# NHS E&I Healthwatch Carer Experience of Hospital Discharge Final Project Report

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**Organisation: Healthwatch Wandsworth**

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## Executive summary.

Healthwatch Wandsworth has previously spoken to people in Wandsworth about hospital discharges. However, they way that hospital discharges happen changed during the Coronavirus Pandemic under Discharge to Assess arrangements when the aim was to discharge people home as early as possible and provide support to people at home to help them recover. Patients are not necessarily immediately able and ready to look after themselves without the support of a carer or family member who may or may not have been involved in the discharge process or asked if they are willing and capable of providing carer support. Once someone has returned home, there are detailed assessments of the patient and ongoing care and equipment are organised.

Healthwatch England and NHSE/I approached us and seven other Healthwatch to be involved in a national study to understand the experience of carers supporting people who are discharged since May 2021. It is a priority to understand carer experiences because being a carer is seen as a social determinant of health and helping carers to provide better care and to stay well themselves leads to better lives for those needing care and more effective use of health and care service resources.

Healthwatch Wandsworth undertook 10 interviews with carers between 8th December and 22nd February 2022.

It is important to note that not all carers lived in Wandsworth and neither did all of the people cared for. Services in a variety of geographies were described. The following are key themes that carers' feedback suggested is important to their success in supporting the person they care for and looking after themselves. More detail is described later in the report.

### Improving identification of carers

- Often carers are family or friends who may not see themselves as cares but see their role as part of 'a duty' as part of their existing relationship.
- Hospital visiting is important and it is useful to have the possibility of and recognition of multiple visitors
- There is usually an increase in the level of care needed from a carer and increased pressure on them after hospital admission. It is important to recognise new carers, or when patients are or have been relatively independent previously and there is a change leading to a caring role or an increased caring role
- There is a need to better identify patients who are carers

### Keeping carers informed and updated whist in hospital

- Often there were multiple calls to hospitals from a carer needing information and updates, and some described confusing information about ward changes and discharge. Co-ordinated or improved communication is important.
- Timing and dates of discharges often changed, some carers made multiple trips to the hospital

(and transport can be difficult for the carer) and some did know they needed to be at the person's home.

**Communicating information about ongoing care**
- Consistent information is needed about: medication, information about the care programme (which services and who is coming to the person's home why, when and contact details) and increased needs a patient may have that the carer must meet.
- Carers of those with complex or long-term conditions were more often involved.

**Focus wider than the immediate health issues.** Some suggested that ongoing health conditions were not always attended to, to the degree necessary, and reported issues with food and drink provision.

**Assessment of carers needs and ability to support someone**
- Not all carers had a discussion with staff before discharge
- There should be recognition of carer health issues – or their physical and mental capability
- Physiotherapy to help a patient regain independence and reduce physical support from carers was needed in a timely way
- Information is needed about social care or other support with daily living that could be available, and it is especially helpful if given before discharge to ensure the home was ready. As a patient's support needs had increased, carers used up available or previously agreed levels of support
- Visiting staff could communicate with carers more. In contrast, video calls to staff could bring more inclusion of carers
- Delays or lack of visits from staff added a co-ordination and administrative burden
- Issues arose when the cared for downplayed or resisted support

**GP support**
A carer's own GP was often not informed about changing circumstances by the carer or did not check in with the carer. More valuable support was reported from GPs of the cared for. Benefits included that they focused on more holistic care and in cases they knew the patient, carer and circumstances well (although not if they were not always seen by the same GP within the practice).

**Consideration of carer transport and hospital pharmacy delays**

At a workshop in May 2022 we discussed the themes with staff working on discharges across different organisations in Wandsworth. This generated ideas about how carers can be considered more in the process of hospital discharges and supported to better to help the person they care for as described later in the report.

Healthwatch Wandsworth will produce and circulate a report to senior stakeholders in the borough once the NHSE/I report has been published. We will continue to communicate with the staff involved in the workshop to encourage improvements. A follow up meeting has been arranged and we are reporting to the Wandsworth Carer's Board.

## Method/Process.

We advertised the opportunity to take part in interviews via social media, our website, our newsletters, and the Wandsworth Carers' Centre bulletin. It was also directly advertised to community groups, including Roehampton Community Shed; WoW Mums Group Meeting; Asian Carers Peer Support Group; Side by Side Wandsworth; NHS Wandsworth Thinking Partners group meeting; Wandsworth Council Co-production and Partnership Group; and Wandsworth Carers' Centre.

People were offered a £40 shopping voucher for taking part in the research. Interviewees were self-selected; a total of 24 individuals expressed an interest in being interviewed, however some did not meet the interview criteria, while others decided to withdraw from the research without providing a reason for doing so.

Healthwatch Wandsworth conducted **10 Zoom interviews** (4 audio only) between the 8th of December 2021 and the 22nd of February 2022. Interviewees said they were unpaid carers for their **mother** (3), **father** (3), **husband** (3), **daughter** (1), **grandfather** (1) and **uncle** (1). Two people said that they were caring for more than one person. Interviewees spent varying times looking after their loved ones: **50+ hrs per week (3)**, **20-49 hrs (3)**, **1-20hrs (1)**, **prefer not to say (1)**, **no response (1)**.

Demographics

**Gender:** 7 women, 3 men

(48% of Wandsworth are male)

**Age:** 18-24 (1), 25-49 (1), 50-64 (5), 65+(3)

(Wandsworth: 16-65 = 72.6%)

**Ethnicity:** White British (6), Black or Black British (3) and British/Indian (1)

(Wandsworth: 48% White British, 13% Black ethnicity, 13% Asian ethnicity)

**Marriage/partnership:** 6 Married, 4 Single/never married

(Wandsworth: 33% Married)

**Religion:** Christian (4), No Religion (2), Agnostic (1), Atheist (1), Muslim (1)

(Wandsworth: 27% No Religion, 53% Christian, 8.1% Muslim)

**Sexual orientation:** Heterosexual/straight (8), No response/prefer not to say (2)

(Wandsworth: 2.6% of population identified as LGBTQ+ in 2013-5)

**Health/disability:** Lasting health problem/disability (3) Mobility issue (2), Unspecified condition (1)

(Wandsworth: 6% disability that limits mobility)

In the interviews, there was a slight underrepresentation of men and younger age groups (most participants were over 50). There was a slight overrepresentation of individuals identifying as White British (10% more) and Black (20% more) and married people (100% more). We had a higher representation of people living with disability and/or mobility issues than the Wandsworth population. Due to the sensitive nature of the topic and non-disclosure, it is difficult to tell how representative the current sample was of the Wandsworth population with regards to sexual orientation.

Focus Group selection/attendance.

A **total of 22 people** attended the Focus Group, including 2 people from Healthwatch Wandsworth (Healthwatch Manager; Research Volunteer) and 3 people from NHS E&I (London Region Carers Lead x1, National team Commitment to Carers programme x2), who were facilitating the workshop. Other attendees included representatives from local councils, NHS services, community groups and charities. A full list of attendees can be found in *Appendix 1* at the bottom of this report.

A number of people did not attend because they were not able to. These are indicated in the appendix. In all cases another representative from their organisation did attend. We were not able to identify a GP to attend, but on reflection we think a representative of GPs would have been useful. We divided in to two groups to hold the discussion and there was a good level of contribution from the attendees.

## Key findings. Interview content/ themes.

### 1. Identification/recognition of caring role

All interviewees considered themselves the main carer of the person they cared for; they felt that as family members it was part of their responsibility to do so. Most of them had been caring for their loved ones for years to some extent, with varying degrees of support from other family members and their workplace.

Regardless of overall experiences, all interviewees agreed that carer identification upon their loved ones' hospital admission was key, impacting on the cared for's recovery as well as the carer themselves. Two interviewees, for example, who were identified as main carers straight away in A&E had positive experiences at admission, discharge, and recovery of their family members. However, this was not the case for everyone; not identifying carers straight away had a knock-on effect on communication and the knowledge a carer had to support the patient. If someone was not identified, they could not work with the various organisations as effectively.

Further, recent hospital admissions almost always added pressure, and the level of care increased (most people required full-time care after their admissions; follow-up appointments, and alterations of living space required carers to familiarise themselves with new procedures). Other Healthwatches felt that issues were common across carers whether identified or not. However, for our interviewees, experiences appeared more positive for those who were able to work with care teams and those more used to the system, compared to those who were new carers or where their loved one was previously more independent. Practice also was likely to have empowered carers (for example, knowing how to 'tick the boxes' for discharge and how 'to navigate the system' and asking for support).

Many felt there was a presumption the carer would 'get on with it' and only the patients' situation was relevant. Carer issues were considered less for example, if the carer was not local, if they had a job or the toll caring for someone had on their own health (most carers mentioned extreme physical and mental fatigue due to responsibility, low mood or worrying). Only a couple of carers felt their mental health was not affected significantly by their caring duties. Additionally, while some were supported at work with flexibility, others had to give up jobs and volunteering activities, which had an economic impact on their lives.

### 1b. Recognition of patient's caring role

Two people admitted to hospital with injuries were both carers themselves.

One carer said that despite her emphasising that she is caring for two people and cannot afford to 'just rest' after discharge, none of the medical staff considered her circumstances when discussing aftercare and recovery with her. She also said that no one checked who was taking care of the people she was looking after while she was in hospital.

Another interviewee felt it was a problem that the hospital had not looked into her mother's circumstances more; her mother was caring full time for the interviewee's father who was unable to look after himself. Leaving him alone would have had serious consequences, however luckily the interviewee was able to look after him.

### 1c. Hospital visits

Carer identification affected overall carer experiences during hospital visits as well.

One carer said that being in environment with medical professionals and assistance allowed them to relax a bit. At home there wasn't anyone else around, there were less machines to monitor so they had to be more present and committed.

Another carer (who had been looking after her husband for years) was pleased that exceptions were made for multiple visitors which helped patient ‘delusions’ relating to advanced Parkinson’s Disease. Others, however, explained that it was tiring to be the sole carer during the hospital stay and would have appreciated a rest whilst another family member visited.

One carer felt uncomfortable due to the scrutiny of visitors (perhaps heightened during COVID restrictions); this carer was not recognised on multiple occasions on the same day by same receptionist.

## 2. Communications and information

### In hospital and preparing for discharge

Some maintained constant communication with the hospital (and some with the GP too). Most carers mentioned that they were the main initiators of the communication to get information. About half of the interviewees were satisfied with the information they received once they got through – the other half thought the information was ambiguous. More than one interviewee was not notified about the ward their loved ones were taken to or rang multiple wards to locate them. Some carers, however, received help staying in touch with the patient themselves (for example, video or telephone calls), although this wasn’t necessarily a way they would find out information they wanted.

One interviewee said that in the past when her mother was admitted in hospital, staff would be good at involving her in decisions, but on this admission, staff were very busy, so it was more difficult to be kept in the loop. She said that the ward had a ‘Navigator’, who would call to give updates every now and then – they got details from nurses and then rang family. This worked well.

We had mixed feedback on the discharge process, as it was delayed at times. Factors making it difficult to respond to the changing situation included the carer not living in London, the carer being at work, or the carer not having their own transport and having difficulties organising transportation when the day or time changed.

One carer was not told at all about when their mother would be discharged; he only found out when an ambulance arrived at his door on a day when fortuitously he was working from home. Carers raised their concerns about what would have happened if they hadn’t been able to respond to the emerging situation.

Others, on the other hand, knew in advance when the discharge would happen and reported no difficulties with returning their loved ones to their homes.

### Discharge and aftercare

The level of care needed changed or increased after discharge. It was appreciated when medications and aftercare was explained, and the carer felt prepared to take care of the person. One interviewee felt that they were able to ask questions during discharge, were given good explanations about aftercare and knew how to look after their mother after discharge. The hospital was good at asking what follow-ups and referrals they might need. But this carer said that they are quite proactive themselves and made sure that any referrals needed were done before mother was discharged.

Unfortunately, many others often felt that they did not know enough about looking after their loved ones, or that they did not have enough information on care programmes arranged by the hospital team. This inhibited them in ensuring that the person they cared for had all the possible support and rehabilitation they could get.

For patients with long-term and/or complex needs it seemed that hospitals did involve and engage carers more often. It appeared less so with those who were relatively independent previously.

Information given to the patient wasn’t always passed on or shared with the person looking after them.

Additionally, some information was not transferred across wards or to the GP, and some carers felt more integration of social care was needed. However, we also heard examples of where it worked well and led to positive experience.

When asked what they would like, many suggested there should be contact numbers (including social services or support with day-to-day living, district nurses and carer support), or a summary letter about which services have been contacted and who is coming why and when - indicating this was information they felt they did not have.

### 3. Holistic health support in hospital

All carers spoke positively about medical care for the issue at hand. Multiple carers felt that medical staff in hospitals were excellent at monitoring the recovery of patients after hospital treatment, but this was focussed on the immediate health issue.

Most of the patients had ongoing health conditions, which a number of carers felt were not attended to, to the degree necessary, due to attention on the immediate health issue. This resulted in multiple carers requesting discharge earlier than intended. More than one person was said to have been left without any food or drink for long periods of time, while others required feeding which was not provided. One patient spent a day on a recovery ward with low blood pressure due to dehydration.

One interviewee described how the GP picked up a need for a test relating to a long-term health condition that would be needed after the treatment during the hospital stay.

### 4. Timing of discharges

Some experienced delays to discharges due to lack of coordination between hospital services, such as delayed medications, unavailability of discharge doctors and delays with preparing the discharge letter. Some patients were waiting for collection or transport for a long time; a couple of carers reported that they found them waiting somewhere uncomfortable, with one patient ‘sitting inadequately dressed in public spaces’ where they became very cold. Carers at times had to make multiple trips to and from the hospital due to delays in discharge.

Multiple patients were discharged sooner than intended despite the request of the carers who thought their loved ones were still unwell or limited in their movement, while another person thought that the discharge team were too rigorous and delayed discharge despite hospital stay causing deterioration where the team was focused on the injury and not the other aspects of the person’s health.

### 5. Carer/caring needs post-discharge (including social care, health care and wider living needs)

Assessment for social care or carer support whilst the person was in hospital and when at home was praised when it happened, but several carers felt it was needed if they didn’t have it. Some carers were given no information about carer/social care support and did not always feel the home situation was adequately assessed or appreciated either. Some said a booklet would be useful – including what needs to be arranged and who to contact. One interviewee said that they needed prompts about what support would be needed and what measures would need to be put in place. They only realised practicalities when got home and saw the mess as their husband (who is living with multiple long-term conditions) was too tired to put things away or maintain the house. The interviewee had not anticipated these things and the hospital team did not ask about them either. There was also no discussion about putting them in touch with services that could support them. The carer thought a call from support services a few days after discharge to check how they were coping would be useful.

A few carers had a discussion with staff prior to discharge about arrangements at home, but not all. Those with experience of discharge or who had been put in touch with organisations to help prepare for discharge felt this helped a lot; multiple carers praised Age UK service in getting the home prepared before discharge. Wandsworth Carers' Centre was mentioned as a brilliant support by one interviewee.

We were told that often no account had been taken of carer health issues or whether the carer could manage to the extent needed including other commitments or physical/mental health limits, for example, whether stairs were involved for patients with limited mobility, whether lifting or carrying was needed and if a carer could support this.

A few carers mentioned that community/district nurses were not available. One said the hospital had said district nurses would come, but they didn't. When they phoned the GP had no record of this. They came four days after discharge and gave pain medication that otherwise had not been given. Some said visiting staff often communicated mainly with the patient, yet they could have supported the patient better with more information from them.

Usually after hospital admission there were follow-up physiotherapy appointments which led to 'small resolutions'. Physiotherapists received a lot of praise as particularly important and because they tended to understand the broader situation and they adapted to emerging things. One carer paid for additional physiotherapy support to speed up the recovery of their relative – they otherwise struggled with the physical limitations of the person they were caring for. Another mentioned it took a while for the community Occupational Therapist to visit.

Video appointments and virtual access to support were described as helpful in the right circumstances.

Many carers talked about 'just getting on with it' and feeling responsible, – 'you don't allow yourself to be ill'. One interviewee said they don't leave their home for longer than 30-45 minutes, unless someone else was there to look after their husband. Care packages and programmes were often paid for by the unpaid carers and their families themselves and they emphasised they were lucky they could afford this. One carer had an assessment but was not entitled to funded services and therefore pays for some privately.

### 5b. Intensity of support needed post-discharge

The level of care required from our interviewees increased a lot after their relatives were discharged from the hospital. Including: personal care, administration, transport, errands, maintaining the house, 'sacrifices' and 'hidden duties'.

Carers were often responsible for managing follow-up appointments their relatives had and usually drove them and accompanied them to appointments. Therefore, they preferred when medical professionals came to their relatives' homes. However, we were told that these visits were often delayed or doctors/nurses simply did not turn up, requiring carers to chase it up with the hospital, adding further administrative duties to the long list of responsibilities and slowing down the recovery of their loved ones.

Even when respite or other social care support was available, it was highlighted that carers can quickly use it up.

### 5c. Cared-fors' attitude around receiving support

Some people who have lived relatively independently with limited support from our carer interviewees before their hospital admission resisted being admitted to hospital, wanted to leave hospital as early as possible, minimised the amount of support they said would be needed after discharge and/or found it difficult to accept help from supporting services arranged for them (such as carers and physiotherapists). Rejection of outside help inhibited the carers' ability to support the cared-for, who would not have the support needed before issues escalated or became stressful for the carer.

One carer told us that their father needed full time support when their mother was injured, which had not been factored in by any health and care professional during the hospital admission/discharge of the mother. They said that their mother had been exhausted since before the injury but refused help from ‘outside’, making everything difficult.

### 6. Support from own GP or patient’s GP

Only a few carers told their GP about their carer status. Most of the carers’ GPs did not check in with them about how they were doing; only one carer said their GP touches base with them regularly and ensures annual check-ups. Another interviewee’s GP practice has expanded, so they do not see the same doctor at their appointments anymore. They try to mention that they are caring for someone during appointments but are unsure what is on record and what doctors can see.

Some did not see a point in notifying their GP due to past experiences and some had not spoken to their GP for some time and did not think to post-discharge.

Carers instead were more involved with the GP of the cared-for and this made a difference to their experience. GPs were often cited as source for support, advice, medication information, check-ups, and monitoring, and video catchups with GPs helped keep the carer involved in conversations. Some acted as a link between the hospital and the cared for and carer.

## Focus Group

During our workshop discussions with local staff working on hospital discharge, the following points were shared by staff working on hospital discharge.

### Was the experience of carers what people expected?

People said it was striking to hear about and reflect on the following:

- The difference between the experience of known carers and new carers
- The impact of ‘false starts’ where discharge dates and times change
- The lack of connections made if a patient was a carer
- There is a relief for service staff when they know there is a carer because it means they can focus, but they don’t tend to check their abilities and this has highlighted how it is important
- Carer attitudes to their caring role and the impact of their culture affects identification and getting support
- The change in care needs after a hospital stay – this is particularly the case when someone has dementia or delirium
- The need to give carers information, but it is difficult when patients have capacity and do not want information sharing with others. The findings highlighted the complexity about the cared-for attitude to receiving support and that we tend to take for granted what is said without a sense-check with family and friends. There can be difficulties matching patient and carer needs as they often want different things and have different expectations.
- Carers often complain that they are not kept fully informed or provided with updates
- That there is unclear communication about the intensity of support needed and a lack of preparation when someone leaves hospital
- Staffing levels and communications between wards have an impact
- Patients and carers have lost a lot of control and power in the discharge process with the emphasis on patient flow and sustaining it at all costs. Carers are no longer seen as an important stakeholder

- Patients are often sent to the discharge lounge too early in the day which can cause them to end up waiting around until they are finally discharged
- Visiting restrictions have exacerbated the issues
- There is a lack of focus on home situation assessment/carer ability to manage
- Community nursing delays in follow-up

**Suggestions for how this could inform good practice:**

- Importance of recognising carers when cared-for arrives in hospital and using right language to trigger response
- Earlier contact and conversations are valuable. There was a suggestion that conversations earlier in the admission process would be helpful
- Consistent planning for a carer in an emergency situation, at least having a conversation. Urgent Care Plans have to be part of solution to supporting patients who are carers
- We need to ensure it is standard practice to check carer abilities
- We should think more about carer attitudes to their caring role and the impact of their culture because it affects identification and getting support
- Commissioners are hoping to introduce more short-term support for delirium at home
- Support for hospital staff in communicating with families and managing expectations and providing leaflets. Generic information about support available could be given to carers, family members and others even if a patient has capacity or doesn't want information shared. The new St George's Hospital patient portal might be a place information could appear and be accessible.
- Providing leaflets that include information and signposting to services and resources
- More information should be added to discharge summaries
- Carer liaison roles in Trusts work well/ discharge facilitators are being trialled
- Carer passports can be effective, creating a carer-friendly hospital experience
- Identify carers on electronic record management systems

There wasn't time to specifically talk about how carer experience could inform formal quality measures as a separate topic, instead we focused on using the above to talk about the next steps and suggestions for possible 'easy win' changes. Since the workshop we have created a draft plan of possible actions suggested and the outcomes and targets could inform or be incorporated in strategic monitoring or oversight of the local carer's board.

We suggested that delegates become ambassadors for the project by sharing what they have learnt. They have been asked not to share the presentation as the final report is not yet published.

### Focus Group - Next steps

At the end of our workshop we discussed which actions could be a quick or 'easy wins', including actions to raise the profile of carers.

We have summarised the two discussion sessions into a draft action framework to promote reporting on actions in the action plan, including possible actions discussed at the workshop and the 'quick wins'. We incorporated suggestions carers had made about improvements that would be most helpful:

### Topic 1. Identification of carer

- ➢ Action A: Consistent emergency planning for carers and use of Urgent Care Plans.

- ➢ Action B: *Identified as quick win*

  Identify a trigger question to help recognise carers.

Think about their attitudes to caring more, due to the impact of culture and view of caring role.

Recognising carers when the cared for arrives in hospital and use right language to trigger response.

- Action C: *Identified as quick win*
  Use of carer passports and identification on hospital management systems

- Action D: Review support for people who have dementia or delirium in hospital because there is often a significant change in the person who is discharged. Commission more support for delirium at home and redesign the service so there is more short-term support

- Action E: *Identified as quick win*

  A carer liaison officer role in hospitals to provide advice & information to carers and staff has worked elsewhere. This could be a base for the carers' centre in hospital to give advice and information and to advocate help people navigate.

  Carers suggested they would like a 'check in' to see how they are doing and to check they have the carer support at the right level. They would like a 'Carer Champion' to advocate support.

- Action F: *Identified as quick win*
  Improve internal communications and staff training to increase confidence and awareness around carer issues.

**Topic 2. Keeping carers informed and updated whist in hospital**

- Action G: Have earlier conversations with carers, noting that staffing issues can have a significant impact on communication.

  Carers suggested that regular updates from the hospital, for example, once per day would help avoid continuous phone calls from carers and be less time-consuming for in hospital staff.

  Consider conversations with carer as a 'handover'.

- Action H: Avoiding 'false starts' for discharge, including those sent to the discharge lounge too early in the day

**Topic 3. Communicating information about ongoing care**

- Action I: *Identified as quick win*
  Providing general information and support for carers for pathways 1-3 (where there are sensitives for people who have capacity and do not want information sharing with others)

  Leaflets can be stocked and given out in the Transfer of Care area.

  A letter or leaflet about what people are going home with could be used, similar to that used in 'Neuro'.

  Carers would like information about organisations that could help post discharge (including social services or support with day-to-day living, district nurses and carer support) including who is coming why and when. Those who are not entitled to social care would still benefit from information about organisations and things that could support them, including links with community and voluntary sector services should be made early on, for example, one person said Wandsworth Carers Centre helpfully signposted to Age UK to get the home prepared.

- Action J: More information to be added to discharge summaries

- Action K: Support for hospital staff with communicating with families and managing expectations, including training for transfer of care hubs.

- Action L: Conversations about plans also need to include conversations about finances and potential means testing.

- Action M: Patient portal may hold information that would be useful but this has only just launched so unsure about whether discharge summaries will be on there: https://www.stgeorges.nhs.uk/patients-and-visitors/mycare-st-georges-patient-portal/

**Topic 5. Focus wider than the immediate health issue e.g. ongoing health conditions not always felt attended to the degree necessary, food and drink provision.**

No action suggestions made at the workshop

**Topic 6. Assessment of carers needs and ability to support someone**

- Action N: Service staff standard practice should be to check abilities of carers
- Action O: Use a sense-check with family/carers, to counteract the tendency to take what patients say about circumstances for granted.

**Topic 7. GP support**

No action suggestions made at the workshop

**Other topics**

- Action P: There is no attendee from St George's Hospital on the Carers' Board
- Action Q: Carer feedback suggested consideration of carer transport
- Action R: Carer feedback suggested review of hospital pharmacy delays

We agreed that people would contact Healthwatch Wandsworth by the end of April with actions they have taken and that we could follow up some of the work at the local carer's board.

As there seemed to be some enthusiasm to continue to discuss the issues, we have organised a session in early May to talk about any measures people have implemented and sharing the findings.

**Reflection and concluding remarks from involvement in the project**

Positives

- Working with NHSE raised the profile of the work and encouraged stakeholder participation
- The multi-stakeholder workshop was useful - we do not often work in this way
- People who shared their experiences were really open to share their experiences
- We have some really useful/relevant insight to take forward in our work

Possible improvements/issues

- Impact of the Omicron wave of COVID:
- We began recruiting and interviewing at the end of November 2022 after the interview questions were confirmed. The Omicron wave had already impacted on cancellations of community group meetings and voluntary sector staff absences. We were not able to visit people in the community and interview them face to face, which would have helped us speak to carers, especially those preferring not to use the phone or online technology.
- Carers had additional challenges through limitations on social contact and possible COVID infection, on top of the usual challenges on their availability and time.

- Our staff were also impacted by COVID infection. Interviews were cancelled and rescheduled and we had reduced capacity for reporting and preparing for the workshop.

- By not having had a transcription service, we had to review and write up notes from all interviews which took over 50 hours we had not planned for, at a key time for reporting and preparing for the workshops. With hindsight we could have anticipated the potential issue sooner, taken steps to mitigate it and found another resource. We could have taken more notes during interviews.

- We could have included more information and signposting to interviewees.

- GP involvement seems important in the carer experience and was not explored at the workshop because they were not represented, although there was not an obvious representative to invite. It would be useful to find out how results could be discussed with GP networks nationally and locally.

- Many carers paid for private care – it would have been useful to capture financial status to understand this further.

- We would have liked to have interviewed some younger carers.

- It could have been informative to compare interviewee demographics with what is known about the carer population.

*Appendix 1.* Attendance report from the Carers Discharge Focus Group

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| Edna Porter | Adult Social Care and Public Health | Head of Community Services | Managing social work team. Lead for carers across Richmond and Wandsworth Local Authority | |
| Steve Shaffelburg | Adult Social Care and Public Health | Commissioning Manager, Prevention and Wellbeing | Including leading the Carer’s Board and Carer’s Strategy refresh and support services | |
| Bonnie Ross | Adult Social Care | Hospital Social Worker | | |
| Hannah Gordon | Adult Social Care | Hospital Social Worker | | Did not attend |
| Alexander Adams | Adult Social Care | Social Work team. Carers Champion for St. George’s Hospital | | |
| Nadine Hassler | Adult Social Care | Interim Information and Projects Manager and Transformation Programme Manager | | Did not attend |
| James Isaacs | Adult Social Care | Head of Early Help and Enablement | | |
| Charlotte Allen | AGE UK Wandsworth | Better at Home Lead | E.g. handy person project, supporting older people and their carers | |
| Sandy Keen | SWL Wandsworth Clinical Commissioning Group | Assistant Head of Integrated Care and Transformation | Working with council on commissioning carer support | Left at 2:32 |
| Jane Byworth | SWL Wandsworth Clinical Commissioning Group | Project Manager Long Term Conditions | Working with council on commissioning carer support | |
| Mark Mbogo | Central London Community Healthcare NHS Trust (CLCH) | CBU Manager- Wandsworth Borough Lead, Wandsworth Unplanned Care and Specialist Nursing and Therapies Services, CBU | | Did not attend |
| Jess Humphreys | Central London Community Healthcare NHS Trust (CLCH) | Patient Experience Facilitator | | |
| Gemma Allen | Central London Community Healthcare NHS Trust (CLCH) | Clinical Quality Lead | | |
| Philip Gitaari | Central London Community Healthcare NHS Trust (CLCH) | Clinical Operations Manager | Managing district nurses | |
| Rachel Benson | St George’s Hospital NHS Trust | Divisional Director of Operations | | Did not attend |

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| Gemma Phillips | St George’s Hospital NHS Trust | Deputy Divisional Director of Operations | Oversee the discharge elements of operations | Left at 2:30 |
| Lorna Okoloekwe | St George’s Hospital NHS Trust | Part of discharge team | | |
| Eglionna Treanor | Wandsworth Carers’ Centre | Chief Executive Officer | | |
| Lorrie Beasant | Alzheimer’s Society | Dementia Support Worker | | |
| Angela Kelly | Adult Social Care | | | Left at 2pm |
| Debbie Hustings | NHSE/I | Leadership Support Manager<br>Commitment to Carers Programme | | Left at 13:32 |
| Paul Carter | NHSE/I | Commitment to Carers Programme<br>Experience of Care Team<br>Nursing Directorate | | |
| Helen Benn | NHSE/I | Project Manager Commitment to Carers Programme | | |
| Sarah Cook | Healthwatch Wandsworth | Manager | | |
| Athana Kangesu | Healthwatch Wandsworth | Research volunteer | | |