



Carer experiences about hospital arrangements through to discharge

December 2023

healthwatch

Executive Summary

Background

Healthwatch Wandsworth holds events to discuss recent developments in health and social care and how to improve services with the Wandsworth community. In collaboration with St George's Hospital, an event was organised for carers on the 7th of December 2023 to discuss how to improve arrangements for people in the community when they leave hospital. This report outlines what was heard from those who attended.

During the event, we listened to the experiences of carers supporting friends and family leaving hospital. We also asked for their perspectives on how to improve arrangements for leaving hospital. The event offered a space for carers to meet other carers in the community and provided information and resources.

We held discussions in smaller groups to address two questions centred on arrangements for leaving hospital:

- What can we give carers to help them support the person they care for? Follow up questions included: How can we involve and include carers on the ward? What is important to consider about a carer's lifestyle, needs, and culture?
- What things must the NHS consider before offering virtual wards (e.g., cultural sensitivities, lifestyle of patient/carer, suitability of home)?

Here is a summary of the key points discussed:

What we can give carers to help them support the person they care for

The following suggestions were made during the event:

- **Encourage carers to focus on their physical and mental health.**
- **Carers should be integral to all parts of the hospital experience.** This should include encouraging reciprocal, respectful, and open communication between carers and hospital staff; making sure carers are included in plans for diagnosis, care, and leaving hospital; and providing joined up, integrated care.
- Ensure carers are connected to organisations who can make sure they have **carers support at home**, including meal support, pet support, and bill support.
- Carers would like **personal considerations such as culture, food, and religion** to be thought about in their hospital stay and through to discharge. This could involve gathering information on both the patient's and carer's faith, language, and dietary needs to support practical

requirements while they are in hospital and as they prepare to leave.

Virtual ward considerations

- Carers would like virtual wards to **simplify the language about the service**, including the name.
- Virtual wards should **be mindful of carer distinctions**. Carers noted that the expectations of paid and unpaid carers should be explicitly stated in information around virtual wards, as well as the role of carers that are relatives, friends, or neighbours when there is or isn't a paid carer present.
- Hospitals should **keep carers integral to the virtual wards**, specifically to the decision to join virtual wards and to the experience of being on a virtual ward once admitted.
- Carers would like information and reassurance about **emergency response protocols** that may already be in place.
- Virtual wards should **establish integrated ways of working** to create seamless, joined up working across organisations.
- Carers would like the virtual wards to **provide training and information about equipment and technology**.
- Carers would like the virtual wards to **provide training and clear information about virtual wards**. This should include an FAQ sheet to answer the questions they have.

Conclusions

Overall, there are a variety of items to consider to support carers in caring for their friends and family. Based on the discussions, some areas where improvements can be made are as follows:

- Create awareness around the importance of carers' taking care of their physical and mental health so they can support their friend or family member upon leaving hospital. This may include signposting to support, especially around bills.
- Ensure carers are respected as integral to all aspects of their friend or family member's hospital stay. A ward induction or similar process at the start of a hospital stay can allow hospital staff to welcome carers and carers can share important information with hospital staff. This can secure a pathway of open, respectful, and reciprocal communication throughout the diagnosis, care, and discharge process.
- Consider language supports already in place, and ensure communication is in plain English, with communication support provided where needed.

There are also several points to consider before offering patients virtual wards. Based on the discussions, the following points were suggested:

- Consider simplifying the name to make it more accessible.
- That carers are kept integral to all aspects of a virtual ward stay and that reciprocal communication is supported through having information available in multiple languages and plain English.
- Evaluate the suitability of virtual wards for patients on a case-by-case basis in collaboration with carers and their individual varied needs and circumstances.
- Implement and communicate clear pathways for emergency response protocols and integrated working.
- Provide an FAQ sheet to carers as well as bespoke training for carers about virtual wards and equipment to provide clear information and expectations around the wards.

It is important to note that these recommendations are based on the discussions and recommendations of the carers and their knowledge about the topics discussed. Some of the suggestions that were made are already delivered by other parts of the health and care system, making it important to work collaboratively with the wider community to consider the suggestions that carers made.

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Introduction

Improving arrangements for leaving hospital has been an ongoing priority the community of Wandsworth has told us about. During the pandemic, the NHS started Discharge to Assess arrangements which used a multidisciplinary approach to get people home from hospital quicker. In addition to this, care is increasingly provided at home using technology to create a 'virtual ward' to give patients care at home so they can leave hospital early or avoid going into hospital altogether.

At Healthwatch Wandsworth, we spoke with carers in 2021 and 2022 to understand their experiences leaving hospital. We then worked with local organisations to share what people told us and to understand how things could be improved. In response, the NHS changed their guidance to make sure the needs of carers were considered more, and a toolkit was created for London hospitals to make sure important steps are taken to involve carers when arranging hospital discharges.

In 2023, Healthwatch Wandsworth again identified plans for leaving hospital as a research priority. St George's Hospital is using the carers' hospital toolkit to address issues around leaving hospital. To make sure their implementation of the toolkit reflects the needs of the community, St George's Hospital is gathering and responding to the experiences of carers and their families. In addition, the NHS are working to create virtual wards to support health at home. St George's Hospital and Healthwatch Wandsworth are working together and are committed to improving the experiences of carers by providing events welcoming carers to share their experience of discharge and virtual wards to help inform improvements.

On the 7th of December 2023, Healthwatch Wandsworth and St George's Hospital held an event focused on how to improve arrangements for people in the community when they leave hospital. The attendees were people from Wandsworth who support their friends and family members (including those who identify as carers) with their health and/or daily living. During this event, the carers shared their experiences of caring for someone leaving hospital and described how the discharge experience could be improved for patients and carers.

The topics discussed are as follows:

- What can we give carers to help them support the person they care for? Follow up questions included: How can we involve and include carers on the ward? What is important to consider about a carer's lifestyle, needs, and culture?
- What things must the NHS consider before offering virtual wards (e.g., cultural sensitivities, lifestyle of patient/carer, suitability of home)?

What we discussed

What we can give carers to help them support the person they care for

During the first discussion, carers focused on a few questions:

- What can we give carers to help them support the person they care for?
- How can we involve and include carers on the ward?
- What is important to consider about a carer's lifestyle, needs, and culture?

As the carers discussed these questions, the following themes emerged:

- Encourage carers to focus on their physical and mental health.
- Keep carers integral to all aspects of the hospital experience.
- Support carers at home.
- Think about personal considerations such as culture, food, and religion.

Encourage carers to focus on their physical and mental health

Carers discussed the importance of maintaining their own physical and mental health while supporting the person they care for. When a person has caring responsibilities, it can be easy for one's own health and wellbeing to drop down the priority list. However, to provide care in a sustainable way, carers must be well. Therefore, carers felt that receiving a holistic health and wellbeing assessment could be helpful. This would empower the carers to understand and address their health and wellbeing needs.

The carers discussed how an annual health review would support them to keep up to date with their physical health needs. When the conversation turned to mental health, the carers discussed how they are often worried about their responsibilities. One carer specifically mentioned that carers have many responsibilities that often lead to burn out and exhaustion. When a loved one is admitted to hospital, the extra caring responsibilities could take them to the breaking point. Based on this, the carers asked if ad hoc psychological support could be made available for carers to ensure mental health support is available. Moreover, carers wanted the physical and mental stress that they may be under to be recognised. This way, carers can be linked to mental and physical health support.

Similar to mental health support, carers discussed the importance of carving out space for self-care while supporting their friend or family member. Participants noted that it would be helpful if carers were encouraged to pursue their hobbies and interests. While the carers discussed how factoring in their own hobbies and interests is important to maintaining wellbeing in the present, it also had important implications for the future. Maintaining their hobbies and interests

gives carers something to support their wellbeing if the person they are caring for passes away.

Keep carers integral to all parts of the hospital experience

The carers discussed how they need to be valued as integral to their friend or family member's care at all stages of the hospital experience. To achieve this, they suggested the following:

- Carers should have reciprocal, respectful, and open communication with hospital staff.
- Carers should be included in plans for diagnosis, care, and leaving hospital.
- Their friend or family member should receive integrated care where hospitals, GPs, and carers are kept up to date.

Reciprocal, respectful, and open communication

Throughout the diagnosis, care, and discharge process, carers shared that they want open, respectful, and reciprocal communication with hospital staff. The carers discussed how a ward induction could be key in establishing this. The ward induction would create a specific process to identify and welcome carers, conduct a carers assessment, and offer any needed support to carers. Carers went on to say that this ward induction would be a good opportunity to share vital information with families, such as visiting hours, and gather information from carers like family rota and language requirements. This induction would be a critical point to establish reciprocal, respectful, and open communication between carers and staff, making the family feel welcomed and supported.

Language barriers came up for carers when thinking about maintaining reciprocal communication where carers can share and receive information with hospital staff. They noted that language support is important to make this possible. Additionally, carers emphasised that all information, especially for diagnosis, care, and leaving hospital, should be available in simple English. They requested that this information be available in a 'carers' pack' that is accessible in a digital app and paper format. Moreover, communication in hospital could be aided by each carer having a named person to speak with, making the care received more personal.

Plans for diagnosis, care, and leaving hospital

Several carers noted that, in order to have a smooth discharge process, they should be integral to their friend or family member's hospital journey from the earliest stages. From hospital admission, carers' voices should be integrated into hospital processes as they can support both the patient and staff with diagnosis. This is because carers often have information about their friend or family member that the hospital staff, or in some cases, the patient themselves, will not know. Several carers also said that they should be included in the creation and implementation of the care plan because they are often the ones who will implement it on behalf of the person they are caring for once they leave hospital. Finally, the carers noted that they would like to sit with the discharge

panel to understand the process of discharge and co-create safe discharge plans.

Receive integrated care

Carers raised points about maintaining communication across other services. They wondered how hospitals are connecting information from the GP during the hospital admission process. Moreover, after leaving hospital, carers questioned whether a discharge summary would be created for both carers and GPs. This would make the process of leaving hospital and reconnecting with primary care simpler for both primary care providers and carers.

Support carers at home

Carers have many responsibilities while a friend or family member is in hospital and preparing to leave hospital. The carers discussed support that would be helpful such as meal support and care for pets left at home during the hospital stay.

Carers have many responsibilities once they leave hospital, leading our group to ask about the support they can receive from other organisations once they are at home. One of the major concerns carers noted was around bills. One carer shared that they take care of their loved one's bills when using the hospital equipment at home. Because of this, they wonder if carers can be offered advice and support around the potential energy bills incurred because of hospital equipment. As internet access is required to use the technology and equipment often sent home with patients, carers also wondered if support could be provided for internet bills. Following the same theme, another carer wondered if any support is available around their electricity, water, gas, and other bills whilst fulfilling caring responsibilities. It was felt that signposting carers to organisations such as the council or voluntary sector organisations that can facilitate access to support would be helpful.

Think about personal considerations such as culture, food, and religion

Carers noted several personal considerations that hospitals can think about when supporting carers both when on the ward and preparing to leave hospital. One suggestion is for staff to engage in cultural sensitivity training as it could help them understand the cultural needs of carers and the person they are caring for. For example, some carers may want access to religious support as part of their hospital stay. The practices surrounding this could impact the carers and patient's care while in hospital and leading up to discharge. If staff can engage in cultural sensitivity training, this empowers them to identify needs and be responsive to them.

Following on from this, carers noted that staff should ask about the patient's and carer's faith, language, and dietary needs to support practical requirements while they are in hospital and as they prepare to leave. Carers wanted to ensure they raised this important point in the discussion as this consideration is integral to quality care.

Finally, a specific concern for carers centred around food. It was important to carers that the hospital staff welcome family and friends bringing in food. A

tangible way to facilitate this would be having a ward meal preparation facility with a microwave available for use.

Virtual ward considerations

In the second discussion, carers turned their attention to virtual wards. The question at hand was:

- What things must the NHS consider before offering virtual wards (e.g., cultural sensitivities, lifestyle of patient/carer, suitability of home)?

As the carers discussed this question, the following themes emerged:

- Simplify the language.
- Be mindful of carer distinctions.
- Keep carers integral to virtual wards.
- Provide reassurance around emergency response protocols.
- Establish integrated ways of working.
- Provide training and information about equipment and technology.
- Provide training and clear information about the virtual wards.

Simplify the language

Right away, carers noted that the name 'virtual wards' felt inaccessible as it did not clearly convey the essence of virtual wards- to give patients care at home so they can leave hospital early or avoid going into hospital altogether. Once the carers heard a description of virtual wards, it put them at ease. This leads us to wonder whether a name such as 'Hospital at Home' may be more accessible and easier to understand for patients and carers.

Be mindful of carer distinctions

When discussing virtual wards, carers raised the importance of understanding the distinctions between the roles and responsibilities of different kinds of carers. In this session, we spoke with carers who were the family members and friends of people receiving care. Therefore, one key distinction raised by the carers is the role of paid and unpaid carers on virtual wards.

Carers expressed that there needs to be clear expectations around what paid and unpaid carers will do on virtual wards because, in many situations, both will be present. Following on from this, there should be reciprocal communication between paid and unpaid carers to provide the best support for the person receiving treatment. For example, if a paid carer doesn't arrive, the unpaid carer will have to step in, so it is vital that they are kept in the loop about treatment. Carers also noted that there might be more than one unpaid carer (family member or friend) involved, leading to further questions of how communication works with and between groups.

Finally, one participant highlighted that not all carers are relatives. In this particular case, the carers were supporting a neighbour because their children lived in another country. This can bring up issues around how much carers who are not relatives can be involved on the virtual ward alongside how much information can be disclosed to them.

Keep carers integral to virtual wards

Similar to the section titled 'Keep carers integral to all parts of the hospital experience', carers have raised the importance of being kept integral to all parts of the virtual ward, including when deciding to enter virtual wards and the experience of being on the virtual ward.

Keep carers integral to the decision to enter the virtual ward

Several carers shared the importance of being involved in the initial choice of whether the person they are caring for is put on a virtual ward or if they seek care in a traditional hospital. There are several factors impacting on the decision to enter a virtual ward. Each situation is unique, making it pertinent to decide whether virtual wards would work on a case-by-case basis. The hospital should have open conversations with carers about what it would take to enable care at home.

Once this is made clear, other elements should be considered. For example, participants wanted clarity on what carers would be expected to do in virtual wards. Carers discussed how a virtual ward may not be a suitable option for carers if they have other commitments. They also noted they may feel tethered to their friend or family member's home if they were on a virtual ward, which might in turn interrupt their ability to fulfil their daily commitments, including going to work. On the other hand, participants did see that it could give carers more control over their lives. If the patient was being monitored through equipment (to be discussed further in the section titled 'Provide training and information about equipment and technology') and carers had access to this information, carers might not have to be physically present. Regardless of the role carers have in virtual wards, it is important to identify and support the needs of the carer and understand how the carer can and cannot support someone. For example, it is important to know if the carer is likely to be physically present for the duration of the virtual ward stay.

Following on from this, the carers felt it was essential that the mental health of carers was considered when deciding if a virtual ward is appropriate. They noted that many carers may already be at capacity. As carers tend to have other responsibilities such as work or children, they worry that additional responsibilities, administrative tasks, or expectations from the virtual ward would impact negatively on their mental health and exhaustion levels. It would be important to make sure that the additional responsibility of virtual wards does not take them to the 'breaking point' as some noted they are already close to this. A participant noted that if carers become unable to cope mentally and physically with further caring demands, it could have an extremely negative impact on their wellbeing, such as suffering a nervous breakdown.

Another important factor when deciding who should be on virtual wards is disabilities and long term conditions of both patients and carers. Carers

specifically raised concerns around if they themselves or patients struggle with visual impairments, hearing loss, arthritis, or a learning disability and how this would impact the functioning of virtual wards. The carers stressed that assignments to virtual wards should be made on a case-by-case basis and consider people's ability to understand and use the equipment.

Keep carers integral to the experience of being on the virtual ward

Once admitted to a virtual ward, the carers noted they should be integral to decisions made on the ward. Following on from the suggestions made in the section titled, 'Keep carers integral to all parts of the hospital experience', carers noted the importance of carers being integral to all processes on the ward, including diagnosis, care, and discharge. During this discussion, one carer shared that their mum was admitted to hospital, discharged, and then readmitted after a few days. They believe that part of this was due to medical staff not listening to relatives about the medicine and its effect. This leads us to highlight questions around how medical staff listen and respond to the input of carers. This would be especially important to consider on virtual wards where medical staff are not physically and immediately present if problems arise.

If the patient is discharged from hospital to virtual wards, carers noted that the discharge home arrangements for equipment such as a hospital bed with rails and hoists must be explicitly shared with carers so they can know the items they will be provided. Moreover, some people who live alone and who have spent time in hospital may experience issues such as the electricity shutting off whilst they've been away, so this should be addressed prior to entering a virtual ward after a hospital stay.

Finally, following the themes in the section titled 'Keep carers integral to all parts of the hospital experience', carers noted the importance of reciprocal communication between themselves and hospital staff. To facilitate this, it would be helpful to have information available in multiple languages and have a named person who they can communicate with about the needs of the person they are caring for. This would facilitate open and reciprocal communication between virtual ward staff and carers.

Provide reassurance around emergency response protocols

Carers noted the importance of having emergency response protocols in place to respond efficiently to incidents that may occur on the virtual wards. The carers had major concerns about the response time to emergencies such as falls, sudden changes in pressure monitoring and diabetes monitoring, and pass out incidents. Carers also questioned if the equipment could send an alert to the virtual ward team or carers in an emergency when a piece of equipment isn't switched on or being worn by the patient. For example, a carer shared that when a neighbour had fallen without a neck alarm on, they were not attended to for hours. While these protocols may already be in place, carers would appreciate clear communication around what the emergency response protocols are.

Establish integrated ways of working

Virtual wards function as part of a wider health and social care system, leading carers to wonder how they link with wider multidisciplinary teams, social care services, and care homes. Several questions were raised including:

- Would the technology provided by social care work in tandem with virtual wards?
- How are local councils kept in the loop with virtual wards to ensure social services and their finance departments are kept up to date?
- How would contact with care homes be facilitated if carers need additional help from outside organisations and companies?

These questions around integrated working led the carers to worry that current arrangements around virtual wards are not seamless and will require more intentional planning between organisations to create a smooth experience.

Provide training and information about equipment and technology

During their discussion, the carers talked about paid and unpaid carers receiving bespoke training on how to use the technology and equipment required by virtual wards. Through this training, the carers wanted to:

- Learn how to use the equipment correctly.
- Build confidence in knowing that the equipment is working properly.
- Learn how to take readings and transmit these readings to the central monitoring hub.

Carers explicitly noted there should be an assessment about whether they are comfortable with the monitoring equipment after the training is complete. This is important to ensure it is used properly and that if any concerns arise, they are confident in reporting them.

The cost of using equipment was also a concern for carers. They noted that while virtual wards are free, electricity is not. Moreover, the internet facilities needed to operate the equipment and technology could incur extra costs. This particular concern holds extra weight as people in Wandsworth, and often carers, are struggling with the cost of living crisis. This led carers to wonder if there would be support available around electricity and internet costs while on virtual wards.

Carers also noted concerns around the limitations of the equipment. For example, would the virtual ward team know if a patient was not wearing equipment? What happens if the patient forgets to wear these gadgets? How does the health professional know and intervene? One participant said that she would not use a virtual ward as a patient because she did not think that the monitoring equipment would provide enough reassurance that she was okay. She said that she would prefer to have health staff see her as, if something is wrong, it may be visually apparent but not detectable by a machine.

On the topic of technology, a carer wondered if virtual wards are making use of available Artificial Intelligence (AI) to support the functioning of virtual wards for patients, carers, and their families. As part of this, some carers questioned whether invasive equipment would be part of virtual wards. They also wondered if support would be provided to carers who do not have smart phones so they can use the technology required. Finally, some carers shared they might be worried about security when there is expensive equipment in their home.

Provide training and clear information about the virtual wards

Carers desired bespoke training on their role in the virtual ward. The group felt that a pilot program could be useful to understand what the training should cover to support carers and give them confidence in supporting their friend or family member on the virtual ward.

Participants felt that it would be good to have a **frequently asked questions sheet with case studies** that responded to the following concerns that people have about virtual wards:

- What happens in an emergency? Will an ambulance be called, and will I need to wait a long time for treatment in A&E? Does it help patients avoid A&E?
- What or who can help me with the monitoring equipment?
- Where is the central monitoring hub located?
 - How long will it take for someone to respond if I need help?
 - How many patients are the hub monitoring? How can I be confident that someone will notice if things go wrong when they are monitoring many others at the same time?
- Do patients need to pay for the monitoring equipment?
- Do people need internet access? What are the electricity and internet costs of using the equipment per day?
- What happens if the equipment is broken or stolen? Will the patient need to pay?
- How is clinical governance monitored? Is the patient's data secure?
- How much space is needed to have the equipment at home? How does the hospital assess home suitability?
- Will carers be updated by the central monitoring hub if a patient's condition worsens? Will this information be available in languages other than English?
- Can non-native English speakers use virtual wards? What support is given to the people who have language barriers?
- Can people who are blind use the equipment?
- Will there be IT support?

- How would patients and carers know they would be kept up to date and not left after discharge?

Conclusion

To summarise, it's clear that there are a variety of considerations to improve support for carers during hospital admissions, discharge processes, and in using virtual wards. The following recommendations are based on the discussions and recommendations of the carers. Therefore, these recommendations are specifically from the carers that attended the event and may be relevant to more than one health service provider. To address the points made by the carers throughout this report, we suggest the following:

- Increase awareness of the need for carers to take care of their physical and mental health so they can support their friend or family member on discharge. This may include signposting to support, holistic assessments, and especially support with bills and mental health support.
- To ensure carers are respected as integral to all aspects of their friend or family member's hospital stay, we recommend a ward induction or similar process at the start of a hospital stay so hospital staff can welcome carers and carers can share important information with hospital staff. This can secure a pathway of open, respectful, and reciprocal communication throughout the diagnosis, care, and discharge process.
- Language support should be considered, and communication should be in plain English, with communication support where needed.

Virtual ward considerations

- We suggest that the virtual wards consider simplifying their name. For example, the name 'Hospital at Home' may offer a clearer picture of what is being offered to carers and their friend or family member.
- Similar to the above, carers are integral to all aspects of a virtual ward stay. One way to do this is establishing reciprocal modes of communication. Carers should be listened to on the ward, and information should be available in multiple languages and plain English.
- We recommend the evaluation of the suitability of virtual wards for patients is made on a case-by-case basis. The decision should be made in collaboration with carers by thinking through factors such as carer distinctions, mental capacity, disabilities, and their individual varied needs and circumstances.
- We recommend clear communication pathways for emergency response protocols and integrated working. This should be communicated to carers

as part of a commitment to keep them integral to the processes of the virtual ward.

- We recommend that virtual wards provide bespoke training for carers about virtual wards and the equipment that will be used. Carers would also value a FAQ sheet that provides clear answers to the questions posed throughout this report.



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