



Sussex Carers Partnership NHS/ICS Engagement Work 2023-24 Unpaid Carers Insights – Hospital Discharge Process, March 2024

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Introduction- Carer Insights on Hospital Discharge

In the last quarter of 2023, the Sussex Carers Partnership (SCP) was asked by the Integrated Care Board (ICB) to review the progress against the carer informed recommendations from the [Spring Carer Engagement Report, 2021](#).

Between April 2022 and September 2023, we conducted a desk-based review of the progress which was shared with the ICB on December 21, 2023. After that, the SCP was then asked to review how carers felt about the process of patients (that they support) leaving the hospital.

On January 11, 2024, we talked with colleagues from within our own organisations. These colleagues, who work closely with carers in hospitals across Sussex, shared their experiences, which helped us understand how patients and carers move through Transfer of Care Hubs. We made a separate summary report about this – see [Appendix 1](#).

Instead of getting new information, we looked back at six important suggestions from our talks with carers in Spring 2021. Together with what we learned from our colleagues, this guided us in creating a survey that we sent out between February 9 and March 5, 2024. This survey asked unpaid carers pan-Sussex about their experiences with the hospital discharge process for the person they care for.

Initially, 113 people started the survey, but we had to exclude 12 because they hadn't experienced the person they care for being discharged from the hospital. So, we analysed the responses from the remaining 101 participants. It's important to note that not everyone answered every question, so some questions might have fewer than 101 responses. The survey analysis was followed up with a focus group discussion with a small group of carers online and over the phone.

Additionally, to give more background, the main points from the previous report are included in [Appendix 3](#) at the end of this report, as many of them were about hospital work. We matched these points with the six key recommendations.

We would like to thank all the carers and colleagues who engaged with us as part of this review.

The Survey

Please Note: Graphical representations of the main statistical points below are shown in [Appendix 2](#) at the end of this report.

Of the 101 survey respondents:

- Majority (27%) were aged 56 – 65 years old.
- 55% were caring for their partner.
- 35% lived in Brighton & Hove, 34% East Sussex, 30% West Sussex and 1% Other.
- Majority carers (31 respondents) experienced hospital discharge for the person they care for over a year ago compared with 22 respondents who had an experience within the last month.
- On a scale, majority of respondents (41) felt that the staff at the hospital were 'not well-prepared' in equipping carers with information and skills for post-discharge of the person they care for.
- Majority (61) disagreed with the statement *"I felt that during the discharge process my well-being as a carer was taken into account by some healthcare professionals during and after the discharge"*.
- The top three challenges experienced by carers during the discharge process were:
 1. Lack of clear communication regarding the discharge plan and insufficient information and/or support for the person providing care
 2. Concerns about the person's (patient) emotional well-being after discharge
 3. Difficulty coordinating follow-up care and appointments.

In addition to the responses provided regarding the challenges, 45 respondents provided further insights through open-ended comments. They expanded on the challenges identified and underscored the significance of enhancing communication and co-ordination with unpaid carers during the discharge process. These insights are summarised in the table below, along with relevant quotes. Furthermore, a spreadsheet containing all anonymised comments has been shared separately alongside this report.

Summary Insight Points	Carer Quotes
Abrupt Discharge: A number of respondents mentioned last-minute discharges without warning or proper information, leaving them feeling unprepared.	<i>"I wasn't given any notice about discharge until I arrived at hospital day he was discharged and I was worried it was too soon and how we would cope back at home."</i>
Lack of Communication: Numerous instances of poor communication between healthcare providers and carers, including instances where important details about the discharge were not shared or explained.	<i>"My father was discharged without me or the carer being informed and my mother that he lives with also has dementia."</i>
Concerns about Patient Readiness: Carers expressed concerns about the readiness of the discharged person, citing instances where they believed the individual was not physically or mentally prepared to return home.	<i>"I didn't think the person was ready to come home. It felt uncaring, just wanted to free up the bed."</i>

<p>Challenges in Coordination: Delays in finalising discharge dates, difficulties in planning, and coordination with community or social services were common themes.</p>	<p><i>"I required hospital to delay discharge for a week (after a stroke) because they did not have a care plan in place at time they wanted to discharge. I insisted one was in place Pre discharge."</i></p>
<p>Medical Oversight Issues: Several responses highlighted problems with medication management, contra-indications, and the lack of follow-up care or proper assessments.</p>	<p><i>"We were just left to it after being blue lighted to A&E direct from GP office for pneumonia, 3 hours stay and antibiotics shot, then just sent home with extra antibiotic tablets. No follow-up, no info on post discharge care."</i></p> <p><i>"My husband was discharged on Monday with 10 different meds and there are clear contra-indications with one drug. It is impossible still to get a face-to-face GP appt to review."</i></p>
<p>Inadequate Support Services: Complaints about the quality and availability of support services, such as home care, nursing, and social services and the follow-on impact of cared-for being hospitalised due to falls or deteriorating health conditions.</p>	<p><i>"Paid carers were really bad, safeguarding concerns. Currently still under investigation. On second lot of carers. No real support for terminal illness after discharge. (No 24 hour number) Haven't listened what commitments I could make to carry on caring. I am back to picking up the pieces, 3 weeks after discharge!"</i></p>
<p>Geographic Barriers: Challenges related to the distance between carers and the discharged individuals, making it difficult to provide timely support.</p>	<p><i>"He was discharged from a hospital in Surrey which meant I had to push for relevant local follow up."</i></p>
<p>Impact on Carers Life: Carers often faced personal challenges, such as taking time off work, dealing with additional costs, and feeling ignored or unsupported in their role.</p>	<p><i>"No nurse to attend wound for over a week. Patient was 90 and wife 88. Help dressing and undressing, washing and caring for wound were non-existent."</i></p>
<p>Transportation and Logistic Challenges: Problems related to transportation, parking, and logistical issues during the discharge process.</p>	<p><i>"My wife was discharged to a nursing home for NHS funded palliative care and subsequently died. The discharge was first delayed a week by the hospital and when it did take place it was chaotic and she was moved late in the day two hours after the Home had asked for her to arrive to settle in. All her clothes disappeared in transfer."</i></p>
<p>Inadequate Post-Discharge Care: Concerns about the lack of follow-up care, post-discharge assessments, and ongoing support for both patients and unpaid carers involved.</p>	<p><i>"...the 6-week post hospital care that we were promised in the hospital could not be provided as there was not any availability in the system for us."</i></p>

The Positives

Despite most comments being negatively weighted, there were positives to take on board and build on. For example, medical care was described as “exemplary” by one carer and referenced several times as being very good. One carer referenced support staff “stepping up”. Another while stating that they received no practical help, did mention that speech and language help was given.

Two carers stated that:

“Everything this time was great and well-coordinated thankfully. Far better than other times.”

“No challenges.”

It was also mentioned during the focus group meeting that carers understood the pressures that the NHS and other services are under and want to be able to help by using their expert knowledge of the patient to assist, not hinder. There are frequent references to the patient wanting to get back home and not “block a bed”, but also a recognition that if the discharge is not communicated effectively, follow up care is not prepared and the carer is left with little to no information, there is a likelihood of readmittance.

From the phone conversations, one carer “X” stated:

“The local MH Crisis Team provided me with a resource containing detailed information about various medication options. This proved incredibly helpful, as it allowed me to review and discuss the options with clinical specialists.”

The Focus Group

The focus group was offered to all carers interested in further discussing their survey responses. While 19 respondents initially expressed interest, only 3 carers were able to participate in person. Two others were contacted by phone since the scheduled date/time didn't suit their working schedules.

As previously mentioned, the survey identified several areas of concern for carers. The focus group delved into many of these specific areas, aiming to determine if there was any consensus on the main concerns among the majority of carers.

The focus group discussions centred on various concerns, including:

- Abrupt Discharge
- Lack of Communication
- Concerns about Patient Readiness
- Challenges in Co-ordination
- Medical Oversight Issues
- Inadequate Support Services
- Geographic Barriers
- Impact on Carers Life
- Transportation and Logistic Challenges
- Inadequate Post-Discharge Care



Carer C

“The main issues here are lack of communication, challenges in coordination, transport and logistics.”

“I care for my wife. Just before Christmas 2022, she was rushed (after 9 hours) at 3 am to A&E at Worthing. She spent 48 hours in ICU and was then placed on a ward. The medical care was exemplary. We had made arrangements for her to go to a Nursing Home upon release, since she was not fit enough to come home. Luckily, the Home was flexible on dates.

Getting the release date from Worthing, and any form of coordination, was really difficult. As I understand it, a 'release' date is set by a doctor; on that date, the Pharmacy provides the drugs, which are checked on the ward; transport is arranged - my wife was in a wheelchair. Whatever the process, it did NOT go smoothly. No Doctor at all on the given day.

The next day, very late; uncertainty between Pharmacy and the ward regarding drugs; no transport was then available. I had to get my wife to the Home by 7.30 pm at the latest, so she was taken in a friend's camper van and arrived with minutes to spare.

For reasons I do not want to revisit, I did not want my wife left on the ward a moment longer than absolutely necessary. Her lack of care was a scandal. No need for her to 'bed block,' but without constant and positive intervention on my part, she would have been there longer”.

Carer K

“The operation went great, then a couple of days later I got a call saying come and get mum. I asked if they were sure as this was only a few days after a major operation... It was not even 12 hours before she was back in hospital, and this took up ambulance services as well as hospital at a time when we know all these services are stretched.”

"This started two years ago. Here's the background: my mum had a stroke and required some care. It took a long time for her to recover. Then, she started feeling unwell on a Friday and was admitted to Eastbourne District General. They discovered she had a strangulated hernia and transferred her to Hastings for treatment.

The operation went well, but a couple of days later, I received a message telling me to come and get my mum. I questioned if they were certain, considering it had only been a few days since her major surgery. They assured me she could walk but was feeling slightly faint. When I arrived, they brought her out to the car in a chair, which should have raised concerns for me, but I didn't question it at the time. However, she didn't seem okay when we got home. They provided no information regarding her medications or what to do, so I stayed with her for a couple of hours to monitor her condition. Mum seemed to think she was fine, so I left for home.

A few hours later, my mum called me, saying she needed my help. She was experiencing internal bleeding and was unable to get up from the toilet. An ambulance arrived, and fortunately, we had a "Lifeline" system in place as well.

When the paramedics arrived and consulted with Hastings, they advised taking her back to Eastbourne. She required two blood transfusions and spent a month there before transitioning to a care facility. Additionally, due to the stroke, she had started to develop dementia, which further complicated her situation.

Less than 12 hours after being discharged, she was back in the hospital. This placed additional strain on ambulance services and hospitals, especially considering the current demands on these services.

As her carer, I felt ignored throughout the discharge process. They never asked about her living situation or how she would be supported. Yet, my mum would always assert, 'My daughter will take care of this,' without being prompted. While her intentions were clear, they didn't consider that I don't live with her and have work commitments to manage."

Carer E

Carer E has been providing care for multiple family members, particularly one individual referenced as Z, for many years. Z suffers from bipolar disorder, ADHD, and addiction issues.

At the end of 2023, Z was abroad and required treatment, but became unable to return to the UK. Bringing them back cost Carer E's family a significant sum of money and caused immense stress. Z had discharged themselves from a hospital abroad, and Carer E explained that they lacked the mental capacity at that time to understand the consequences, including loss of insurance.

Upon arrival at a UK airport, Z was sectioned due to obvious signs of distress and was subsequently admitted to a hospital. Carer E expressed concern about the situation and was informed that Z would remain in the hospital and be re-categorized under the Mental Health Act from "section 2 to section 3". However, after a few days, Carer E was informed that Z would be discharged. It seems Z was discharged into the care of someone whom Carer E believes to be in addiction recovery. Within a week, Z was readmitted via Accident and Emergency.

After another brief period in the hospital, Z was discharged again but was detained by the police for allegedly stealing a car. Subsequently, Z revoked Carer E's consent to share information, was discharged again, and managed to board a flight out of the UK, where local police detained him.

Carer E explained that there was no system of care co-ordination, Carer Leads, or Co-ordinators at the hospitals. Z was considered to have the capacity to revoke Carer E as his carer:

"[Z]...was deemed to have capacity to revoke me as his carer and therefore no longer share information with me about."

Carer E noted that it appeared Z's health plan was created by two doctors when he was well and consented to share information, understanding that Carer E was there to help. However, Carer E explained that the revocation seemed to occur while Z was experiencing psychosis. Carer E believes that if consent is given when capacity exists, it should not be revocable if capacity diminishes.

The revocation of consent also meant that support from Patient Advice and Liaison Service (PALS) could not continue. Additionally, Carer E stated that on four occasions when Z was discharged from hospitals in the UK, he did so without medication.

The Mental Health Crisis teams had no knowledge of Z. Carer E stated:

'We all knew he wasn't okay, but the doctor said he was and signed him off.'

Carer E mentioned that a carer support worker made a difference, but only after Z had been discharged.

Main Points from the Focus Group

The carers in the focus group expressed that they would resist discharge unless they were certain the patient was ready and adequate support was in place.

Additionally, the group believed that having designated carer leads in hospitals would be beneficial, providing a point of contact for addressing concerns (some locations already have these in place).

According to the focus group respondents, communication was once again emphasised as needing improvement, particularly regarding what to expect upon discharge, such as the patient's expected health status and requirements.

The group suggested that updated discharge forms outlining expectations, carer involvement information, prescribed medication (including contraindications), and contact information in case of unexpected patient conditions would be helpful. Although these forms might already exist, consistency in their use may be lacking.

Phone Interviews

Carer Phone Interview 1

“Communication, clarity and consistency – that is what I as a carer need during the discharge process”.

X, responsible for caring for her daughter diagnosed with a mental health condition, shared their experience with the discharge process from acute hospital settings in East Sussex.

Emphasising the importance of early involvement, X highlighted the need for carers to be engaged in the discharge planning process as soon as possible. This early involvement allows for the exchange of crucial information among all parties involved, facilitating the development of a clear and actionable discharge plan.

Reflecting on a specific instance, X shared a situation where her daughter was planned to be discharged to her father's care. However, the oversight of her father living in shared accommodation was not considered, rendering the proposed discharge environment unsuitable for her daughter's needs and the discharge plan being abandoned.

“Without involving carers early on, discharge planning can lack crucial information. For instance, there was a plan in motion to discharge my daughter into her father's care, despite him being unable to provide the necessary support and living in shared accommodation, which wasn't suitable for her health needs. Eventually, the plan fell through, wasting valuable time that could have been saved if they had included me as her carer from the start.”

X stressed the necessity for carers needing to understand their role and responsibilities post-discharge. Clear guidance within the discharge plan is therefore essential, outlining tasks that carers may need to undertake at home. This includes detailed instructions on medication schedules, dietary restrictions, activity limitations, warning signs of medication complications, and named contact information for healthcare providers for assistance or queries.

Furthermore, carers should be directed towards available resources, such as medication information sheets, to ensure consistent access to vital information - a practice not uniformly observed across some services in Sussex as noticed by the carer (see [Shared Care medicine information sheets](#) as an example resource).

“The local MH Crisis Team provided me with a resource containing detailed information about various medication options. This proved incredibly helpful, as it

allowed me to review and discuss the options with clinical specialists. I'm aware of carers who are uninformed about the medications the person they look after is taking, highlighting the need for more consistent sharing of information with carers after discharge."

X expressed frustration when expectations outlined in the discharge care plan, such as a full multidisciplinary meeting to review medication and diagnosis, and new care plan to be agreed within the AST for her daughter in timely way, did not happen. This lack of follow-through rendered the discharge plan ineffective and left the carer without a clear point of contact for post-discharge care and support for her daughter.

"Looking back, I don't think the discharge should have happened. The plan said there would be a multidisciplinary meeting to review diagnosis and medication, this did not happen. It made me realise that the plan was just words on paper – promises that disappeared into thin air. It felt like they were just rushing to get my daughter out of the hospital without any intention to action or commit to the plan post-discharge."

X also brought up concerns regarding the structure of ward review meetings. These meetings are typically organised internally, with little consideration given to involving carers. For instance, X received a date and time for a ward meeting, rearranged her work schedule to attend, only to be informed later that the meeting had been rescheduled for a different day.

These meetings often involve various professionals, yet it's unclear who will be attending and what their roles are. X suggested that having a carer co-ordinators or leads could alleviate the stress on carers by helping them navigate these meetings and systems, providing consistent support and updates. These advocates should be integrated within hospital teams, serving as the primary point of contact for carers from admission to discharge.

X has adopted a proactive approach to prepare for meetings with professionals by creating her own summary document. This document includes a timeline detailing her daughter's interventions, medications tried, and their outcomes. This concise summary proves invaluable in meetings where time is limited, enabling X to advocate effectively for her daughter's health and care needs.

It is essential to ensure that patient records involving carers are regularly updated. Having quick summary information readily available in the system would facilitate a consistent understanding of the patient's needs across various teams and departments and would support a more effective and informed discharge planning.

Carer Phone Interview 2

"...I feel like I'm on a tick-list where people direct you to this and that, but no one really listens to what it is you need help with when it comes to the discharge process."

For the past six years, Carer A has been taking care of her husband, who has dementia and Parkinson's disease. He's been going to the hospital because of falls, and this experience is about what happened during the last year.

After a big fall, an ambulance took him to the hospital. While he was there to get better, Carer A visited him every day. Then one day, when she visited, they told her he was leaving the hospital. This surprised her because she hadn't heard anything about him leaving, even though she had been visiting him regularly for the past 10 weeks.

"When I arrived at the ward to see my husband, they surprised me by saying he'd be leaving that day. It was strange because nobody had told me earlier, despite me

visiting every day. They mentioned he'd be moving to a care home. I asked where exactly and told them I wanted to see it first to make sure it's good for him. But I could tell they didn't like it, and I felt like they thought I was being difficult."

Carer A thought she caused a problem by asking for time to check if the place they wanted to send her husband was okay. She noticed the ward staff started avoiding her and weren't as friendly as before. She knew they needed to free up beds, but she didn't want her husband to go somewhere that wasn't good. She checked online and saw bad reviews for the care home they suggested. So, she wanted to see it herself. When she did, it was better than she thought, and she felt it would be a good place for her husband. But even though he got great care in the hospital, the way they handled the discharge made her feel disappointed and let down.

But there was one person who helped her - someone from the Adult Social Care team. Even though she wasn't sure what his job was exactly, she felt better knowing she could talk to him at the hospital. He listened to her concerns and explained what he could and couldn't do. Just having someone on her side made a big difference. Carer A thinks hospitals should have someone like him to help carers through the discharge process.

"There was a man at the hospital who worked for Adult Social Care. I didn't have his number, but I often saw him around the reception area. He was helpful. He listened to my concerns and gave me advice on what to do next, like following up on social care referrals. Just having him there in person made a big difference for me as a carer. Usually, I feel like I'm on a tick-list where people direct you to this and that, but no one really listens to what it is you need help with when it comes to the discharge process."

Carer A also stressed that people don't realise how the discharge process affects the health of carers. For instance, carer A always agreed to bring her husband home after discharge, but it became hard to take care of him whilst also working. She felt like she couldn't be there for him properly, and the stress of caring role left her tired and exhausted, unable to sleep (sleep deprived), and eventually burnt out. Only then did she understand the importance of asking all the right questions during the discharge process. This ensured that her husband received the care and support he needed, and that he was discharged with a plan that prioritised his health and well-being.

Overview Analysis of Survey, Focus Group and Phone Conversations

The results indicate that communication with carers and their level of information regarding post-discharge care often appear to be lacking. Even when the correct process has been followed, it has proven inadequate for many of the carers who provided feedback. This deficiency has led to distress - both physical and emotional - on numerous occasions and has frequently resulted in readmission.



Conclusions

The top issues highlighted therefore indicate the improvements that are needed:

1. Communication about potential discharge should be early, accurate, and, when uncertain, transparent. This ensures that carers do not waste time away from other activities, including work. The tone and manner of communication were also highlighted as needing improvement.
2. Discharge should not be communicated on the day it is happening initially. This does not allow time for necessary adaptations to be put in place, whether physical or in terms of routines and schedules.
3. Carers must be provided with full information to effectively manage care needs outside of the hospital. Additional support should be offered where appropriate.
4. It would be highly beneficial for carers to have an advocate in place at hospitals, that they could turn to if they felt the discharge process or timing was incorrect and their views were being disregarded by ward or discharge team staff. This was mentioned repeatedly during conversations with carers.
5. Consistency in communication, process, and decision-making appears to be an issue. While some carers described a smooth discharge process with no issues, these instances were significantly overshadowed by situations where the discharge and follow-up were not considered adequate by the carer. Consistent use of discharge papers also appears to be lacking.
6. Some location-based references were made during the focus group, but we cannot ascertain from the survey if issues exist to a greater or lesser extent at particular locations.
7. Carers still seem to be regarded as a barrier rather than experts in the care of a particular person.
8. Instances where staff have gone out of their way to help have been viewed very positively. This includes individual members of Adult Social Care and voluntary support workers acting as carer liaisons in hospitals.

Addendum: An aspect of care not mentioned in any form was discharge to a “Virtual Ward.” The survey didn’t ask about this, but it should be noted that no carers mentioned this in their responses.

Recommendations

1. It is recommended to implement regular monitoring of the six key recommendations from the Spring 2021 engagement, focusing on increasing training for NHS staff to enhance their understanding of the role of carers and promote partnership development between NHS staff, carers, and patients. This training not only benefits staff but also reduces the likelihood of readmission due to failed discharge or follow-up care plans.
2. Carer advocates should be considered in all discharge settings to provide support to carers who feel unheard about their concerns, ensuring their voices are acknowledged and valued.
3. Carers request a roadmap of services and providers, including a clear outline of the discharge process, contact information, medication details, and follow-up appointments. This roadmap should be consistently applied and readily accessible to carers to facilitate smoother transitions from hospital to home care. Ideally, it should be collaboratively developed with input from carers alongside representation from discharge teams.
4. Given the lack of specificity regarding locations, it is recommended to apply any measures across all Sussex NHS sites where discharge occurs, rather than targeting specific locations. This ensures consistency and standardisation in discharge practices across the region.

Appendix 1 – Insight from Colleagues (Transfer of Care Hubs)

Online Consultation with Carers Support Hospital Team Colleagues

We have collated the notes from the online consultation with colleagues and presented the summary notes, and notable quotes, with further analysis for each of the relevant recommendation points.

Summary of Discussion

In some areas, carers do not have many chances to self-identify themselves. Initiatives like the Carers Passports, which could help with better carer recognition, are not always given out or talked about regularly. This might be because of certain internal rules about who is considered a carer and/or limited budgets within the wards.

“It seems the Carer's Passports are being used for carers who are helpful to the ward, so if they're going to be there at feeding times or help keep some one settled whose may be unsettled rather than actually for the needs of the carer. Because there is a financial cost to the ward, and the hospital ward has a set amount for the subsidies issued (parking or food, for example) and it comes out of their budget for that ward...so it is not issued to all carers in general, but mostly those who are helping with or providing some personal care on the ward”.

NHS hospital staff appreciate carer awareness training, but scheduling is challenging due to ongoing time constraints and strikes. Some of our colleagues have found it beneficial to attend hospital-led discharge training instead.

“... we've had lots of cancellations of our carer awareness trainings and changes to the format (having to shorten the duration or deliver online, for example) as the training lasts 2.5 hours, but that was too long for some teams so we're having to adapt. It's been hard to engage with NHS staff as well due to the time pressures and strikes. The other thing that we have found helpful is attending the discharge training workshops, which we found helpful as we learnt a lot about the discharge planning process and the challenges NHS staff face, and how we can fit in and help them”.

The level of communication during discharge depends on the individual handling it. The pressure to discharge quickly can result in varying communication standards, affecting the quality of information provided to patients and their families/carers and most often or not resulted in failed discharges and/or readmission shortly after discharge. Colleagues we spoke with highlighted the need for early carer identification, rather than at point of discharge.

“...we get carers very late. They need to be identified early at the point of admission...on the admission form, a box could be ticked to say if a carer is involved and whether they would like to be referred now and/or receive further information....we need to be involved at the front door...because the discharge team is the back door if you like...and we are getting carers on the day of discharge sometimes, and that's just too late”.

Worryingly, there is undue pressure on families/carers to take on care responsibilities without a proper care package in place. So, family members/carers are bridging the care gap without understanding the consequences.

“We are hearing regularly about failed discharges, carers being 'forced' to take back home the patient they care for when conditions at home are not ready for it. And often this is the case for carers / patients with complex needs (health and other - housing, financial etc)”.

Many carers often feel overwhelmed and struggle to find relevant information about the discharge process. Navigating the system is compared to "walking through mud," emphasising the need for clearer and consolidated guidance and support – whether this be in written literature or signposting support to carers' services who can support carers one-on-one.

"...there's a need for a consolidated piece of information for carers to know the discharge pathways... I think carers are overwhelmed by where, or who, to go to. They feel like they're walking through mud trying to get information. And that information can vary from person to person. So, it's hard for them to navigate the discharge system on their own".

A suggestion includes having summary information included with the discharge paperwork, which carers are most likely to read.

"Some of the carers we support, were not identified at the hospital site. They were referred in after the person has been discharged and then they are signposted to us, or our Home from Hospital service. Because we know carers are reading the discharge summary note, it would be helpful to add in an extra paragraph explaining who they need to contact when home and/or if things go wrong, when the care package will start and then add in information about support from carers' support services".

Review Against Six Recommendations from Spring 2021

Incentives to Identify Carers

- Issue of not allowing carers to self-identify was raised and mention of challenges with Carer Passports (CP) being controlled by the wards and mainly based on whether carer provides personal care.
- Others agreed that recognition of carers is ward-dependent, and CP's are often given based on the perceived helpfulness of the carer to the ward. For example, carers coming in to helping with feeding times, bathing, or changing etc.
- CP's are also limited as some wards have set budgets for the subsidised funding on parking and/or food, so this also influences how many CP's are issued rather than based on carer identification.
- Some colleagues must therefore advocate on behalf of carers to ensure they are issued the CP.
- Carers' support staff are being proactive in having a presence on the wards and attending meetings so that healthcare staff can easily pass on carer referrals. Highlighting the manual side of encouraging carer referrals and carer identification.

Introduction of Mandatory Carer Awareness

- The discussion revolved around the preparedness of hospital staff in recognising and involving carers in the discharge process.
- In some hospitals, carer awareness training is being added on to existing NHS staff training which ensures good attendance/footfall.
- The add on training includes a 10-minute talk on the identification of carers and addressing the challenge of carers not self-identifying.
- This is a good first step in introducing the topic of unpaid carers, but all agreed a standalone mandatory training would be more effective – this echoes the carer-informed recommendations from 2021.

- Additional challenges in engaging NHS staff includes cancellations of carer awareness training sessions, or reducing duration of training, and the on-going impact of the strikes in scheduling training.
- All noted that Teams like Occupational Therapists (OTs), Physios, and dementia teams may have more capacity to recognise and involve carers, as they spend more time with carers so understand their needs.
- While training is acknowledged as important, colleagues stressed the need for additional measures beyond training to make the discharge process smoother on the NHS side.
- All agreed that despite efforts to raise awareness about unpaid carers, the fundamental issue lies in the lack of capacity and time for staff to adequately support carers one-to-one.

Centralised Carer Records

- Suggestion that every discharged patient should receive a discharge summary with clear information for the carer on who to contact and what to expect regarding care packages. This inclusion, which could be limited to just a paragraph, would prevent the confusion faced by carers when they are unsure about contacting the hospital, leading to potential readmissions and strain on healthcare systems.
- Important to identify carers at the point of admission, for example, on the intake form, add a box that can be ticked to notify that a carer is involved. This would help carers' support services to reach out to carer a point of admission rather than support them at point of discharge, when things are very stressful and overwhelming.

Reduce Negative Impact of Caring on Mental Health

- There is a need for a more holistic view of a person's health rather than focusing solely on medicine, and this should be incorporated into the training for nurses, doctors, and medical staff.
- Some have noted a significant increase in the complexity of cases, with patients being sicker before entering the hospital. This adds challenges to the discharge process, requiring additional support for both patients and carers, with carers also having their own underlying health issues.

Regular and Consistent Messaging

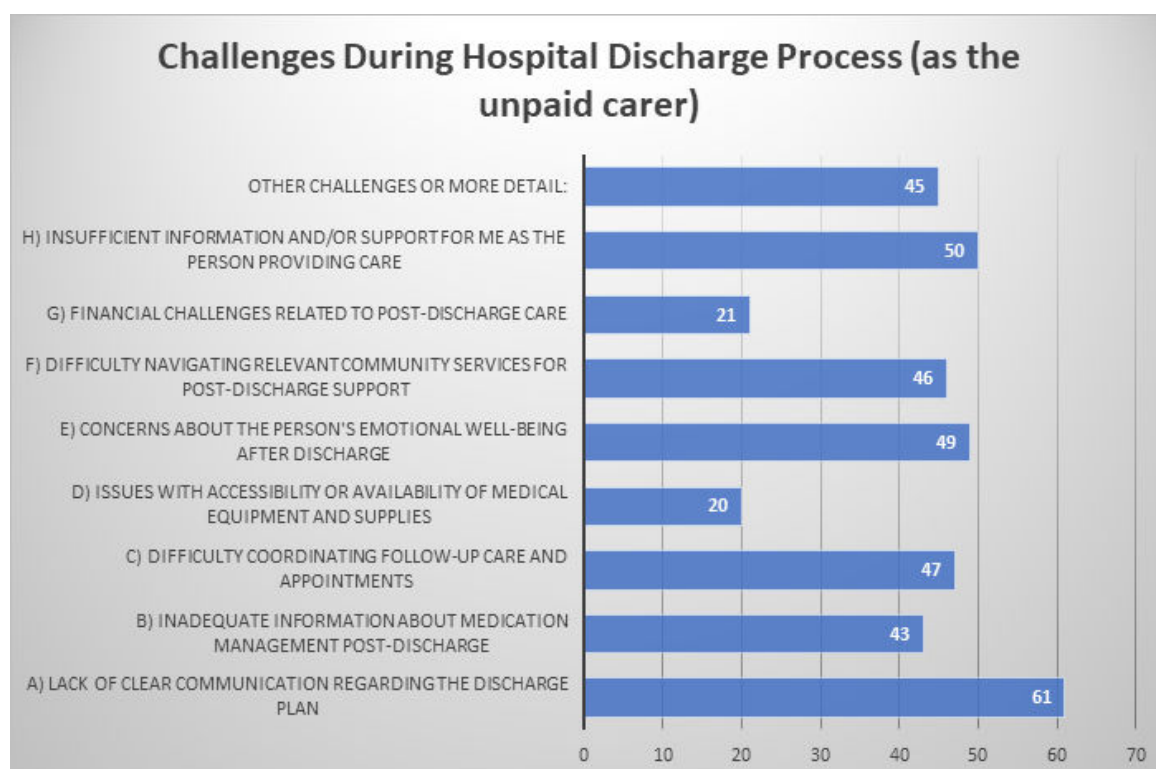
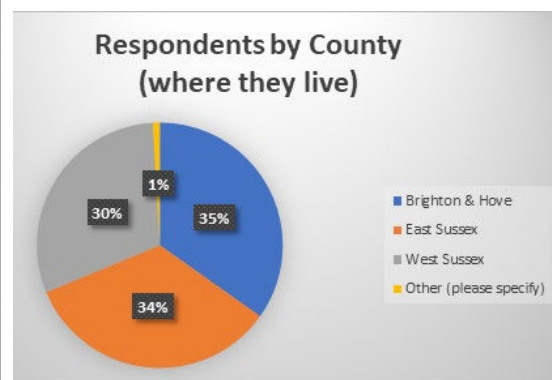
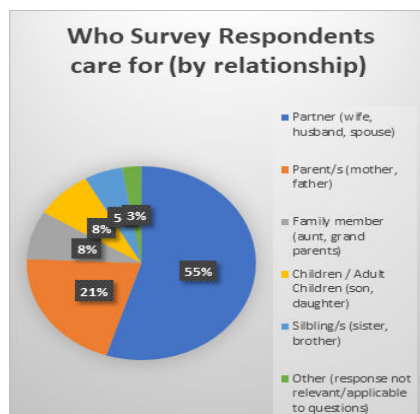
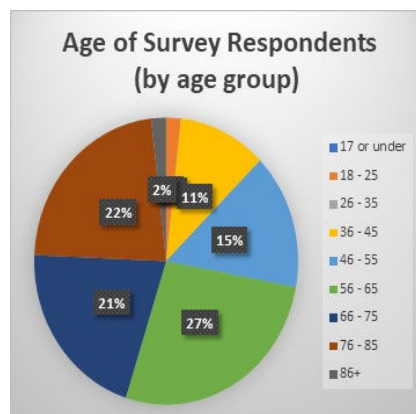
- Support for carers varies among different wards, with some being more versed in supporting carers than others.
- Discussion about the impact of winter pressures on the recognition and support for carers, noting a reduction in communication and the need for clearer processes at these busier times as carer identification and involvement seem to become less of a priority.
- However, there have always been pre-existing challenges where staff lack the time to involve carers in the discharge process, even though this is best practice, resulting in failed discharges and/or readmission shortly after discharge.
- Some therefore emphasised the importance of good communication and providing one-on-one guidance to help carers navigate the hospital system and their options available, so carers can make an informed choice.
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Road Map for Services and Support

- Discussion around better co-ordination of discharge information, as most carers have little or no knowledge about what package of care they are leaving with, what transport home is being arranged, if any, and who they need to contact once home after hospital.

- Observations about the concerns about the diminishing choices for carers and patients during the discharge process. Therefore, there is a need to manage expectations, given the reduction in available options for care providers.
- All agreed, identifying carers is not enough; there must be adequate support, which includes time and resources for follow-on support.

Appendix 2 – Graphical Information (from Survey)



Appendix 3- Previous Key Points from Dec '23 Engagement Report

1. Improve the Identification of Carers:

- Carers Support West Sussex - Between April 2022 – September 2023, 15% (or 1211) of all new carer registration were hospital referrals and 6% (or 482) were from Primary Care sources.
- CSWS- On average, we register 454 new carers each month, with around 67 referrals from hospital sources and 27 referrals from Primary Care.
- Brighton & Hove Carers Centre – Carer awareness and Carer Champion online training was developed and went live during Carers Week 2023. 63 organisations totalling 156 individuals have completed this updated version.
- B&H – New link worker roles set up (June '23) at Royal Sussex County Hospital. Weekly carers café created (Nov '23), and carer network being explored. 163 direct referrals via RSCH source. *Update March 2024: RSCH now has a Carer Champion, a staff carer network and a weekly carers café meet up.*
- Care for the Carers – 333 referrals for the period were from Primary Care sources, which makes 3.5%, with self-referrals and unknown deducted the referral rate is at 11.5%. 437 referrals were made by secondary care providers (incl. hospitals, community teams and Sussex Partnership NHS Foundation), which makes up 4.7%, or just under 15% of non self-referrals; 63 referrals were identified in the period as received from the hospitals.
- CftC – New Hospital Carers Support project set up at Conquest (Hastings), with comms developed and distributed to staff, patients and carers. Hospital Carers Support Workers started in September, with first carer referral received at the end of that month.

2. Introduction of Mandatory Carer Awareness (in Primary Care):

- CSWS - Continued delivery of Carer Awareness sessions to local partners, including Primary Care Networks.
- CSWS/All - Carer co-produced online training aimed at raising awareness of ethnically diverse carers launched in September 2023. To date (November 2023) 71 health and social care professionals, in clinical and non-clinical roles self-enrolled for training.
- B&H – 11 Carer Champions now in place covering 14 GP surgeries (33% coverage). Champions are also in place in BHCC, HASC, SPFT and various VSCE organisations and employers. Great response to new online Champion and Awareness training.
- CftC – 2 dedicated Carers Leads event and training days delivered (April 2022 and April 2023) with 17 staff attending in 2022 and 12 in 2023.
- **RED - Still outstanding is that the take up of Carer Awareness training is dependent on individual departments, organisations and Primary Care providers.**

3. Centralised Carer Records:

- CSWS - As part of our Primary Care Project, 77 GP surgeries interviewed, and all have a Carers' Register.
- CSWS - In January 2024, we will be working with those GP surgeries interviewed to understand how their Carers' Register is being used to support identified carers.
- B&H – Our Primary Care link worker is in regular contact with PCNs and individual surgeries to ensure that carers are registered with us and also their surgery.
- CftC – 3 GP Surgeries in Havens are part of Primary Care Carers Support project; all have carers register but the numbers remain low, e.g. Havens Health have 305 registered, out of a population of 18,000.
8 surgeries in Hastings are part of the Primary Care Carers Support project, all have carers register. Some surgeries in Hastings are implementing new carers registration forms either online or in their new patient registration packs.

- CftC - We work with 27 GP surgeries who have a nominated Carers Lead(s); all have been advised about carers register, but we don't currently hold data on which do have it. We know some of them do.
Good practice example – one GP surgery (Manor Park, Polegate) has a message promoting carers awareness and encouraging carers registration as part of the surgery voicemail, during call waiting time.
- **RED - Still outstanding is a Carers Passport within Sussex NHS. Some carers report that the various carers cards are sometimes accepted as proof they are carers and consideration given accordingly.** Hospital Carers Passport is due to be developed and piloted at Conquest Hospital in 2024.

4. Reduce Negative Impact of Caring on Mental Health

- CSWS - 436 carers supported with 1:1 counselling support to help them improve their mental wellbeing, and a further 14 carers supported through our bilingual counselling offer.
- CSWS - 50 carers supported through our Carer Coaching Programme to help improve carer resilience and 76 carers attending our Mindfulness programme.
- B&H – Increased the number and variety of support groups. We ran a “Banish those Blues” day in Spring 2023, we have new reflexology sessions, and we also have a new worker within our Changes Ahead support for carers of people with mental health conditions.
- B&H – We ran 867 events and 533 individual carers attended, totalling 3036 attendances (average 5.7 times each).
- B&H - We worked with the Helix Project (Imperial College London) to give carer information and opinion. This project is looking at seamless mental health services for the ICS.
- CftC – 325 carers supported with 1:1 counselling support to help them improve their mental wellbeing.
- CftC – our Mental Health Project identified on average 575 new carers each year, with 355 carers caring for people with severe mental health accessing project's support.
- CftC – on average over 200 carers access our regular Carers Groups each year which provide peer support and are often one of the most sought after support.
Annually, over 350 carers benefit from activities, with at least 25 activities provided through our main adult carers programme; those have a strong focus on wellbeing, mental health and offering carers a break and time away from caring. There has been additional 65 activities, groups and events (in the reporting period) provided by our project supporting carers caring for those with severe mental health.
- **AMBER - Still outstanding though progress has been made, is that there is no single Sussex wide offer for carers struggling with their mental health. There are Sussex wide services such as “Staying Well” which is a partnership of NHS and voluntary sector organisations. The lack of a universal offer was reported in June '22 to the ICS.**
[Staying-Well-Services](#)

5. Regular and Consistent Messaging

- CSWS/All - Continued pan-Sussex messaging as part of Sussex wide Winter Campaign, with +39% (year on year percentage) increase of professional referrals to carer services, and +17 increase in new carer registrations.
- B&H – Increased number of channels being used to send information including a twice monthly e-newsletter which has increased in scope, to include information and events from other organisations.
- B&H/All – The Making Carers Count project has ensured that information is available to carers speaking/reading a number of languages other than English. Interpretation services have also been available for events.
- B&H – Currently undergoing a major refresh of our website to ensure we offer the best available information and support at the correct time in a carers journey. Expected delivery in 2024.

- CftC – extensive social media, monthly e-newsletter and quarterly printed and on-line Carers Magazine is used to support relevant comms for carers.
On social media we have shared NHS messaging on average once a month, and then as required ad hoc for example around strikes etc.
12 e-newsletters over the reporting period included NHS related articles. 8 of the total 20 articles related to services available e.g ‘Help to access the right NHS services’ and ‘Flu vaccinations at GPS and Pharmacies for carers’.
In the Careline Magazine, we have included ‘Better Health’ campaign article, ‘Help us help you stay well this winter’, article on pharmacies services article and prescription ordering service. In Autumn 2023 we started a new series of articles called “Unravelling the NHS”, with a Primary Care Networks explanatory article.
GREEN – messaging is generally timely and abundant. Issues remain with reaching everyone that may need to know.

6. Road Map for Services and Support

- CSWS - Creation of five bespoke online [Carer Toolkits](#) on the following topics: Bereavement, Cost of Living, Benefits, Dementia, and Mental Health, to help carers understand and navigate the available support options and services.
- CSWS - Dementia Navigation Service, including piloting a bespoke Bi-Lingual Memory Navigator service, to help carers and their families navigate a dementia related diagnosis in West Sussex.
- B&H – Working with Brighton and Hove City Council strategy groups to ensure consistency and plan/identify services. Carers Rights Day 2023 involved co-working to refresh the BHCC Carer Friendly City strategy.
- All – “Making Carers Count” mapped out services and partners in relation to ethnically diverse groups.
- B&H – Mapping carer’s journeys and information needed at each stage as part of our brand and website refresh.
- CftC – launched annual East Sussex Carers Voices Report to bring together comprehensive data and feedback from local carers to share a comprehensive picture of what is important to carers in East Sussex. This annual publication is based on what Care for the Carers and other local charities heard from carers through a range of engagement events, surveys and consultations.
- CftC - In Autumn 2023 we started a series of quarterly articles for the Careline Magazine (replicated on the website) called ‘Unravelling the NHS’, with Primary Care Networks being the first topic.
- **Still outstanding is that there is no single Sussex wide carers roadmap explaining the process of obtaining care and services available.**