Virtual wards evaluation

Patients' and unpaid carers' stories



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Introduction

This document presents a collection of patient and unpaid carer stories gathered during the evaluation of virtual wards. These stories provide a personal perspective on the experiences of those who have engaged with the service, highlighting individual journeys, challenges, and outcomes. The stories use pseudonyms and have had some personal details amended to protect the identity of the participants. These stories offer valuable insights into the experience of virtual ward care, complementing the broader findings detailed in the main report.

• Main report: Virtual Wards Evaluation: Patients' and unpaid carers' experiences, Final report, June 2025

Patient / unpaid carer	Brief description	Page
<u>Aisha (patient),</u> <u>Fatima (sister)</u>	 Aisha has complex health needs and limited communication abilities. Fatima, her sister, is her primary carer. The virtual ward enabled home care with remote monitoring. Communication, language, and technology barriers. Carer burden necessitated additional family support. 	3
<u>Beryl (patient),</u> <u>Caroline</u> (daughter)	 Beryl has complex health needs and recurrent infections. Caroline, her daughter, is her full-time carer. The virtual ward provided home care and avoided repeat hospitalisations Carer supported by virtual ward team Personalised long-term care. 	6
<u>June (patient),</u> <u>Mark (husband)</u>	 June has terminal cancer and COPD. Mark, her husband, is her primary carer. The virtual ward provided compassionate home-based end- of-life, palliative care Previous negative hospital experience Carer inclusion and support. 	8
<u>Rachel (patient)</u>	 Rachel had pneumonia and undiagnosed COPD Her husband supported her with technology setup The virtual ward enabled home recovery with remote monitoring Monitoring enabled discovery of sleep condition Previous experiences of inconsistent care. 	10

Patient and unpaid carer stories

Patient / unpaid carer	Brief description	Page
<u>Sharon (patient)</u>	 Sharon has multiple chronic conditions and lives in poor temporary accommodation Her teenage daughter supports her care The virtual ward provided remote monitoring despite challenging living conditions Impact of poor housing Highlighting a need for follow-up care. 	12

Aisha and Fatima's story

Aisha has complex health needs including epilepsy, lung failure and learning disabilities. She requires continuous care and monitoring. She is currently living with her sister Fatima, who is her primary carer. She has limited communication abilities and relies heavily on her sister and her sister's family (husband and son) for support. **Fatima** has been living in the UK for over 40 years and is well-versed in navigating the healthcare system. She balances her job alongside her deep involvement in Aisha's care, including managing her medical needs, communicating with healthcare professionals, and supporting her wellbeing. Her husband (who is retired) and son also support Aisha.

What happened?

- Aisha was referred to the hospital due to severe lung failure and low oxygen levels. Her GP recognised the urgency and immediately sent her to the hospital for intensive care.
- Towards the end of her stay in hospital, Aisha's clinical team discussed her returning home for care with a supply of oxygen as a virtual ward patient. Fatima agreed and Aisha was discharged from the hospital.
- The first visit from the virtual ward team was not scheduled. At the visit, Fatima initially declined the monitoring equipment because she struggles with technology and her husband was not around to support her during the demonstration. With notice, she would have made sure that he was.
- During a follow-up phone call, which Fatima found stressful, the nurse indicated that Aisha could not remain at home if Fatima did not accept the equipment. A return visit was rescheduled for a time when Fatima's husband would be present. This was more successful, and the monitoring equipment was set-up.
- Fatima, her husband, and son were then able to support Aisha with monitoring and communicating with the virtual ward team.
- Aisha was monitored at home for a fortnight with a tablet for video calls, a wearable device to track her oxygen levels, blood pressure, and heart rate, and regular remote check-ins from the respiratory team .
- Aisha was discharged from the virtual ward when the team were happy with her breathing and oxygen levels. Fatima was relieved to have the oxygen tank removed from the house, as she had had some safety concerns, and for the reduced night-time monitoring.

- **Communication:** the respiratory team maintained regular contact, providing updates on Aisha's condition. Fatima appreciated their responsiveness.
- **Home setting:** Aisha had a more comfortable place to recover, and it was easier for Fatima and family.

- **Support from respiratory team:** Fatima praised the team's professionalism and quality of care.
- Family involvement: Fatima's husband's and son's support eased some of her stress.

"As soon as [Aisha's] oxygen went down, they called me and said to me, '[Fatima], please put [Aisha] on the oxygen because her oxygen level is down.' Their monitoring was fantastic. They called me in the middle of the night, they called me when I was at work, then I called home, whatever, who is there, either my son or my husband, I told them. So, the service was perfect. I'm quite happy."

What challenges did Aisha and Fatima face?

- **Choice/concerns regarding equipment set-up:** At the first, unscheduled, home visit and follow-up phone call, Fatima felt pressured to accept the remote monitoring equipment, particularly when a nurse said they would otherwise remove the oxygen, and Aisha would have to return to hospital. This caused significant stress.
- Language and communication barriers: Aisha's limited English and learning disability made communication difficult. Fatima is the only person who can effectively communicate with Aisha, (as her family, and health and care services, do not speak Fatima and Aisha's native language) which added to her stress, especially when she was at work and needed to communicate between Aisha and other family members or health care professionals.
- **Technical issues:** there were occasional connectivity problems with the monitoring equipment, requiring multiple attempts to get accurate readings.
- **Oxygen safety concerns:** Fatima was nervous having oxygen equipment in her home due to potential safety risks, such as fire hazards. However, she accepted it as a necessity for her sister's health.

"They called to say, 'we will take the oxygen if you don't accept [the remote monitoring equipment]." And I said, 'Please bring anything you want to bring. Please come any time you want to come. Because if you take the oxygen my sister, she will end up in the hospital or worse."

- Communication prior to admission: describing how the virtual ward will work, including remote monitoring processes and carer roles and responsibilities, more clearly before patients are sent home will ensure a smooth admission, where patients and carers can be more prepared.
- Alternatives to remote monitoring: where patients and carers are not confident and comfortable using remote monitoring technology, virtual ward staff should offer alternatives such as increasing the number of in-person visits.

- **Culturally competent care:** health care professionals communicating directly with the patient in a language they understand and speak takes the burden of caregivers having to translate often complex messages.
- **Support for carers:** additional support for carers can be necessary, particularly with managing the technical aspects of remote monitoring and dealing with the emotional stress of caring for a loved one with complex needs.
- **Family dynamics:** even when there are other family members available to support, caregiving responsibilities often fall primarily on one person and services should explore how they can support these individuals and address any needs that may arise from providing care on the virtual ward.
- **Healthcare system navigation:** even for people with extensive experience navigating the healthcare system, staff should be mindful that new services and ways of working can be challenging at first.

Caroline and her mother's story

Caroline's mother Beryl is in her 80s with complex health needs, including recurrent infections, diabetes, and mobility issues and is at risk of hospitalisation. **Caroline** has been living with and caring for her mum full-time (as well as working from home) for three years, in a remote village. She previously moved back home with her partner from another region, after her mum had a couple of long stays in hospital and could no longer live independently. She supports her mum with personal care, meals, catheter care and medication.

What happened?

- Beryl was referred to the virtual ward for the first time in 2022 after a sepsis infection returned following a four week stay in hospital. Caroline phoned the GP who sent out the urgent response team who support the virtual ward.
- The virtual ward service was introduced to Caroline when her mother developed another infection. The service was recommended by her GP, and since then, Caroline has relied on the virtual ward team to manage her mother's recurrent infections at home rather than hospital.
- Caroline's mother has been on the virtual ward multiple times, typically for four to ten days, depending on the severity of the infection. The team continues to monitor her until her blood tests show improvement, at which point she is discharged from the service.
- The virtual ward team provides daily home visits, including blood tests, urine tests, catheter changes, and monitoring of her mother's condition. They also liaise with the hospital and GP to ensure she receives the right antibiotics and treatment.

- **Daily home visits:** the virtual ward team provided consistent, daily home visits, which Caroline describes as "*phenomenal*." They monitored her mother's condition, took blood and urine samples, and ensured she was on the right treatment plan.
- **Personalised care:** the team came to know Caroline's mother well, having cared for her for three years across multiple admissions. They recognised her unique symptoms and provided tailored care, even when her observations appeared normal despite her being unwell.
- **Support for Caroline:** the team provided significant support for Caroline, advising her on medication administration, catheter management and other care tasks. They also liaised directly with the hospital and GP, reducing the burden on Caroline.
- **Avoiding hospitalisation**: Caroline believes the virtual ward has kept her mother out of hospital multiple times, which she described as being important given her mother's frailty and the risks associated with hospital stays.

"I can absolutely, positively without doubt say that without the support of the team and the nurses who have come out... my mum would be in hospital most of those times. They are absolutely so good. At the end of the day, it takes the pressure off the hospitals having a team like this."

What challenges did Caroline face caring for her mother?

- Limited local healthcare resources: living in a remote village means that access to immediate healthcare resources was limited. The virtual ward team has been essential in bridging this gap, but Caroline has faced challenges with other services, such as delayed flu and COVID vaccinations.
- **Carer burden:** while the virtual ward team provides significant support, Caroline still bears the primary responsibility for her mother's care. This includes managing her catheter, administering medications, and coordinating with an increasing number of healthcare professionals.

- **Importance of personalised care:** the virtual ward team's deep understanding of the patient's condition highlights the value of personalised, long-term care relationships. This has been crucial in managing recurrent issues and avoiding unnecessary hospitalisations.
- **Support for carers:** there is a need for ongoing support for carers, particularly those managing complex health conditions at home. The virtual ward team has been instrumental in providing this support and helping carers develop capabilities to support patients at home, but additional resources could further ease the burden on carers.
- **Remote and rural healthcare access:** the virtual ward *"has been a lifeline"* for those who live in remote areas with limited access to healthcare services. This highlights the importance of expanding virtual ward services to other rural communities.
- Integration with other services: even with effective and 'exceptional' care from virtual wards there can be challenges with other parts of the healthcare system, such as delays in vaccinations. Better integration between services could improve the overall care experience for patients and carers.

June and Mark's story

June is a 69-year-old woman living in a small industrial town with her husband, **Mark**, who is her primary carer. June has terminal cancer, lung cancer and COPD, which significantly impacts her mobility and overall health. She relies on Mark for daily support, including personal care and managing her health needs. After a difficult hospital experience, June was introduced to the virtual ward, which has since become a critical part of her care. The team provides home-based care, allowing June to avoid hospital stays and remain in the comfort of her home.

What happened?

- June was initially hospitalised for her conditions, where she had a negative experience. She felt
 rushed and poorly informed about her treatment options, including discussions about a do not
 attempt cardiopulmonary resuscitation order (DNACPR) order, which caused significant
 distress.
- After her hospital stay, June was introduced to the virtual ward by a district nurse. The service was presented as an alternative to hospitalisation, allowing June to receive care at home.
- The virtual ward team provided comprehensive support, including regular home visits, medication management, and coordination with other healthcare services like Occupational Therapy. They also helped June and Mark understand her condition and treatment options.
- June has used the virtual ward service multiple times, most recently for a urinary tract infection, during which the team visited her daily for a week to monitor her condition and provide treatment.
- Although June is no longer actively using the service, she knows she can contact the virtual ward at any time if her condition worsens, providing her with a sense of security and continuity of care whilst she manages her terminal condition.

- **Personalised and compassionate care:** the virtual ward team took the time to explain June's condition and treatment options in a way that was easy to understand. They addressed her concerns about the DNACPR order and provided reassurance, which helped reduce her anxiety.
- **Home-based care:** June and Mark both emphasised how much more comfortable and relaxed they felt receiving care at home compared to the hospital. The virtual ward team allowed June to avoid the stress and discomfort of hospital stays.
- **Support for carers:** Mark, as June's primary carer, described feeling included in the care process. The team took the time to ensure he understood June's condition and treatment plan, which helped him feel more confident in his caregiving role.

• **Continuity of care:** the virtual ward team provided consistent support, even after June was no longer actively using the service. Knowing she could contact them at any time gave June and Mark peace of mind.

"I can't praise them enough. They have so much patience, unbelievable. I mean, they're as busy as anybody else, but they do take the time." (June)

What challenges did June and Mark face?

- **Negative hospital experience:** June's initial hospital stay was described as traumatic, with poor communication and a lack of empathy from staff. This experience left her feeling anxious and distrustful of hospital care.
- **Complex health needs:** managing terminal cancer, lung cancer, and COPD is challenging, including for Mark, who bears the primary responsibility for June's care. The virtual ward has been essential in providing support when June has become acutely unwell.
- Limited understanding of treatment options: June and Mark initially struggled to understand terms like "'fast track' and 'DNACPR,' which were poorly explained by hospital staff. This caused unnecessary distress until the virtual ward team clarified these terms.

- Importance of clear communication: it is crucial that healthcare providers communicate clearly and compassionately, especially when discussing sensitive topics like end-of-life care. The virtual ward team's approach to explaining treatment options and addressing concerns are a key factor in a patient's positive experience.
- Value of home-based care: the virtual ward model can be configured to provide care for patients with complex health needs and end of life care. It reduces the stress of hospital stays and allows patients to remain in a familiar and comfortable environment.
- **Support for carers:** it is important to include carers in the care process. Providing clear information and emotional support to carers can help them feel more confident.
- **Continuity and accessibility of care**: ongoing availability of virtual ward support, even after active care has ended, provides patients and carers with a sense of security.

Rachel's story

Rachel is a 60-year-old woman and works as a part-time cleaner. Although she has no previous medical conditions, she was hospitalised in November with severe respiratory problems, including pneumonia and undiagnosed COPD. She was introduced to the virtual ward team during her hospital stay, where she heard it being discussed with another patient. She was then admitted on to the virtual ward and supported to recover at home with continuous monitoring. Rachel's husband, who is confident with technology, helped set up the monitoring equipment and supported her throughout the process.

What happened?

- Rachel was admitted to hospital with severe respiratory issues, including low oxygen levels and hallucinations. She was initially diagnosed with pneumonia and later found to have undiagnosed COPD.
- During her hospital stay, Rachel was introduced to the virtual ward team by a nurse who was discussing it with another patient. The team explained the service and offered her the option to recover at home with continuous monitoring.
- Rachel was discharged from the hospital early and sent home with monitoring equipment, including an armband, an iPad, and a blood pressure monitor. Her husband helped set up the equipment, and Rachel began her recovery at home.
- The virtual ward team tracked Rachel's oxygen levels, heart rate and blood pressure. The monitoring revealed that Rachel had sleep apnoea, which was previously undiagnosed.
- Rachel's discharge from the remote monitoring service was described as abrupt and poorly communicated, leaving her feeling unsettled and without clear follow-up care instructions.

- **Continuous monitoring:** Rachel felt safer at home than in the hospital because the remote monitoring team tracked her condition 24/7. The team alerted her when her oxygen levels dropped or her heart rate spiked, which helped her manage her condition more effectively.
- **Personalised care:** Rachel appreciated the personalised attention from the team, particularly from a nurse, who checked in on her regularly and provided emotional support.
- **Discovery of sleep apnoea**: the remote monitoring revealed that Rachel had sleep apnoea, a condition of which she was unaware. This was an important discovery by the service, allowing her to seek further treatment.
- **Support from husband:** Rachel's husband played a crucial role in setting up the monitoring equipment and supporting her throughout the process, which made the transition to home care smoother.

"I felt really safe, I'll be honest with you... from that monitoring, I learned a lot about myself... I wouldn't have known without the hub, without all this equipment."

What challenges did Rachel face?

- **Abrupt discharge:** Rachel's discharge from the virtual ward was sudden and poorly communicated. She received a call telling her to remove the monitoring equipment without any prior warning or follow-up care instructions, which left her feeling unsettled.
- **Inconsistent communication:** while Rachel described most of the team providing excellent care, she found that some staff members were dismissive and did not listen to her concerns. This inconsistency in communication was frustrating for her.
- Lack of follow-up care: after her discharge, Rachel did not receive any follow-up care or information about her condition. She was left unsure about whether her pneumonia had fully resolved and what steps she should take next.
- **Limited information:** Rachel felt that she lacked sufficient information about her condition and how to manage it. She would have appreciated a booklet or guide explaining what to expect and how to care for herself after discharge.

- **Reassurance of continuous monitoring:** for conditions where symptoms can change quickly, continuous monitoring can empower patients/carers and provide reassurance that changes can be noticed by the healthcare team.
- Importance of clear communication: it is critical that all communication is clear and consistent, particularly around discharge. Where possible, patients should be given information at the start of their admission to the virtual ward about how long they are likely to require care for. The discharge process should be explained, and patients should be provided with detailed follow-up care instructions.
- **Patient education:** providing patients with clear, written information about their condition and how to manage it at home would help them feel more confident and supported during and after their recovery.
- **Consistency in care:** ensuring all team members provide the same level of care and attention is crucial.

Sharon's story

Sharon is a 50-year-old Jamaican woman living in temporary accommodation (a hotel) with her teenage daughter. She has multiple health conditions, including asthma, diabetes, high cholesterol, and a history of respiratory issues. Sharon has been placed in the hotel by the local authority for over eight months; despite being told it would be a temporary stay of 56 days. The living conditions are poor, with no working lift, cockroaches, and limited access to hot water, which has exacerbated her health issues. Sharon was admitted to the hospital with severe respiratory problems and was discharged on the same day to continue her care at home with remote monitoring through the virtual ward service.

What happened?

- Sharon was admitted to the hospital after experiencing severe chest pain, vomiting and difficulty breathing. She called 111 and later 999, and an ambulance took her to the hospital, where she was diagnosed with a chest infection and Norovirus.
- Due to a lack of available beds, hospital staff advised Sharon could be discharged the same day and sent back to her temporary accommodation and admitted on to the virtual ward with remote monitoring equipment. Sharon described having to walk up five flights of stairs because of the lift being broken.

"The doctor came and said they haven't got a bed, so they're going to send me back to the hotel, because it is in front of the hospital... just five minutes' walk from the emergency service. So, they said I should take my time to walk over...it was very cold. It took me probably about two hours to get to my room, because I had to take one step each on the stairs."

- The virtual ward team set up the equipment in her hotel room and provided her with an iPad for video calls and text communication.
- Sharon was monitored for a week and a half, during which the team tracked her oxygen levels, heart rate and blood pressure. She also received daily video calls from the team to check on her condition and adjust her medication.
- Sharon's daughter helped her with daily tasks, including taking her blood pressure and collecting medication from the pharmacy. Sharon's living conditions made her recovery more challenging as it was cold.
- Sharon was discharged from the virtual ward after completing her medication, but she continues to experience some respiratory issues and at the time of the interview had an upcoming appointment with an asthma clinic as part of follow-up care.

What worked well?

- **Continuous monitoring:** Sharon felt that the remote monitoring provided her with the same level of care as being in the hospital. The team tracked her vital signs and adjusted her treatment as needed, which helped her manage her condition effectively.
- **Daily communication:** the virtual ward team maintained regular contact with Sharon through video calls and texts, ensuring she felt supported throughout her recovery. This daily communication helped her feel less isolated and more connected to her care team.
- **Support from daughter:** Sharon's teenage daughter played a crucial role in her recovery, helping her with tasks like taking blood pressure readings and collecting medication. As her daughter was under legal age to collect the prescribed medicine, Sharon had to call the pharmacy at the hospital and agree for them to give the medicines to her daughter.

"They were on the phone, (whilst she was on the road), the pharmacist with my daughter, and I was on the phone as well. I couldn't speak long, because when I speak, my chest hurts. She collected my inhalers, and whatever I needed at the pharmacy. They were telling me one time, if I needed my medication could be delivered, but because I'm diabetic, I've got high cholesterol and asthma, I needed to get my prescription now."

• **Avoiding hospital stay:** Sharon appreciated being able to recover at home rather than staying in the hospital, especially because of her perception of what it was like in the pandemic. The remote monitoring allowed her to avoid the risks associated with hospital stays while still receiving high-quality care.

What challenges did Sharon face?

- **Poor living conditions:** Sharon's temporary accommodation in the hotel was not conducive to recovery. The broken lift forced her to climb multiple flights of stairs, which worsened her asthma. The presence of cockroaches and lack of hot water added to her stress and discomfort.
- **Limited follow-up care:** After her discharge from the virtual ward, Sharon did not receive any follow-up care or information about managing her condition. She felt that more guidance, such as a booklet or instructions on self-care, would have been helpful.
- **Constipation from medication:** Sharon experienced severe constipation as a side effect of her medication, which added to her discomfort during recovery. She felt that the team could have provided more support in managing this.
- **Abrupt discharge:** Sharon's discharge from the virtual ward was sudden and she felt that more communication about the process would have been beneficial. She was left unsure about what to do next and how to manage her ongoing symptoms but expressed gratitude for the service she got when there were no hospital beds.

- Importance of suitable living conditions: poor living conditions can have a detrimental impact on health and on recovery. Patients in temporary or inadequate housing may struggle to manage their health, even with remote monitoring. Conducting a housing/environment assessment and addressing any issues identified should be a priority for healthcare providers. Providers should also consider how they can work with other organisations, for example the VCSE sector, to provide further support to patients around housing and accommodation if required.
- Need for additional support during admission and follow-up care: providing links to supporting organisations who can support with prescriptions and other routine activities is important. Patients should receive guidance on managing their condition, including potential side effects of medication and when to seek further help.
- Support for young carers: young carers can often play a vital role in providing care whilst also going to school and managing household responsibilities. Healthcare providers should consider the particular needs of young carers and provide additional assistance when necessary.
- **Clear communication during discharge:** the abrupt nature of discharges can leave patients feeling unsupported. Clear communication about the discharge process and what to expect afterward would improve experience.

The Strategy Unit.

The Strategy Unit

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