend or relative to the cared for individual. According to the State of Caring Survey completed by Carers UK in 2022, over half (51%) of Carers took over a year to acknowledge their caring role, with a third (36%) of Carers taking over 3 years.

1.2 The Hconnect project

To learn more about the hospital discharge process from the perspective of Carers based in Derby & Derbyshire, the Hconnect project was launched in November 2024. This project was launched by the Derbyshire Carers Association (DCA) and funded by the Accelerating Reform Fund from the Department of Health and Social Care. The purpose of the project is to improve awareness, recognition and inclusion of Carers through the discharge pathway and ensure Carers from all communities are provided with the resource to self-identify and access ongoing support. Improving hospital discharge processes is particularly important given ongoing pressures on acute services and the growing role of unpaid Carers in supporting care at home.

As part of the project, healthcare professionals within 8 hospital pilot sites across Derby & Derbyshire are being trained in Carer awareness and identification.

To support this work, a qualitative interview study was conducted by Jackson Pountney to take a deep dive into the experience of hospital discharge in Derby & Derbyshire. This study was split into 2 phases, phase 1 focused on the on the Carer experience, whilst phase 2 obtained the views of healthcare professionals. Areas of focus for interviews included communication between Carers and healthcare professionals, Carer involvement and support throughout the discharge process and Carer identification.

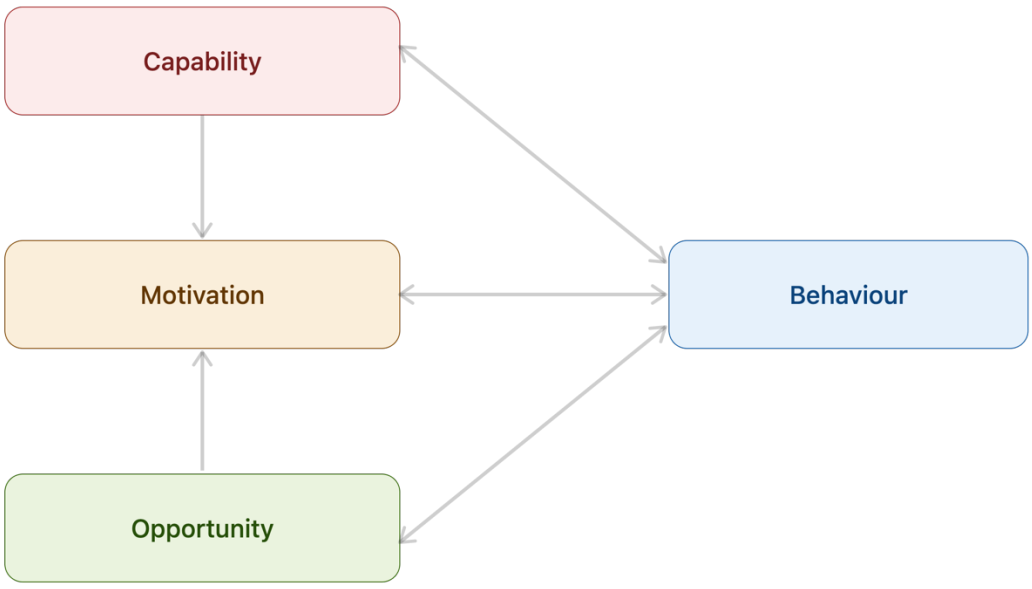
1.3 The COM-B model

The Capability, Opportunity, Motivation and Behaviour (COM-B) model was applied to explore the factors influencing both Carer identification and Carer involvement throughout the hospital discharge process. While the early identification of Carers was a particular focus of the analysis, the model was also used to examine the behavioural, organisational, and environmental factors that influence whether Carers are recognised, involved in decision-making, able to contribute their expertise, and adequately prepared for the responsibilities they may assume following discharge.

The COM-B model proposes that behaviour is influenced by three interacting components: Capability (an individual's knowledge, skills, and capacity to perform a behaviour), Opportunity (the social and environmental factors that enable or hinder behaviour), and Motivation (the conscious and unconscious processes that influence behaviour). Changes to any of these components may increase or decrease the likelihood that a behaviour will occur. A depiction of the COM-B model can be found in Figure 1.

For example, healthcare professionals may lack knowledge about who should be considered a Carer, the role Carers play in supporting patients, or the importance of involving Carers in discharge planning. This may reduce their Capability to identify and engage Carers effectively. Likewise, organisational factors such as workload pressures, time constraints, fragmented communication systems, or limited opportunities for interaction may reduce opportunities for meaningful Carer involvement. Motivational factors, including professional attitudes, competing priorities, and perceptions of Carers' expertise, may further influence whether Carers are recognised as partners in care and involved in decision-making.

Figure 1. The COM-B model (Credit: Michie, van Stralen and West, 2011[6])



This figure exemplifies the COM-B model, with three determinants of behaviour: capability, opportunity and motivation. *Credit: Michie, van Stralen and West (2011)*[6]

Applying the COM-B model allows the identification of both barriers and facilitators to effective Carer involvement within hospital discharge processes. This behavioural understanding can then be used to inform the development of targeted recommendations aimed at improving Carer identification, communication, involvement, and preparation for discharge.

Research objectives

The overall aim of the Hconnect research study is to improve understanding of how Carers are identified, involved, and supported during the hospital discharge process, in order to inform improvements in discharge practice and post-discharge support.

The specific objectives of the research are to:

- Explore unpaid Carers' experiences of the hospital discharge process, with particular focus on communication, involvement in decision-making, and support at the point of discharge
- Identify behavioural, organisational, and systemic factors that enable or hinder Carer identification and self-identification during hospital discharge
- Obtain healthcare professional feedback on recommendations relating to Carer identification, involvement and discharge practice
- Use insights from both Carers and healthcare professionals to inform practical recommendations to provide post-discharge support for Carers

2.0 Methods

2.1 Overall study design

A qualitative research design was employed for both arms of this study. During phase 1, interviews were used to explore the lived experience of the hospital discharge process, from the perspective of unpaid Carers based in Derby & Derbyshire.

The interviews were semi-structured. This means that set questions were asked, but there is flexibility to explore any unique topics that may arise during the discussion. These interviews were audio recorded and transcribed word for word to ensure participants accounts have been accurately documented. Then, reflexive thematic analysis[7] was conducted on the transcribed data.

The original study design included a second qualitative interview phase with healthcare professionals. However, due to project timescales and governance requirements associated with conducting research in NHS settings, it was not possible to complete the necessary approvals within the funded project period. Instead, healthcare and social care professionals were invited to provide feedback on draft recommendations derived from Phase 1 through a stakeholder consultation survey.

2.2 Interviews with unpaid Carers

2.2.1 Recruitment

Carers were recruited through the Derbyshire All Age Carers Support Service (DAACSS), which provides advice and support to Carers of all ages and backgrounds across Derbyshire.

DAACSS maintains a mailing list of registered Carers and several social media channels, through which invitations to participate in the research were shared. In addition, the study was promoted informally through word of mouth at Carer-related events attended by staff from the Derbyshire Carers Association (DCA) and DAACSS.

Citizens Advice Mid Mercia - who previously delivered the Universal Services for Carers programme - also supported recruitment. They shared the study poster through their Carers Register, community groups, and wider networks, helping ensure that carers who had engaged with earlier services were aware of the opportunity to participate. Their involvement broadened the reach of the recruitment activity and supported access to carers who may not currently be registered with DAACSS.

The study aimed to recruit Carers of varied ages, genders, and caring contexts in order to reflect the diversity of the Carer population in Derby & Derbyshire.

Inclusion criteria:

- Individual with a caring role with experience of the hospital discharge process
- Over 18 years of age
- Based in Derby & Derbyshire
- Able to read and understand study materials which were written in English

Exclusion criteria

- Under 18 years of age
- Based outside of Derby & Derbyshire

2.2.2 Data collection procedures

Following completion of the informed consent process, Carers were contacted by the research associate to arrange an interview at a time and location of their preference. Interviews were conducted either in person or online, depending on participants' needs and availability, and took place in a range of settings including Carers' homes, DCA offices, Carer support groups, or other community locations.

Data collection was guided by a semi-structured interview schedule, which provided consistency across interviews while allowing flexibility to explore issues raised by participants. Topics included experiences of the hospital discharge process, communication with healthcare professionals and multidisciplinary teams, Carer identification and self-identification, and views on how discharge practice could be improved. The interview schedule was developed collaboratively by the research associate, the principal investigator, and members of the Hconnect project team, drawing on professional and lived-experience expertise.

All interviews were audio recorded with participants' consent and transcribed verbatim to ensure accurate representation of Carers' accounts.

2.2.3 Data analysis

Transcribed interview data were analysed using Reflexive Thematic Analysis[7]. This approach was selected to identify meaningful patterns across participants' accounts and to explore shared and divergent experiences of hospital discharge among Carers. Analysis focused on generating themes that captured key aspects of Carers' experiences, with illustrative quotations used to exemplify each theme.

Following inductive theme development, findings relating specifically to Carer identification and self-identification were examined in relation to the COM-B model of behaviour[6]. This provided a framework for understanding the capability, opportunity, and motivation-related factors influencing Carer identification within hospital discharge contexts and for identifying potential areas for service improvement.

2.2.4 Ethical considerations

Ethical approval for Phase 1 of the study was obtained prior to data collection from the University of Derby Health, Psychology and Social Care Research Ethics Committee. All participants were provided with a participant information sheet outlining the purpose of the research, what participation would involve, and how their data would be used and stored. Written informed consent was obtained from all participants before interviews took place.

Participation was voluntary, and Carers were informed that they could decline to answer any questions or withdraw from the study at any point without giving a reason. Given the potentially sensitive nature of discussing hospital discharge experiences, interviews were conducted with care to minimise distress. Participants were reminded that they could pause or stop the discussion at any time, and signposting to appropriate support services was available where needed.

All data were handled in accordance with data protection requirements. Audio recordings and transcripts were stored securely on the University of Derby OneDrive system, and identifying information was removed during transcription to ensure participant anonymity. Pseudonyms were used in all reporting, and any potentially identifiable details were removed or altered to protect confidentiality.

2.3 Healthcare professionals' perspective

The original project design included a second qualitative interview study with healthcare professionals to explore their perspectives on hospital discharge processes and Carer involvement. However, due to project timescales and the governance requirements associated with conducting research within NHS settings, it was not possible to complete the necessary approvals and data collection within the funded project period.

To ensure that healthcare professional perspectives could still inform the project outputs, an alternative stakeholder consultation approach was adopted. Healthcare and social care professionals were invited to complete a short feedback survey on the draft recommendations developed from Phase 1 interviews with Carers. The survey sought feedback on the relevance, feasibility, and practical implementation of the recommendations, as well as potential barriers to their adoption in practice.

This consultation exercise was intended to refine and sense-check the recommendations from a professional perspective, supporting the development of recommendations that were both evidence-informed and grounded in current practice.

3.0 Findings

3.1 Carer interviews

This section presents findings from the qualitative interview phase the study, which explored Carers' experiences of the hospital discharge process. An overview of participant characteristics is provided below, followed by a presentation of the findings from thematic analysis

3.1.1 Overview of Carer interviewees

Participants in the first phase of the study were unpaid Carers with experience of supporting a friend or relative through the hospital discharge process in Derby & Derbyshire, with 16 unpaid Carers taking part. Participants varied in terms of their caring roles, relationships to the cared-for person and caring contexts. This diversity provided insight into a range of hospital discharge experiences across different circumstances. Interviews and were conducted between September 2025 and April 2026. Data were collected using a combination of in-person, online,

and telephone interviews, based on participants' preferences and accessibility needs. Individual interviews lasted between 21-101 minutes, with an average duration of approximately 46 minutes. An overview of participant characteristics is provided in **Table 1.**

Table 1. Demographic characteristics of unpaid Carers interviewed (n=16)

Characteristic	Detail (n=16)
Average age	51.4 (range: 26–82)
Gender	Female: 13 | Male: 3
Ethnicity	White British: 13 | Black British: 3
Employment status	Retired: 3 | Part-time employment: 7 | Full-time employment: 1 | Full-time Carer: 1 | Part-time employment and part-time Carer: 1 | Part-time employment and retired: 1 | Full-time employment and part-time Carer: 1 | Part-time Carer and part-time education: 1
Area of Derbyshire	Amber Valley: 3 | Bolsover: 1 | Chesterfield: 2 | Derbyshire Dales: 2 | Derby City: 3 | Erewash: 3 | South Derbyshire: 2
Country of birth	Nigeria: 1 | UK: 15
Relationship to person supported	Brother: 1 | Daughter: 5 | Daughter-in-law: 1 | Daughter and mother ×2 (three caring roles): 1 | Granddaughter: 2 | Mother: 1 | Partner: 1 | Sister: 1 | Son: 1 | Widower: 1 | Wife: 2

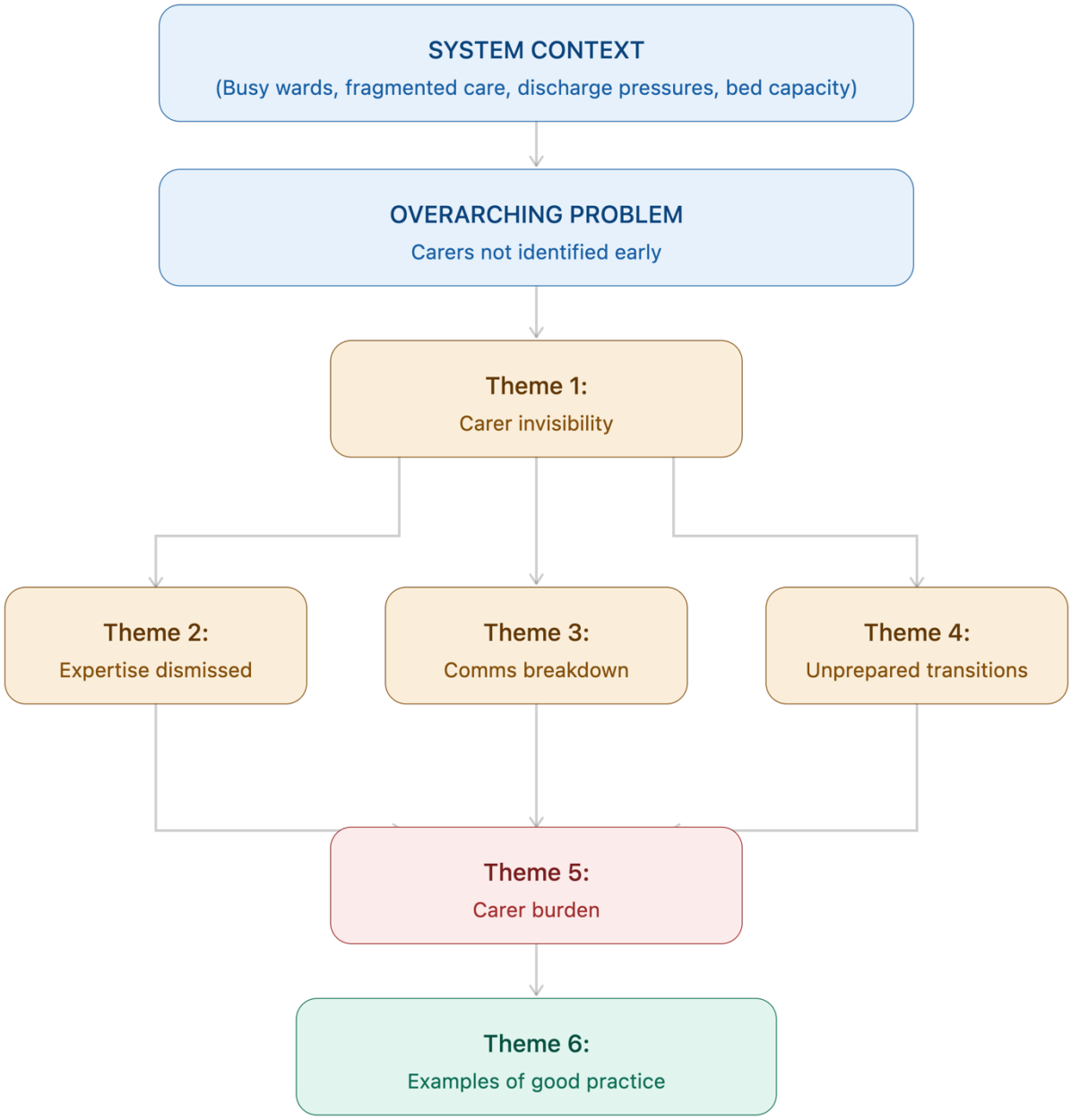
3.1.2 Overview of themes

Thematic analysis of interviews with Carers generated six interrelated themes relating to Carer identification, recognition of Carer expertise, communication between Carers and healthcare professionals, discharge planning, the burden assumed by Carers following discharge, and examples of inconsistent good practice. **Figure 2** provides an overview of the themes and illustrates how they relate to one another across Carers' experiences of the hospital discharge process.

The themes should not be viewed as discrete categories but as interconnected aspects of Carers' experiences. Difficulties relating to identification, communication, involvement in decision-making, and discharge planning were often described as occurring throughout the hospital stay and frequently interacted with one another. Collectively, these experiences often left Carers feeling insufficiently prepared, informed, or supported when patients returned home.

Although less frequently reported, examples of positive practice provided an important contrast to the challenges described elsewhere in the dataset. These accounts highlighted how Carers' experiences could be improved when Carers were recognised as partners in care, communication was timely and transparent, and discharge planning was undertaken collaboratively. Participants often described these positive experiences as being linked to the actions of individual staff members or teams, suggesting opportunities to embed such practices more consistently across services.

Figure 2: Overview of themes illustrating Carers' experiences of hospital discharge.



3.1.3 Carer identity is invisible and unsupported

Across interviews, Carers frequently described their role as being insufficiently recognised within hospital systems. Although some participants reported being acknowledged as family members or points of contact, this recognition rarely translated into meaningful involvement in care planning or discharge decision-making. Instead, Carers often felt that their role was assumed rather than formally identified, with healthcare professionals relying on visible presence, family relationships, or availability rather than systematically exploring who would be providing support following discharge.

Participants described being referred to primarily as a "daughter", "wife", "husband", or "partner", without acknowledgement of the wider responsibilities they undertook before, during, and after hospital admission. As a result, important knowledge about patients' needs, routines, preferences, and home circumstances was not always sought or incorporated into care

planning. Several Carers felt that they became visible only when practical support was required, rather than being recognised as partners in care throughout the patient journey.

> "There was a notice on the board, but I didn't feel they [staff] recognised you as a Carer, just a mum, They didn't say, oh, you could go in touch with X, Y, Z for more [information]."
>
> **(Carer 13)**

Carer invisibility was further reinforced by challenges around self-identification. Many participants did not initially describe themselves as Carers, instead viewing what they did as part of being a spouse, parent, sibling, child, or friend. This was particularly common where caring responsibilities had developed gradually over time or were shared with others. This suggests that opportunities for identification and support may be missed when healthcare professionals rely on individuals self-identifying as Carers, as caring responsibilities often develop gradually and may not be recognised as a distinct caring role.

> "It starts off as just picking up a prescription now and again. But I think you know, we're very good at absorbing all that and going where we should be. But what you don't realise is that by the time you snap, you've managed so much and you've been so strong for so long."
>
> **(Carer 15)**

Importantly, recognition alone did not necessarily result in meaningful involvement. Some participants described being identified as the primary caregiver or point of contact but still feeling excluded from discussions about treatment, discharge planning, or ongoing care needs. Others reported that healthcare professionals continued to communicate primarily with the patient, even when Carers would ultimately be responsible for managing care at home. These experiences contributed to a perception that Carers occupied a peripheral position within healthcare processes despite their central role in sustaining care beyond hospital walls. This was exemplified by a Carer whose daughter had autism and was uncomfortable with speaking to health professionals on her own:

> "I'd like them [staff] to talk to me as her [daughter's] Carer, but I got there [hospital] and they were like 'oh no, she's over 18 now, you don't need to come in, it's only the patient we need', and she [daughter] was kicking off."
>
> **(Carer 11)**

Taken together, these accounts suggest that Carer invisibility is not simply the result of individual oversights, but reflects the absence of consistent processes to identify, recognise, and support Carers within hospital settings. This theme emerged as a foundational issue underpinning many of the difficulties described elsewhere in the dataset. When Carers were not proactively identified and engaged, opportunities for communication, shared decision-making, and discharge preparation were frequently missed, increasing the likelihood that responsibility would be transferred to Carers without adequate information, involvement, or support.

3.1.4 Carers' expertise is marginalised or dismissed

Participants consistently described possessing extensive knowledge of the person they cared for, including their routines, preferences, communication styles, support needs, and early signs of deterioration. This knowledge had often been developed over many years of providing care and managing complex health conditions. Despite this, Carers frequently felt that their expertise was not recognised or utilised within hospital settings.

Several participants described situations in which they attempted to share important information with healthcare professionals but felt that their concerns were overlooked, minimised, or given less weight than professional opinion. This included raising concerns about patients' readiness for discharge, highlighting practical difficulties that might arise at home, or drawing attention to changes in a patient's condition. Participants often described these

interactions as one-sided, with decisions appearing to have been made before Carers were consulted.

> "She [cared for; sister] couldn't have paracetamol. This doctor came in and tried hooking an IV bag of paracetamol to her. We tried explaining that she cannot have paracetamol… it was in red writing 'Do not give paracetamol', but because they know best and it don't matter what everyone else says."
>
> **(Carer 7)**

Across accounts, professional knowledge was frequently positioned as the primary source of authority within care planning and discharge decision-making. While participants generally expressed respect for healthcare professionals' expertise, many felt that their own lived knowledge was treated as secondary or only sought when it aligned with existing clinical views. Some Carers described needing to repeatedly justify their concerns or demonstrate their competence before their perspectives were taken seriously.

> "I think they [staff] saw me as a bit of a hindrance. You feel it's their territory and they use you as a resource. They ask you for the information they want, but they don't necessarily always listen to the information you want to give."
>
> **(Carer 3)**

Importantly, the marginalisation of Carer expertise was not always experienced as overt dismissal. Several participants described discharge planning as a professionally-led process in which they were informed about decisions rather than actively involved in shaping them. In these circumstances, Carers felt that their role was to implement decisions at home rather than contribute to determining what was realistic, manageable, or appropriate for the patient and family.

> "Everything [discharge] was already planned. They [staff] seemed to plan based on what they believe is the right thing to do… I feel like I was only involved to be told what to do."
>
> **(Carer 16)**

These experiences contributed to Carers feeling undervalued and excluded from meaningful participation in decision-making. Participants often described carefully managing when and how they voiced concerns, balancing the need to advocate for the patient against fears of being perceived as difficult or challenging. This emotional labour reinforced existing power imbalances and limited opportunities for genuine partnership working.

Taken together, these accounts suggest that Carers' experiential expertise was inconsistently recognised within hospital discharge processes. Although Carers possessed detailed knowledge of patients' needs and circumstances, this expertise was often afforded less authority than professional knowledge and was not routinely incorporated into decision-making. As a result, opportunities for collaborative discharge planning were frequently missed, contributing to communication difficulties, unrealistic expectations, and the transfer of responsibility to Carers following discharge.

3.1.5 Communication failures across the discharge pathway

Participants consistently described communication during hospital admission and discharge as fragmented, inconsistent, and difficult to navigate. Information was often provided reactively rather than proactively, with Carers frequently reporting that they only received updates after repeatedly seeking information themselves. As a result, many participants felt uncertain about patients' progress, treatment plans, and anticipated discharge arrangements.

Several Carers described receiving conflicting information from different members of staff or across different stages of the hospital stay. Participants often found it difficult to identify who was responsible for communicating key decisions and reported uncertainty about who to approach with questions or concerns. In the absence of a clear point of contact, Carers frequently became responsible for chasing information, relaying messages between professionals and reconciling contradictory advice.

> "There seemed to be no consistency of who's looking after my grandma. There wasn't sort of a named person we could go to build a relationship with or sort of ask questions… It did feel like I never saw the same people whenever I went."
>
> **(Carer 6)**

Communication challenges were not limited to the availability of information but also related to how and when information was provided. Participants described receiving information at short notice, after decisions had already been made, or at points when they were not present to ask questions. Several Carers reported being informed of discharge plans on the day of discharge itself, leaving little opportunity to prepare practically or emotionally for the patient's return home.

> "I got a phone call to say right you can come and fetch her [cared for]. My dad turned up expecting to bring her home… she's got a catheter and nobody knew how to change it. We weren't sure if she'd have a care package. It was like she was kicked out [of hospital] and there was just no communication."
>
> **(Carer 6)**

Carers also described challenges relating to the timing, consistency, and usefulness of information provided during discharge. Participants reported receiving important information at short notice, after decisions had already been made, or from multiple sources offering differing accounts of what was happening. In some cases, information was delivered at emotionally charged moments or without sufficient opportunity to ask questions or seek clarification. These experiences left Carers feeling uncertain about what to expect following discharge and how best to prepare for the patient's return home.

> "I'm going to this discharge meeting… and he said, 'my condolences'. And then he said, your mom's going to be coming home. I cannot even begin to tell you how disturbing it was to go to a discharge meeting and be given condolences — that traumatized me."
>
> **(Carer 4)**

Importantly, communication difficulties were described even by participants who otherwise reported positive relationships with healthcare professionals. This suggests that communication failures often reflected wider organisational and procedural challenges rather than isolated interactions between individual Carers and staff. Participants frequently described communication as reactive, dependent on individual staff members, and poorly coordinated across services and professional groups.

Taken together, these accounts indicate that communication failures were a pervasive feature of the discharge pathway. Difficulties accessing timely, clear, and consistent information interacted with Carers' limited involvement in decision-making and contributed to feelings of uncertainty and unpreparedness. As discharge approached, Carers were often expected to assume increasing responsibility for care despite lacking the information, confidence, or support needed to do so effectively

3.1.6 Discharge as an unprepared transition

Participants frequently described discharge as a transition for which they felt insufficiently prepared. Although experiences varied, many Carers reported receiving little advance notice of discharge, with key decisions often communicated at short notice or on the day of discharge itself. This left limited opportunity to prepare emotionally, practically, or logistically for the patient's return home.

> "One of the nurses saw me going in and said, 'Oh, we're discharging them this afternoon.' You begin to think, 'Well, hang on.' She went home with me. Nothing was ready for her. The stairs are steep, the rooms are small… for somebody who isn't very mobile, it isn't ideal."
>
> **(Carer 9)**

Several participants described discharge planning processes that focused primarily on clinical readiness rather than the realities of managing care within the home environment. Carers reported that changes in patients' mobility, independence, cognition, or support needs were not always fully discussed prior to discharge. In some cases, participants felt that assumptions had been made about the availability of family support, the suitability of the home environment, or their ability to manage care responsibilities without first exploring whether these assumptions were realistic.

> "It felt like we were in a limbo because mom was ready to leave the hospital, but we weren't quite ready at home… Waiting for the occupational therapist, which is going to take more time in terms of equipment that we need to get installed for like home modifications… she's [card for] really fragile and our apartment is like a storey building."
>
> **(Carer 14)**

A lack of coordinated discharge planning further contributed to Carers' sense of unpreparedness. Participants described limited discussion of equipment requirements, medication management, rehabilitation needs, follow-up services, or contingency plans should difficulties arise following discharge. Information was often delivered in a fragmented manner, making it difficult for Carers to understand what support would be available and who would be responsible for different aspects of ongoing care.

> "Their job is to get patients out as quickly as possible… the discharge team said she [cared for; mother] can go straight home. But mum had actually told me, 'I think I should go somewhere to recuperate'. So I spent New Year's Eve visiting nursing homes and phoning nursing homes."
>
> **(Carer 15)**

Importantly, many participants described discharge as a professionally-led process in which they were informed of decisions rather than actively involved in planning them. Even where Carers had concerns about safety, feasibility, or their capacity to provide support, they often felt reluctant to challenge decisions that appeared already finalised. As a result, Carers frequently assumed responsibility for implementing discharge plans without feeling fully prepared or confident to do so.

Taken together, these accounts suggest that discharge was often experienced less as a collaborative transition and more as a transfer of responsibility from hospital services to Carers and families. Difficulties in discharge planning reflected and amplified earlier challenges relating to recognition, communication, and involvement in decision-making. Consequently, many Carers described entering the post-discharge period feeling uncertain about their responsibilities, the patient's needs, and the support available to them.

3.1.7 Carers absorbing responsibility and risk

Following discharge, Carers described assuming substantial responsibility for coordinating and delivering care, often with limited preparation or support. Participants reported becoming responsible for medication management, monitoring symptoms, arranging appointments, facilitating rehabilitation, and responding to deterioration. Although many Carers viewed these activities as part of their role, responsibility was frequently transferred without explicit discussion of whether they felt able, prepared, or supported to undertake these tasks.

> "The main consultant said that a district nurse should have been coming out and doing wound care. And then they asked who had been doing it and I said 'me'."
>
> **(Carer 12)**

Participants also described becoming the primary point of coordination between multiple services, including hospital teams, general practitioners, community nursing services, therapists, and social care providers. In the absence of clear communication and continuity across services, Carers frequently acted as intermediaries, relaying information, chasing referrals, clarifying plans, and ensuring that different parts of the system remained connected.

This often required considerable time, effort, and persistence, particularly when services appeared poorly coordinated.

> "The GP didn't know there's been a change in medication. So, you're the one trying to say, 'the hospital said that he needs to start on this'… You're the one in between primary and secondary care trying to make it go smoothly."
>
> **(Carer 3)**

Many Carers described feeling responsible not only for providing care but also for managing clinical and organisational risks following discharge. Participants reported monitoring symptoms, identifying potential complications, and deciding when additional medical support was required. Several reflected on situations in which they believed deterioration, medication errors, or gaps in care may have gone unnoticed had they not intervened. These experiences positioned Carers as an important safety net within the discharge pathway, despite often lacking the authority, training, or resources associated with this level of responsibility.

> "You feel like you've been abandoned… the reality is that the care is still needed every day and the impact that that has on us as a family, as a couple — massive."
>
> **(Carer 10)**

The transfer of responsibility following discharge was frequently accompanied by feelings of anxiety, uncertainty, and pressure. Carers described remaining vigilant for signs that something might be wrong and expressed concerns about making mistakes or failing to recognise problems early enough. These experiences were closely linked to earlier themes relating to recognition, communication, and discharge planning. Where Carers felt excluded from decision-making or insufficiently prepared for discharge, the burden of responsibility was often experienced more acutely.

Taken together, these accounts suggest that Carers played a critical role in sustaining care following discharge. However, responsibility was frequently transferred to Carers without the information, involvement, or support needed to carry out this role confidently. As a result, Carers often found themselves acting not only as caregivers, but also as care coordinators, advocates, and safety nets within a fragmented system.

3.1.8 Inconsistent good practice

Although participants' accounts were often characterised by challenges relating to recognition, communication, involvement, and discharge planning, Carers also described examples of positive practice. While these experiences were less common than the difficulties reported elsewhere in the dataset, they provided important insight into the factors that contributed to more positive discharge experiences.

Examples of good practice most frequently centred on healthcare professionals who took time to listen to Carers, acknowledge their knowledge, and involve them in discussions about care and discharge planning. In these instances, Carers described feeling respected, informed, and reassured, even when the patient's condition or discharge arrangements were complex. Clear communication, opportunities to ask questions, and a willingness to engage with Carers as partners in care were consistently valued.

> "At the mental health hospital, two of the senior staff there explained to me what would happen. For the first time, I felt like a Carer. They were brilliant, absolutely peerless. I got to find out about how the mental health part of the NHS works. I've never seen such caring people… Incredible."
>
> **(Carer 1)**

Participants also described positive experiences where discharge planning was more collaborative and transparent. These accounts included receiving advance notice of discharge, having care needs discussed openly, being provided with clear information about support arrangements, and feeling able to raise concerns or seek clarification. Where communication

was consistent and Carers were involved throughout the process, participants reported feeling more prepared and confident in supporting patients following discharge.

> "An actual discharge nurse was allocated… who was involved in discharge planning and it seemed to be more seamless… she came and spoke to us several times and asked us about his transport, his medicines and everything else. So that was better."
>
> **(Carer 2)**

Importantly, positive experiences were frequently linked to the actions of individual professionals or teams rather than consistently embedded organisational practices. As a result, Carers' experiences often depended on which staff members they encountered and whether effective communication and involvement happened to be prioritised within a particular service or team. Participants frequently described particular staff members who demonstrated compassion, responsiveness, and a commitment to involving Carers in care decisions. While these interactions had a meaningful impact on Carers' experiences, they were often reported alongside broader concerns about communication, coordination, or discharge planning elsewhere within the system.

> "The consultant was terrific, fully discussed everything, had a really good manner… She said 'where would your mum want to be?' At that point everything was done to make sure that mum went home. Equipment arrived as if by magic. The NHS… at the absolute sharp end are terrific, it's the bits in between that tied together with a bit of string."
>
> **(Carer 15)**

Taken together, these accounts suggest that the challenges described in earlier themes are not inevitable. Participants' experiences indicate that Carers can feel informed, valued, and supported when communication is timely, expertise is recognised, and involvement is actively facilitated. However, the relative rarity of these accounts suggests that such practices may not be embedded consistently across services. As a result, examples of good practice highlight both the potential for improvement and the opportunity to implement more consistent approaches to Carer involvement throughout the discharge pathway.

3.2 COM-B analysis of Carers' experiences of hospital discharge

The COM-B model was used to support interpretation of the Phase 1 findings by examining how Carers' experiences of hospital discharge reflected factors relating to capability, opportunity, and motivation. For more information on the COM-B model, please refer to Section 1.3. The behaviour of interest in this study was the early and systematic identification of Carers within hospital settings, and their subsequent involvement in discharge planning. The COM-B model was applied to explore the factors influencing whether healthcare professionals identify Carers and whether Carers themselves recognise and communicate their caring role.

3.2.1 Capability

Participants' accounts suggest that healthcare professionals do not always possess the knowledge, skills, or confidence required to identify Carers consistently. Carers were frequently treated as visitors, relatives, or family members rather than individuals with ongoing caring responsibilities. Several participants also described not initially recognising themselves as Carers, particularly where caring responsibilities had developed gradually over time or were viewed as part of normal family relationships. These findings suggest uncertainty among both healthcare professionals and Carers regarding who should be considered a Carer and when caring responsibilities become relevant to discharge planning.

Participants also reported that staff rarely asked structured questions about who provides support at home, suggesting that Carer identification is not routinely embedded within clinical communication practices. In addition, examples where Carers' expertise was overlooked indicate that professionals may not always recognise the value of experiential knowledge within care planning. Together, these findings suggest that capability barriers arise not from a lack of

good intentions but from limited guidance, role clarity, and confidence in engaging Carers as partners in care.

3.2.2 Opportunity

Opportunity barriers emerged as the most significant influence on Carer identification. Participants consistently described the absence of systematic processes to identify Carers and involve them in discharge planning. No participant reported being explicitly asked whether they were a Carer, and identification often appeared dependent on assumptions based on family relationships, visibility on the ward, or the initiative of individual staff members.

Participants also described organisational barriers that reduced opportunities for involvement, including limited time for discussions, fragmented communication between services, inconsistent documentation practices, and discharge processes that prioritised operational demands over relational care. Carers frequently missed important conversations because they were not present when decisions were made, while others described being required to relay information between professionals because systems failed to share information effectively.

Importantly, participants' accounts suggest that identification alone is insufficient. Even where healthcare professionals were aware of a Carer's role, this did not always result in meaningful involvement in decision-making or discharge planning. These findings indicate that opportunity barriers operate both at the point of identification and in the absence of mechanisms that translate recognition into meaningful participation.

3.2.3 Motivation

Participants' accounts suggest that professional beliefs, priorities, and organisational culture also influence Carer identification and involvement. Several Carers felt that their knowledge and expertise were afforded less value than professional judgement, while others described reluctance to challenge decisions due to concerns about being perceived as difficult. These findings suggest that Carers are not always viewed as equal partners within discharge planning processes.

Motivational barriers may also arise where Carer involvement is perceived as an additional task rather than an integral component of safe discharge planning. Participants frequently described interactions in which communication appeared task-focused and operational priorities appeared to take precedence over collaborative working. Conversely, examples of good practice demonstrated that when healthcare professionals actively valued Carers' contributions and prioritised relational communication, Carers reported feeling recognised, respected, and more prepared for discharge.

3.2.4 Integrated interpretation

Across all themes, opportunity barriers emerged as the dominant influence on Carer identification and involvement. However, capability and motivational factors interacted with these barriers to shape Carers' experiences throughout the discharge pathway. When Carers were not identified, opportunities for communication, involvement, and preparation were reduced. Consequently, Carers frequently entered discharge processes without adequate information or support and subsequently absorbed responsibility for coordinating care, managing risk, and maintaining continuity across services.

The findings suggest that Carer invisibility functions as a foundational mechanism underpinning many of the difficulties identified throughout this report. Failures in identification were associated with communication breakdowns, limited involvement in decision-making, unrealistic discharge planning, and increased Carer burden following discharge. Improving Carer involvement is therefore likely to require interventions that address capability, opportunity, and motivation simultaneously, whilst embedding Carer identification as a routine component of hospital discharge practice.

4.0 Recommendations for Discharge Practice

The recommendations presented below in Table 2 were developed from the findings of the thematic and COM-B analyses. They are intended to address the barriers and facilitators influencing Carer identification, involvement, communication, and preparation throughout the hospital discharge pathway. Collectively, the findings suggest that many of the difficulties experienced by Carers arise not from isolated interactions, but from a combination of behavioural, organisational, and system-level factors that limit opportunities for meaningful involvement in care and discharge planning.

The recommendations focus on strengthening Carer identification, improving communication and coordination, supporting collaborative decision-making, and ensuring that Carers are adequately prepared for the responsibilities they may assume following discharge. Particular emphasis is placed on addressing Opportunity barriers, which emerged as the most influential drivers of Carers' experiences. However, several recommendations also seek to enhance staff Capability and Motivation to engage Carers as partners in care.

The recommendations should not be viewed as standalone actions, but as complementary components of a more Carer-inclusive discharge process. While some recommendations could be implemented through relatively minor changes to existing workflows and documentation, others may require broader organisational and cultural change. Together, they aim to improve the safety, quality, and sustainability of hospital discharge by ensuring that Carers are recognised, supported, and meaningfully involved throughout the patient journey.

Table 2. Recommendations for future discharge practice

Recommendation	Related Theme(s)	COM-B Domain(s)	Intended Impact
Systematise Carer identification at admission	Carer invisibility	Opportunity, Capability	Ensures Carers are recognised early and consistently, enabling involvement throughout the care pathway.
Embed Carer involvement at key clinical interactions	Carer invisibility; exclusion from decisions	Opportunity, Motivation	Creates routine opportunities for Carers to contribute to care planning and decision-making.
Recognise Carers as safety-critical partners in care	Carers absorb risk; expertise undervalued	Motivation, Capability	Increases recognition of Carers' role in patient safety, continuity of care, and risk management.
Provide training on collaborative communication and listening behaviours	Carer expertise dismissed	Motivation, Capability	Supports staff to value and incorporate Carers' knowledge into care and discharge planning.
Assign a named point of contact for Carers	Communication failures	Opportunity	Improves continuity, accountability, and access to information throughout admission and discharge.

Recommendation	Related Theme(s)	COM-B Domain(s)	Intended Impact
Begin discharge planning early and incorporate Carer context	Discharge as an unprepared transition	Opportunity, Capability	Ensures discharge planning reflects home circumstances, support needs, and Carer capacity.
Provide Carers with clear information about their role and available support	Carer invisibility; emotional burden	Capability, Motivation	Improves role clarity, confidence, and awareness of available support.
Improve information continuity across staff and services	Communication failures; coordination gaps	Opportunity	Reduces information loss, duplication, and reliance on Carers to relay information.
Implement minimum discharge safety standards	Discharge as an unprepared transition; Carers absorbing responsibility and risk	Opportunity, Capability	Ensures Carers receive essential information, resources, and support before discharge.

The recommendations outlined above are closely interconnected. Early identification of Carers creates opportunities for meaningful involvement in communication, decision-making, and discharge planning, while improved information sharing and coordination help ensure that Carers are adequately prepared to support patients following discharge. Similarly, recognising Carers as safety-critical partners in care may help to shift professional attitudes and encourage more collaborative working practices.

Although the recommendations are presented individually, the findings suggest that their impact is likely to be greatest when implemented as part of a coordinated approach. Addressing a single barrier in isolation is unlikely to resolve the wider challenges identified by Carers. Instead, improvements to identification, communication, involvement, and discharge planning should be viewed as mutually reinforcing components of a Carer-inclusive discharge pathway. Collectively, these recommendations seek to reduce the transfer of unsupported responsibility and risk to Carers while improving continuity of care, patient safety, and the overall discharge experience.

4.2 Feedback from professionals on recommendations

The original Hconnect project design included a second phase of qualitative interviews with healthcare professionals to explore their perspectives on Carer involvement in hospital discharge. However, it was not possible to obtain the necessary NHS research ethics and governance approvals within the project timeframe. As a result, a revised approach was adopted to enable healthcare professional perspectives to inform the final project outputs.

A short online feedback survey was developed to gather professional views on the draft recommendations generated from the Carer interviews. The survey was designed as a light-touch stakeholder consultation rather than a formal research study and sought feedback on the relevance, feasibility, and practical implementation of the recommendations. Respondents were also invited to identify potential barriers and facilitators to implementation, prioritise recommendations for action, and suggest any additional considerations that may have been overlooked.

Healthcare professionals working across different roles and settings involved in patient care and discharge processes were invited to participate. At the time of writing, four responses had

been received. The feedback was used to sense-check, contextualise, and refine the recommendations developed from the qualitative analysis of Carers' experiences.

4.2.1 Overview of feedback from health professionals

Respondents to the survey represented a range of professional roles and settings across the discharge pathway, including acute hospital, community, and mental health services. The feedback provided useful insight into the perceived relevance, feasibility and implementation challenges associated with the draft recommendations.

Overall, respondents expressed broad support for the recommendations. 50% of the respondents reported that the recommendations strongly reflected their experience of hospital discharge processes, 25% reported that they mostly reflected their experience, and the remaining 25% reported that they moderately reflected current practice. Collectively, the responses suggest that many of the issues identified by Carers were recognised by professionals working across different parts of the health and care system.

Several respondents highlighted the importance of recognising Carers as partners in care and acknowledged the valuable contribution Carers make to discharge planning and continuity of care. One respondent described Carers as the "eyes and ears from the community", emphasising their detailed knowledge of patients' needs, circumstances, and previous experiences of support. Another respondent noted that Carers frequently report feeling excluded from discharge decisions despite their central role in supporting patients following discharge.

Healthcare professionals generally viewed the recommendations as relevant and achievable. However, implementation was perceived to be influenced by existing workforce and organisational pressures. Staffing shortages, competing priorities, time constraints, and service capacity were repeatedly identified as potential barriers to implementation. Respondents also highlighted challenges relating to communication processes, staff continuity, and the practicalities of assigning a single point of contact for Carers within multidisciplinary teams.

When asked to identify priorities for implementation, respondents most frequently highlighted recommendations relating to Carer involvement in clinical interactions, recognising Carers as partners in care, improving information continuity, providing Carers with clear information, and beginning discharge planning earlier. These recommendations were viewed as having the potential to improve communication, support safer discharge planning, and strengthen collaboration between professionals, patients, and Carers.

Importantly, respondents did not identify major concerns regarding the overall direction of the recommendations. Instead, feedback largely focused on how recommendations could be implemented effectively within existing services. This suggests that healthcare professionals broadly recognised the challenges described by Carers and viewed the recommendations as aligned with current priorities for improving discharge practice.

5.0 Conclusion

This report explored Carers' experiences of hospital discharge and identified factors that influence their involvement throughout the discharge pathway. Through interviews with 16 Carers, six interconnected themes were identified relating to Carer identification, recognition of Carer expertise, communication, discharge planning, the transfer of responsibility and risk, and examples of good practice. Collectively, the findings suggest that Carers play a critical role in supporting patients during and following discharge but are not consistently recognised, involved, or supported within hospital processes.

The findings indicate that difficulties experienced by Carers do not arise from isolated interactions but reflect broader organisational and behavioural challenges. Carers frequently described a lack of formal recognition of their role, limited involvement in decision-making, fragmented communication, and discharge planning processes that did not always account for the realities of providing care at home. These experiences often resulted in Carers assuming substantial responsibility for coordinating care, managing risk and maintaining continuity across services following discharge.

Although examples of good practice were identified, these were often described as dependent on individual staff members or teams rather than embedded within routine practice. This suggests that improvements in Carer involvement are achievable but require greater consistency across services. The findings indicate that relatively small changes to identification processes, communication practices and discharge planning may have a meaningful impact on Carers' experiences and improve continuity of care following discharge.

Application of the COM-B model provided additional insight into the mechanisms underpinning these experiences. Opportunity barriers emerged as the most significant influence on Carer involvement, particularly in relation to identification processes, communication systems, and opportunities to participate in discharge planning. Capability and Motivation factors also played an important role, influencing both healthcare professionals' ability to engage Carers effectively and Carers' confidence to contribute to care and decision-making. Together, these findings suggest that improving Carer involvement requires changes at both the individual and system level.

The recommendations presented within this report seek to address these barriers by strengthening Carer identification, improving communication and information continuity, embedding Carer involvement within routine clinical practice and ensuring that Carers are adequately prepared for the responsibilities they may assume following discharge. Feedback from healthcare professionals broadly supported the recommendations and highlighted the importance of addressing implementation challenges such as workforce pressures, service capacity, and organisational processes.

Overall, the findings suggest that Carers are an essential but often under-recognised component of the discharge pathway. Improving outcomes for patients and Carers requires a shift from viewing Carers as informal supporters to recognising them as active partners in care. By embedding Carer identification and involvement throughout the discharge process, healthcare services may be better positioned to deliver safer, more coordinated and more sustainable transitions from hospital to home.

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