



## **Intermediate Care Insights**

**Patients' and carers' experiences of step-down care access and provision in Westminster and Kensington & Chelsea**

August 2024 Report

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# Healthwatch

Healthwatch Westminster and Healthwatch Kensington & Chelsea are set up to promote and support the involvement of Westminster and RBKC residents in the commissioning, provision, and scrutiny of local health and social care services. Our service is provided by The Advocacy Project.

We collect feedback from residents about publicly funded health and social care services; based on the feedback received, we develop reports and recommendations on how these services should or ought to be improved. We share our data and recommendations with service providers and service commissioners, and monitor if and how the recommended changes are implemented.

For an overview of our previous research projects, please refer to the [Healthwatch Westminster Reports Library](#) and the [Healthwatch Kensington & Chelsea Reports Library](#).

We also offer signposting and advice, directing people to the resources they need; this includes, but is not limited to, helping residents put forward a complaint about services, signposting to advocacy and local support organisations, and explaining how to navigate changes in services.

# Introduction

This is a joint report between Healthwatch Westminster and Healthwatch Kensington & Chelsea; it has been carried out in partnership with the North West London Networked Data Lab (a collaboration between Imperial College Health Partners, Imperial College London, and the North West London Integrated Care System, funded by the Health Foundation) and provides qualitative context to their report on quantitative patient and care data.

In undertaking this work, our intent was to explore the experiences and perspectives of patients and their carers on intermediate care services provided in Westminster and Kensington & Chelsea [RBKC], trying to identify key barriers and challenges to high quality intermediate care provision. Particularly, it follows the experiences of Westminster and RBKC residents and carers who have made use of step-down care services to regain independence following a hospitalisation.

Following a period of community engagement and data collection across Westminster and RBKC, this report presents an overview of our findings and recommendations.

# Background

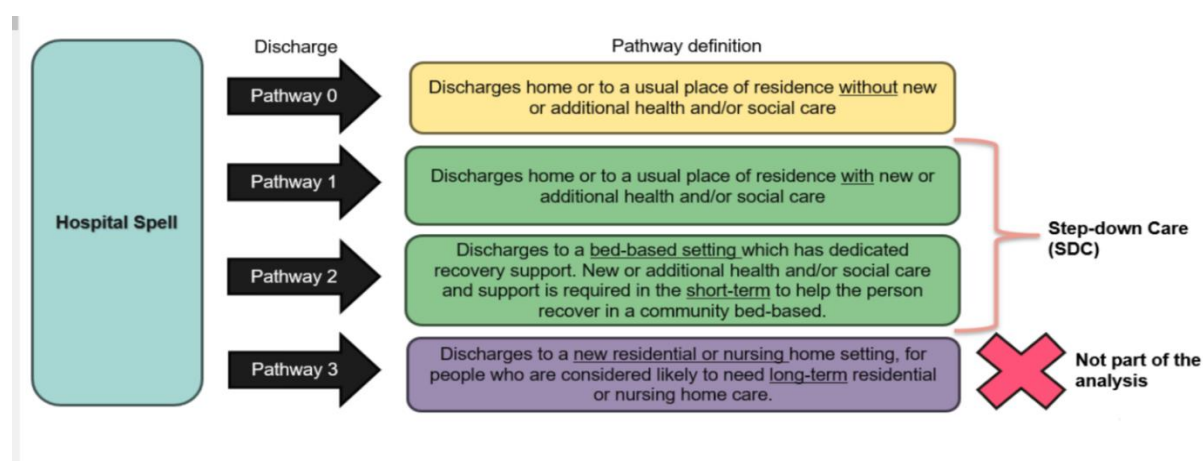
This section intends to provide an overview of the intermediate care system of planning and delivery, step-down care services, pathways of discharge, and related policies, as well as of the status of carers within the North West London NHS Trust.

## Intermediate Care & Step-down Services

Intermediate care [IC], under the NHS, is defined as short-term intensive support provided to patients to maximise their independence<sup>1</sup>. IC services can be entirely health care, entirely social care, or ideally have elements of both delivered by multi-disciplinary teams working in integrated ways.<sup>2</sup> They may be commissioned by the NHS, and/or by local authorities, and delivered by a range of providers across the health, social care, housing, independent and voluntary sectors<sup>3</sup>.

When it becomes apparent that a patient may need support from social care services to aid their discharge and recovery, the NHS trust should inform the relevant local authority of this as early as possible in the person's hospital stay, to allow local areas to co-operate on the person's discharge planning<sup>4</sup>.

IC support can either be provided to a patient after being hospitalised and discharged (i.e., step-down care [SDC]), or to prevent hospitalisation (i.e., step-up care). Home delivery of intermediate care following a hospitalisation falls under discharge Pathway 1, whereas a short term care provided in a bed-based facility falls under discharge Pathway 2 (see image below for further details).



1 - Discharge Pathways<sup>5</sup>

This project focuses on patient cohorts receiving SDC services on discharge Pathways 1 and 2.

<sup>1</sup> NHS England & Department of Health & Social Care (2024), [Hospital discharge and community support guidance](#)

<sup>2</sup> NHS England (2023), [Intermediate care framework for rehabilitation, reablement and recovery following hospital discharge](#)

<sup>3</sup> Ibid., pp. 4-5

<sup>4</sup> NHS England & Department of Health & Social Care (2024), [Hospital discharge and community support guidance](#)

<sup>5</sup> North West London Networked Data Lab (2024), [Intermediate Care Final Report](#)

SDC is a short and intensive reablement service provided free of charge for up to 6 weeks after hospitalisation, based on the individual's needs. For patients discharged on Pathway 1, SDC is delivered in their home and is intended to help patients regain lost skills, acquire new ones, and restore confidence and independence within their domestic setting<sup>6</sup>. Before the care is delivered, a home environment assessment is carried out by a local authority team.

The Networked Data Lab Report has highlighted that the patients who receive SDC in North West London tend to be older, more likely to be living with frailty, have more long-term conditions, and tend to live alone<sup>7</sup>. This is reflected in the composition of our study participants (for more information, refer to the "Participants" section and to Appendix 2).

Per the NHS guidelines on IC, patients receiving these services should be supported to make fully informed decisions, in conjunction with their wider family or unpaid carers (where appropriate, and where the individual consents), their independent advocate or, where a person lacks the capacity to consent, their lasting powers of attorney (LPA) responsible for health and welfare, if they've appointed one.<sup>8</sup> Patient and carer involvement in decision-making should be person-centred, strengths based and driven by choice, dignity and respect<sup>9</sup>. This may take the form of a multidisciplinary team discussion on the person's care plan and post-discharge needs, or alternative conversations where care planning is discussed<sup>10</sup>.

Likewise, under the IC guidelines for patients who have been discharged following an acute mental health hospitalisation, individuals should be regarded as partners in their own care throughout the discharge process and their choice and autonomy should be respected, with carers being involved in the process as early as possible<sup>11</sup>.

### CNWL Carers' Charter

The Central and North West London NHS Foundation Trust [CNWL] has recently developed a Carers' Charter, outlining its commitment to unpaid carers across the trust and the ways in which it recognises, involves, and supports them in their caring role<sup>12</sup>.

As part of the Charter, CNWL has pledged to:

- Recognise and value carers,
- Highlight support in the community,
- Support carers' wellbeing,
- Work together with carers,
- Support young carers,
- Make the Trust aware and receptive to the needs of carers.<sup>13</sup>

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<sup>6</sup> Westminster Council (2024), [Reablement](#),

<sup>7</sup> North West London Networked Data Lab, Intermediate Care Final Report

<sup>8</sup> NHS England & Department of Health & Social Care (2024), Hospital discharge and community support guidance

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> NHS England & Department of Health & Social Care (2024), [Discharge from mental health inpatient settings](#)

<sup>12</sup> CNWL NHS Trust (2024), [Carers' Charters](#)

<sup>13</sup> Ibid.

# Methodology

## Engagement

Engagement for this project was primarily carried out by reaching out to our stakeholder network, particularly to organisations providing support to carers and patients with long-term conditions. Participants were referred to us by local organisations such as Carers Network, Age UK Westminster and Kensington & Chelsea, Open Age, and the British Red Cross. We also encouraged participants to share the invitation to participate with acquaintances who might be interested in sharing their feedback.

An incentive, in the form of a £10 Love2Shop voucher, was provided to participants to thank them for their time and participation.

## Data collection

To gather data, we conducted a series of semi-structured interviews with patients and carers who had experience of using SDC. Each interview lasted approximately 20 minutes.

Conversations were recorded for transcription purposes, but all personal identifiable details have been omitted in this report to preserve the anonymity of participants. Written consent was sought and obtained before each interview.

## Interview questions

The interview guide was designed after reviewing the initial findings from the Networked Data Lab quantitative study, incorporating some of the key themes raised by their Patient and Carer Advisory Group. These themes included: the impact of environmental assessments; involvement of patients and unpaid carers; trust, continuity and quality of care; and communication. To review the interview guide, please refer to Appendix 1.

## Participants

In total, we heard from 15 respondents:

- 5 patients,
- 9 carers (all of whom were family members),
- 1 representative from a local community organisation.

Demographic data of patients who received intermediate care was collected, but not of carers, nor of the community professional. For an overview of the patients' demographic details, please refer to Appendix 2.

To provide context to our findings, we have here included a table outlining the main points from each interview (including the reason for patients receiving SDC), as well as the interviewees' status (carer, patient, or community professionals), and the patients' borough of residence.

Interviewee	Status	Borough	Experience summary
A	carer	RBKC	A is a carer for her husband, who has complex health issues and multiple comorbidities, including Parkinson's disease, diabetes, and chronic kidney issues.
B	carer	W	B is a carer for his elderly mother, who is living with dementia.
C	carer	W	C is a carer for her son, who is living with paranoid schizophrenia.
D	carer	W	D is a carer for her sister, who has multiple psychiatric diagnoses (i.e., depression, anxiety, PTSD) and who is currently pregnant.
E	patient	RBKC	E was hospitalised after a surgery to relieve her endometriosis symptoms. Her SDC was arranged through a private service at Chelsea & Westminster Hospital.
F	patient	RBKC	F has received SDC following her stay in an intensive care unit, after contracting Covid.
G	patient	RBKC	G was hospitalised and received SDC after she injured herself falling.
H	carer	RBKC	H is a carer for his elderly sister, who has mobility issues, diabetes, as well as some cognitive decline.
I	carer	W	I is a carer for her son, who is living with mental health issues, including an unspecified psychotic condition.
J	carer	W	J is a carer for her elderly mother, who was diagnosed with Alzheimer's disease and lung cancer.
K	carer	W	K is a carer for her brother, who is living with mental health issues (including an alcohol addiction), as well as liver cirrhosis. Her brother was last hospitalised and received SDC for a fall six years ago.
L	carer	RBKC	L is a carer for her two daughters; one of them is living with severe depression, the other has lupus and is currently pregnant. Both have been recently hospitalised.
M	patient	RBKC	M has been diagnosed with bipolar disorder and was recently hospitalised after an acute episode.



N	patient	RBKC	N was hospitalised and received SDC after breaking his leg.
O	community professional	W	O is a professional who works for a local community organisation, supporting patients and carers after a hospitalisation.

# Findings

Overall, the feedback provided to us by interviewees was mixed.

In most cases, quality of step-down services was deemed good, however poor coordination between services and inconsistencies in communication between and within health and social care services could cause issues for both patients and their carers. Study participants also highlighted struggling to navigate the system, and carers having to take on an advocacy role in order to better understand and manage their loved ones' care provisions.

From the interviews we conducted, there appeared to be no significant discrepancies or differences in the quality of care provided in either borough.

Notably, a significant number of research participants provided us with insights into discharge and SDC provision following hospitalisation on an acute mental health ward.

The main themes identified in the interviews conducted are: encountering difficulties during the discharge process, communication around intermediate care packages, the role of patients and carers, home environment assessments & equipment provision, and continuity and quality of care provided.

## Discharge process

Most interviewees reported encountering some issues when being discharged following a hospitalisation. Patients and carers that were unhappy with their experiences with the discharge process reported not being given a clear timeline or indications regarding the timing and mode of discharge. Some carers also reported that they were displeased with not being included in the discussions leading to the decision to discharge, and with having been excluded from the intermediate care planning of their loved ones.

"A", who is a carer for her husband, reported that this had been the case for them throughout multiple hospitalisations across different hospitals:

"In all cases where that has happened, which is both Charing Cross [Hospital], and Chelsea & Westminster [Hospital], they have seriously defaulted on their discharge systems. [...] [It] has been extremely poor and rushed. And you know, nobody goes over [it] with you. [...] There had been no indication that [my husband] was going to be discharged, none whatsoever."

Similarly, "C" noted that after her son was discharged from an acute mental health ward:

“There was no discharge meeting held. The family network was never invited to any meetings, so I took my son by car but after that I was not included by [mental health] teams or by Westminster council.”

“F”, who was hospitalised in Lambeth but received intermediate care services in Kensington & Chelsea, reported that her discharge process had been delayed, due to the difficulties in organising care across boroughs:

“The discharge process was very frustrating. I couldn’t be discharged for an extra 10 days because of the confusion over who would take responsibility for my care. In the end, I had to arrange my own care through Kensington & Chelsea Council when I was discharged. My daughter made all the phone calls and sorted it out.”

Carers “L” and “H”, as well as Patient “G” also had similar experiences:

“The discharge process was frustrating [for both my daughters]. My daughter with depression was discharged without any support plan. For my pregnant daughter, the discharge was hurried, and the carer arrangement was inadequate, leaving me to handle most of the care.”

“The discharge process was a bit rushed. [My sister] was discharged early and made to sit in the discharge lounge without breakfast. We were told she would receive help at home, but it wasn’t very clear what that help would look like.”

“There was a lot of back-and-forth, and no one seemed to take responsibility for my care. This delay and confusion extended my hospital stay unnecessarily and caused a lot of stress.”

“D”, a carer whose sister has been hospitalised on a mental health ward, reported that their experience with the discharge process was seamless and efficient, thanks to the positive communication they had had with the medical providers:

“We had lots of different conversations in the run up to discharge. [...] But for us, as a family, we really felt held. And we knew what the plan was, we knew who to reach out to [...]. We knew how to access more help if we needed to.”

## **Communication around intermediate care packages**

Some interviewees remarked that communication with medical providers around care directives and packages was at times problematic. Some carers and patients struggled to understand what care packages entailed.

“O”, a community professional we spoke with, remarked that, from her clients’ experiences, she had noted that communication around care planning and SDC services was at times unclear:

“Some clients [mistakenly] think that the care package should be able to assist with things like cooking, administration, or taking them out of the house for

errands. This needs to be clearly communicated. Also, if clients have the care package discussed while they are in hospital and in a stressful situation, they may forget about the discussion, so should have the outcomes written down.”

Carer “A” had encountered a similar issue, as she could not initially understand the medical terms in her husband’s discharge paper and the care needs this entailed:

“I got the discharge paper and started to read it, because nobody had gone over it with me. But of course it was full of acronyms and so forth [...], luckily there was a nurse there and I said, “I’m stuck” [...], and she went through it [with me].”

Carers felt relieved when communication was clear regarding the terms of care, timing, and provisions.

Carer “D” felt that direct and clear communication about domiciliary care teams had improved her and her sister’s experiences:

“We had a good knowledge of who the team was, we knew [which] person [was] going to come and see [my sister] tomorrow. Or this person said, ‘I’m not here today’, [or] ‘I’m not here this evening, but I’ll be back in two days’ time”.

She also reported that communication around care planning, care outcomes, and what to do once the care was over was satisfactory and reassuring:

“The doctors would have separate conversations with me as the carer. They asked me [if I thought] that my sister would be open minded to having another [hospital] admission before the baby's born, just to kind of monitor her. So I feel like we were given lots of information about how things could play out [...].”

## Role of patients and carers

### Patient & carer involvement

Involvement of carers and patients in the decision-making process surrounding intermediate care, as well as its delivery, was deemed particularly important by most interviewees. Carers and patients felt that having their perspective taken into account by medical and social care professionals made a difference to their overall care outcomes.

Carer “C” was particularly frustrated with her experience, as she felt excluded from the care planning of her son, who has a diagnosis of paranoid schizophrenia and received SDC in a dedicated facility:

“The [family] was never invited to any meetings so I took my son by car but after that I was not included by [Mental Health] teams or by Westminster council. None of them practice the [Triangle of Care]<sup>14</sup> because Carers will say what is wrong and they don’t want that... they don’t like family being included.”

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<sup>14</sup> NOTE: The Triangle of Care describes a therapeutic relationship between the person with dementia (patient), staff member and carer that promotes safety, supports communication and sustains wellbeing. Source: NHS England (2016), [The Triangle of Care](#)

Carers “H” and “P”, and patient “N” were also not pleased about the extent to which they had been involved in care planning and delivery:

“We were informed about some of the decisions, but it didn’t feel like we had much say in what was arranged. Most of the decisions seemed to be made without fully involving us.”

“We weren’t involved at all. Most decisions were made without consulting us. I felt our input was ignored, and we were just informed of decisions after they were made.”

“I wasn’t very involved. Most decisions seemed to be made by healthcare providers without consulting me directly. I didn’t have much say in the type or frequency of care I received.”

Carer “J”, on the other hand, recounted that her mother’s care planning had been quite efficient and accounted for her views:

“I felt that they involved me, they asked my opinion, on loads of different things. And we kind of look at a multidisciplinary meeting between me with social worker and somebody from the nursing team.”

### Advocacy of family carers

Some of the carers we interviewed reported that, in caring for their loved ones following a hospitalisation, they had to undertake an advocacy role to better navigate the post-discharge care system and help set comprehensive care directives.

Carers reporting this, including “D” and “K”, believed that taking on this role had improved the intermediate care outcomes of their loved ones:

“I don’t think everybody has had my sister’s experience or our experience as a family, because I know other people that have received mental health care services [who] talk about not seeing the same people, lots of agency workers, or people not coming, or maybe [being] asked to physically come into clinic as opposed to being seen at home. [...] I wonder if we weren’t as articulate and experienced in health[care], would we have received the same service? Maybe not?”

“If we had not been proactive in making sure we looked at a long-term plan in time, [my brother] could have been in a very vulnerable overlap. But because we were so proactive from leaving the hospital to getting that [care] in place for long term, it worked out really well. It wasn’t until we were informed, by a social worker, this is what you need to do. That made it work, and that we were proactive just to fight for it.”

Similarly, in describing her and her husband’s experiences navigating the system, Carer “A” noted that:

“You have to have enormous amount of energy, dexterity and perseverance. That shouldn’t have to be the case.”

## Support for carers

Some carers remarked that having to advocate and care for their loved ones during the discharge process and throughout intermediate care delivery took a toll on their physical and mental health. Some of them also reported not being able to take care of themselves due to the commitment, struggling, or not knowing where to turn to receive external help.

Carer “B” reported that, despite receiving external support, his mental health had declined since taking on a carer’s role for his mother following her hospitalisation:

“Four nights a week we have a night-time carer [who] comes at half eight or seven in the morning to give me a break so I can get some sleep. Which doesn't actually work, because I can still hear my mom calling me in my head and it's driving me bonkers. [...] It's really scary. And I spoke to my GP about it.”

Carer “L”, who looks after her two daughters, both with long-term health conditions, had encountered similar issues, and often had to temporarily leave the workforce to attend to their needs:

“I end up taking time off work for several months to care for her until she's stable. [...] A carer was supposed to come to help, but they were only there for two hours a day. The rest of the time, I had to take care of her because she couldn't be left alone.”

Carer “D”, on the other hand, remarked that the team delivering SDC to her sister had made her feel supported and looked after:

“As a family we really felt held. And we knew what the plan was, we knew who to reach out to. We knew how to access more help if we needed to.... When they come to our house I find they're very involved. Very supportive. Really nice professionals working in this team.”

Another carer, “J”, had found respite care quite useful to alleviate the burden of care, after her mother’s last hospitalisation and in her initial phase of home-based recovery:

“When she was discharged from hospital, I was actually in respite care at that time, because I was allowed. I've got a certain number of weeks that I can take respite, and I was actually out of the country.”

## Environmental assessments & home equipment provision

Feedback regarding environmental assessments and equipment provision was mixed. Poor quality of equipment or lack of home environment assessment were issues interviewees brought up. Others also reported that the home assessments had been delayed or had not happened satisfactorily.

Patient “F” attributed the issues she had encountered to the fact that, although she was hospitalised in Lambeth, she received SDC in RBKC:

“No, they did not do an assessment, maybe it was because I was staying with my daughter in a different borough. On the day I was discharged everything was rushed, they just wanted the bed, they didn’t care. I’m not sure they fully understood my needs.”

Patients “G” and “N” also deemed their home assessments not up to standard:

“I was asked about my home environment, but it felt rushed and not very thorough. They didn’t seem to fully understand the extent of my pain or how it affected my daily life. They provided no equipment.”

“There was no formal [home] assessment done. The focus was mainly on immediate medical needs rather than long-term rehabilitation or adaptations to my home. There was the first visit to see about adaptations but nothing came from that visit. [...] And I wasn’t sent any equipment to help with mobility.”

Carer “J” remarked that, although with minor delays, they had received good quality home equipment:

“We needed a hospital bed, and that was sent on the same day [...] and then we requested a recliner chair. We had to wait about a week for that to come, but it was given.”

## Continuity and quality of care

### Quality of care & outcomes

Respondents tended to equate the quality of the intermediate care they received to the outcomes they had achieved in terms of reablement and pain management at the end of the six-week period.

Patient “F”, who was hospitalised after contracting COVID-19, reported that, although she has not been hospitalised again, she has not completely regained her independence:

“[RBKC] council referred me to a charity that helps COVID survivors to support me with my care needs. The care met some of my needs, but not all. I still needed a lot of help from my daughter, which was challenging for both of us. I also only had the care for an hour in the morning, my daughter did the rest... [After six weeks] I felt somewhat better but not myself again, not completely independent.”

Patient “G” also encountered issues during the delivery of care, as she was discharged from the service that was supposed to provide her with SDC after one visit; she felt that her health outcomes were impacted by this decision:

“The intermediate care was supposed to assist with pain relief and support my mobility to help me regain some independence. I was referred to the pain clinic at Chelsea & Westminster hospital. The pain clinic discharged me after one visit they said I didn’t qualify for pain management I am still in a lot of pain... The care was intended to be coordinated through the pain clinic [...]. However, I have since been discharged back to

my GP to manage my pain... The coordination was poor, and the level of support was inadequate. [...] I am not equipped to handle my pain management needs effectively."

According to Patient "N", the lack of consistent care and not having received home equipment to aid him after his injury hindered his recovery process:

"While the district nurse's visit was helpful, I needed more ongoing support to regain independence at home. The lack of consistent care made it harder to recover fully. And I wasn't sent any equipment to help with mobility."

Carers "H" and "L" also believed that the SDC provided had not been consistent enough to meet their loved ones' needs:

"I am not satisfied with the consistency and the level of support [provided to my sister]. The carers were often different people each time, and there wasn't enough support to really help [her] improve."

"For my pregnant daughter with lupus, there was supposed to be a carer arranged, but the support was minimal and poorly coordinated."

### SDC following a hospitalisation on an acute mental health ward

Four of the fifteen interviews we carried out focused on discharge and IC provided to patients after hospitalisation on an acute mental health ward. Three of these interviews were with carers ("C", "D", and "I") one with a patient ("M").

Each of the patients had been hospitalised for a different mental health condition, namely: paranoid schizophrenia ("C" 's son), depression and anxiety ("D" 's sister), an unspecified psychotic disorder ("I" 's son), and bipolar disorder ("M"). Following their hospitalisations, each of them had been discharged under a different intermediate care delivery plan. The feedback we gathered on these care plans was varied: carers "C" and "I" shared information about their negative experiences, carer "D" was extremely satisfied with their experience, and patient "M" reported that his experience was mixed but overall positive.

Following his discharge, "C" 's son was transferred to a step-down accommodation in Westminster, where it was expected that he would receive full-time care under the supervision of a dedicated team. His mother was not satisfied with the care he received there, particularly with the administering of medication:

"[...] Sometimes my son has seizures at night, so they were forcing him to take anti-seizure meds (overdosing him) and they were stimulants, so for the first 2 weeks he didn't sleep at all. I did call and explain, and [the carer] said the social workers would get back to me. I contacted the mental health team but none of them would provide us with a care plan nor would they discuss anything with me. The carer at the house said they couldn't question [the meds regimen] but just did as they were told."



“D” ‘s sister, on the other hand, was discharged back home with a domiciliary care package. “D”, her carer, was quite satisfied with the way the treatment was delivered and the outcome it achieved:

“It was part of the discharge plan to assume some support at home, [that is] two visits a day once in the morning, once in the evening, with medication support, and monitoring [of her] mental health and mood. I think once [her health] was stabilised, she was discharged back into her regular mental health team that was seeing her prior to the admission.”

“I” ‘s son and patient “M”, on the other hand, had received outpatient support following a hospital discharge primarily from Mind Westminster and Mind RBKC.

Patient “M” received SDC primarily through Mind RBKC and his GP, and found that the treatment they provided was quite successful in helping manage his condition:

“My family helped me find support through [Mind RBKC], a charity that has been instrumental in stabilising my routine and providing emotional support. [...] They helped me establish a daily routine and provided guidance on managing my condition. They offered a sense of community and practical tools that have been invaluable. [...] My GP has [also] been supportive in finding stable medications that have helped me maintain stability.”

Carer “I”‘s son was discharged from outpatient mental health services, as he was unable to stick to his medication regimen. “I” was unhappy this was the case, and believed that her son had not received enough support to help him cope with his mental health issues; Mind Westminster occupational programmes, on the other hand, had partially been able to help him:

“The intermediate care we have had is cognitive behavioural therapy [CBT], [...], it was very successful, indeed. It was wonderful. [...] On the second time when I felt he needed CBT he didn't pass a test so was sent back to the psychiatrist and he's never had another session of CBT. Unfortunately, which he really did need, but he had to cope. But in Westminster, Mind was wonderful, and he went down weekly. [...] He went [there] to spend a lot of time filling and doing job applications and learning how to do CVs. And that was helpful.”

Carer “I” believed other clinical alternatives should have been provided to her son to tackle his complex mental health needs.

### SDC for patients with diminished mental capacity

Consistency of care and regularity of staff coming to provide domiciliary care was particularly important to carers of patients with diminished mental capacity brought about by neurological conditions or mental health issues.

In these instances, carers argued that, due to their vulnerabilities, consistency and continuity were vital in ensuring their loved ones felt comfortable during the delivery of care. Conversely,

having multiple teams delivering the domiciliary care unsettled their loved ones and hindered their recovery.

Two carers, "B" and "J", who look after their respective mothers, both living with dementia, recounted:

"What we try to do is keep a consistency with mum because [of her] dementia, we try to get the same people in all the time. [...] She was sick and tired of different people coming in every day."

"What I did find quite frustrating was that there seemed to be a lot of teams that were involved with my mum's care. It was hard to keep track of who was visiting."

Similarly, "K", a carer for her brother, who suffers from mental health issues brought about by a traumatic brain injury, told us:

"It took a big adjustment for him to have strangers coming into his home. And we had to be very involved in getting to know those people. Therefore, if we trusted them, he would trust them. So, it was imperative that we did have consistent people coming in."

This feedback was echoed in the feedback and recommendations of local community professional, "O":

"Many of our clients have memory issues and can get confused with different people coming in and out of their house. It would be useful to have regular familiar faces for these clients."

# Limitations

## **Selection of participants**

Those who have an extreme experience, either positive or negative, are more likely to report this and share their feedback. Wanting to share these experiences may have led to participants self-selecting themselves to take part in this project.

A monetary incentive was also offered to participants, and this could have influenced who chose to participate in the research project.

## **Representativeness of participants & accuracy of findings**

Most of the study participants were people of White British or White European heritage, from a middle- or high-income economic background; we also heard mainly from carers, rather than from patients.

Men, people from global majority backgrounds, and people from a lower income background are underrepresented in this report. The under-representation of these key demographic groups in our findings means that in order to be fully representative, further insight is needed to gather a fuller perspective into their experiences accessing and using intermediate care services.

# Recommendations

1. **Improve communication and planning** amongst medical providers, services, local authority, and carers (especially during the discharge process and the setting of care arrangements).

Health and social care professionals should make sure that a clear and effective support plan is in place before discharge, and that patients and carers have fully understood what intermediate care services will entail.

Local authorities should communicate clearly with patients, carers, and medical providers to ensure this is the case, and that service delivery is clearly planned and understood.

2. **Improve the involvement of patients and carers in the decision-making process**, particularly in the care setting and discharge process. This is a requirement set by the [NHS Guidelines on intermediate care](#), and professionals should honour this commitment fully by making sure the perspectives of patients and carers, where possible, are heard.

3. Provide more **tailored support for carers and family** members, especially individuals with mental health conditions and elderly groups. Carers should be made aware of the rights they are entitled to (particularly respite care and mental health support) and signposted to relevant local organisations. Care assessments should be holistic and account for the specific needs of the family and care environment surrounding the patient.

4. More **comprehensive and consistent support** may be needed to address the specific health and care support needs of patients with complex health needs.

**Ensuring continuity of care** for patients who have not regained a reasonable amount of independence may be achievable with further integration of specialist services in the care planning. This would mitigate chances of hospital readmission and improve reablement outcomes.

5. Health and social care staff delivering intermediate care should be kept up to date with the **relevant training** to meet the needs of patients, particularly those who are most vulnerable. Training could cover, for instance, communication between staff and carers/patients, proactive safeguarding, and trauma-informed approaches to complex mental health needs.

# Next steps

Following the publication of this report, we are planning to continue our engagement with carers and patients, monitoring changes in the planning and delivery of intermediate care across Westminster and Kensington & Chelsea. Through continued engagement, we also hope to gather additional insights into the needs and experiences of unpaid family carers. Our drop-in sessions at local community centres and hospitals – particularly Chelsea & Westminster Hospital – will facilitate continued fieldwork to monitor any emerging priorities.

We will disseminate the findings of this report in partnership with the North West London Networked Data Lab, and aim to continue working collaboratively. We will also make this report and its recommendations available to our key stakeholder network and local authorities.

Moreover, Healthwatch Westminster and RBKC are presently seeking professionals and residents with lived experiences of health and social care to join our Advisory Board, which advises and guides the Healthwatch Team on how to achieve our goals and priorities. If you are interested in supporting our work as a volunteer, joining our Advisory Board as a member, or staying updated on our ongoing projects, please email [info@healthwatchwestminster.org.uk](mailto:info@healthwatchwestminster.org.uk) or [info@healthwatchrbkc.org.uk](mailto:info@healthwatchrbkc.org.uk).

# Acknowledgments

We are very grateful to everyone who contributed to the realisation of this report.

This project would not have been possible without the support of our partnered organisations in helping us reach people, as well as the collaboration of residents, carers, and community professionals in sharing their valuable experiences and perspectives with us. We would like to thank the research participants who took time to share their feedback and experiences with us.

Thank you also to the North West London Networked Data Lab at Imperial College Health Partners, Imperial College London, and the North West London Integrated Care System for commissioning and helping in the design of this project, and for providing us with data and insights into intermediate care in Northwest London. We would also like to thank the members of the North West London Networked Data Lab's Patient and Carer Advisory Group for sharing their experiences and priorities to influence the creation of the interview guide.

Finally, we would like to acknowledge the Volunteers, Advisory Board members, and Healthwatch staff who supported this work.

# Appendices

## Appendix 1 – Interview Guide

### *Introductory questions – for patient*

1. Have you previously or are you currently receiving intermediate or step-down care?
2. Could you give a brief description of your care needs and the type of care that was provided to you?
3. How long were you or have you been receiving intermediate care?
4. Which healthcare service provided the care?

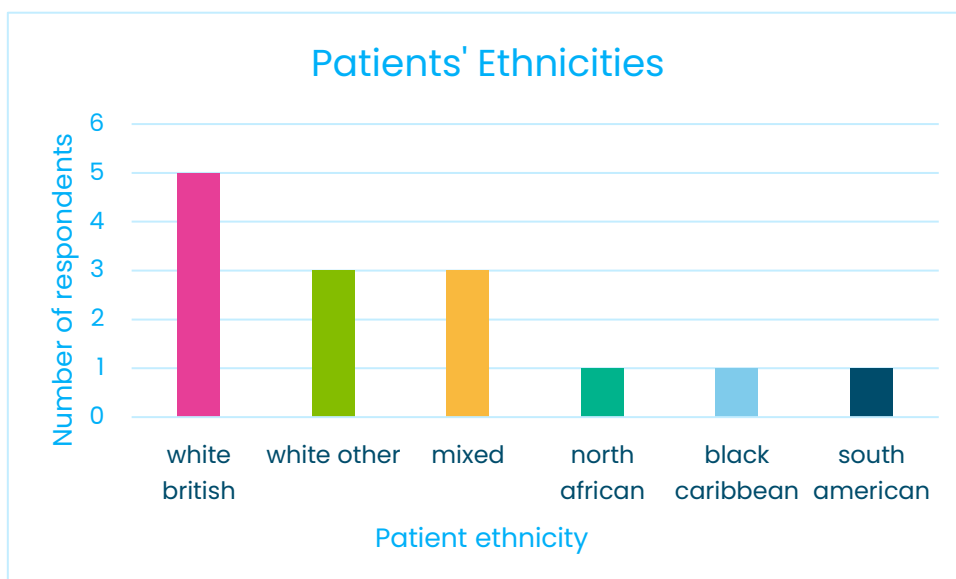
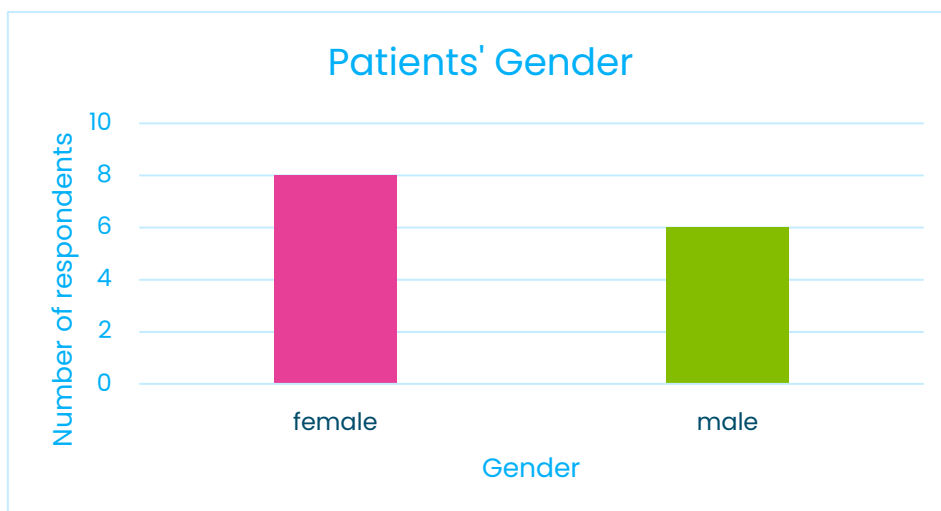
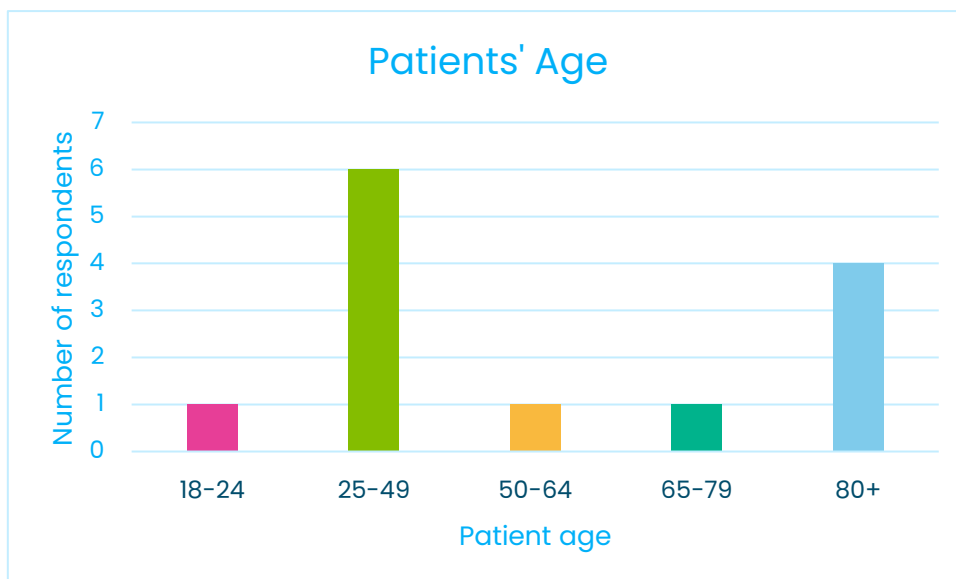
### *Introductory questions – for carer*

1. Are you a carer for someone who is currently or has previously received intermediate or step-down care?
2. What is your relationship to the person receiving the care?
3. Could you give a brief description of their care needs and the type of care that was provided to them?
4. How long were they or have they been receiving intermediate care?
5. Which healthcare service provided the care?

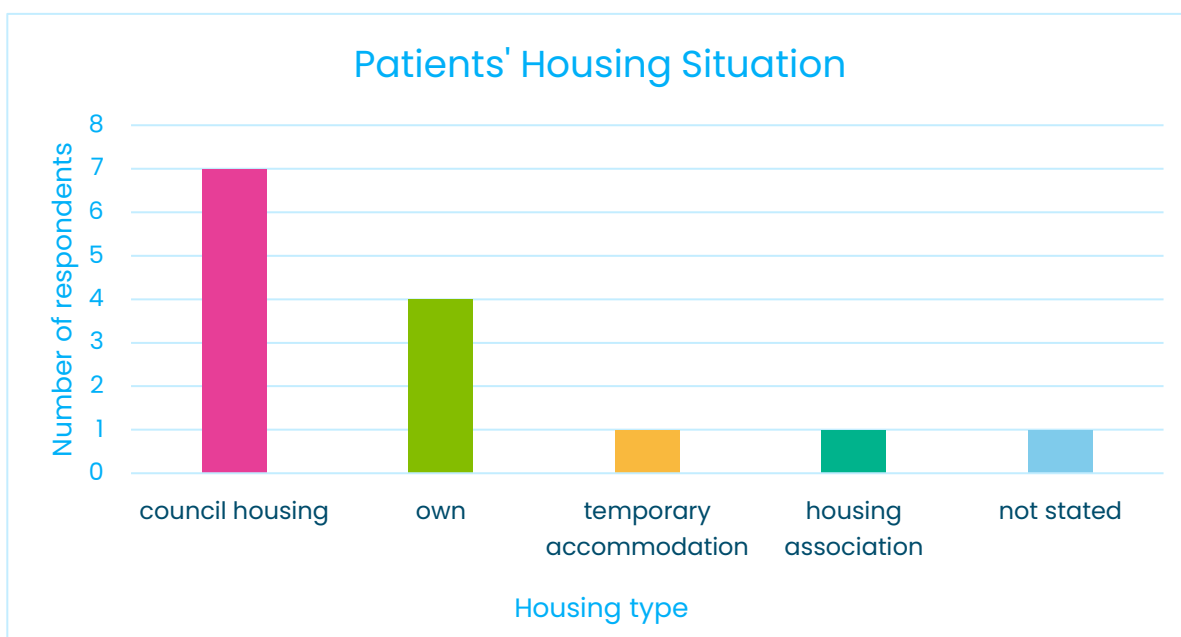
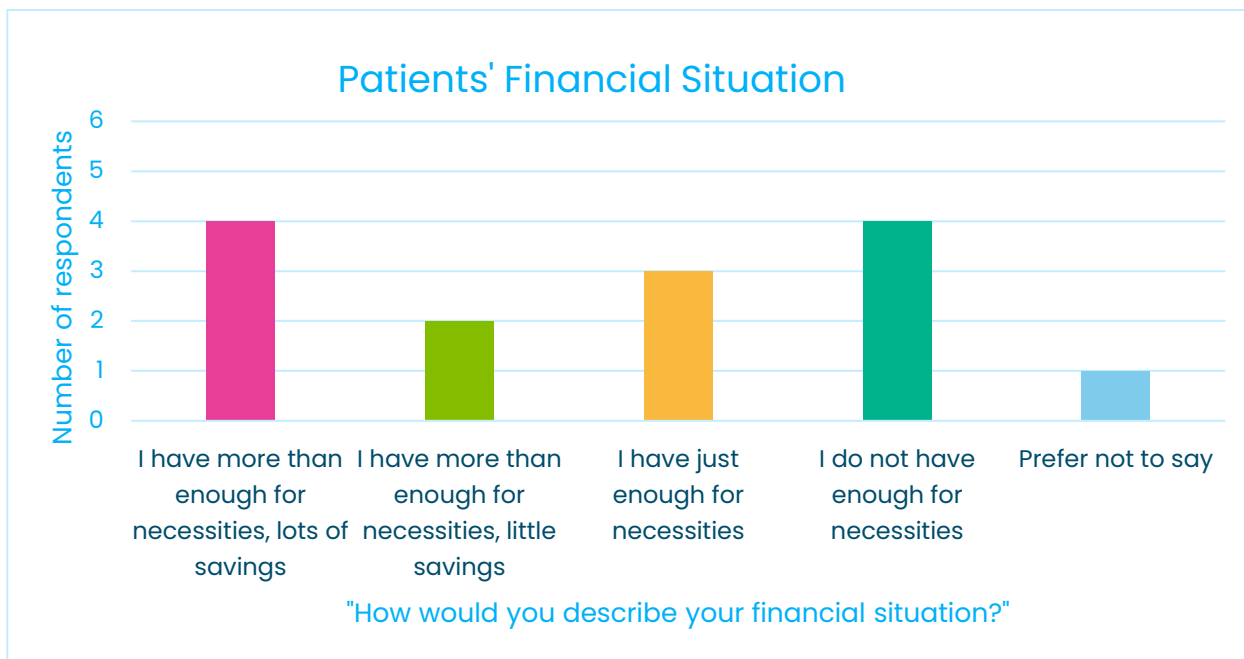
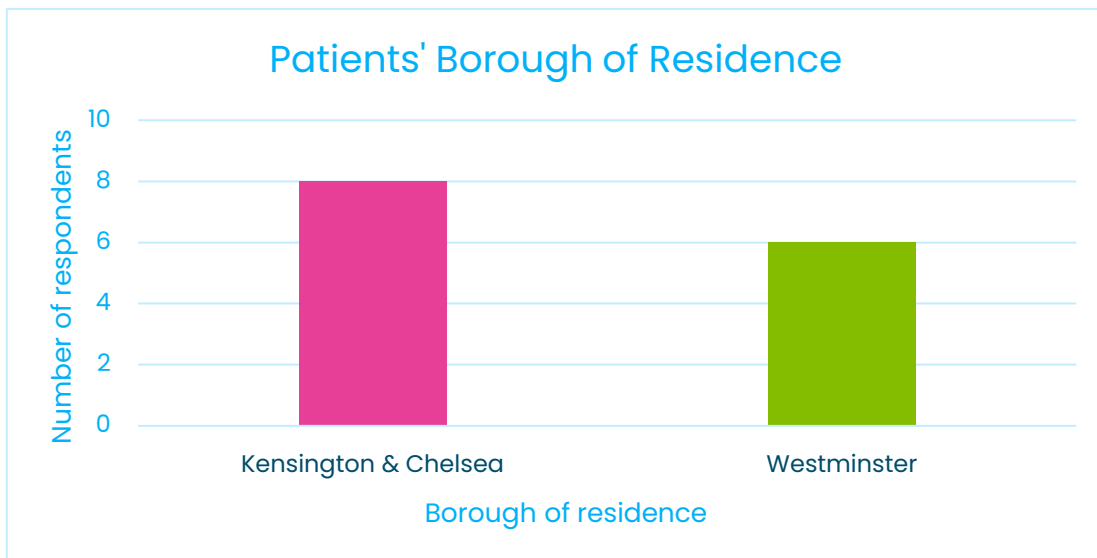
### *Intermediate care experiences*

1. What were your general experiences of the intermediate care provided to you?
  - a. Were you satisfied with the care? What were you not satisfied with?
  - b. Were you visited by the same member of staff each time?
2. How was the hospital discharge process and arrangement of or transition to intermediate care?
  - a. What were you told about the care process/package before you were discharged?
  - b. How long did it take to get care after discharge? If you had to wait to receive the care, what were your experiences like during this time?
3. Did the service provider conduct an assessment of the home environment before providing you with the care?
4. To what extent do you feel that you or your carers were involved in the decision-making surrounding your intermediate care package?
5. Did you receive any equipment from the Community Equipment Service/NRS Healthcare as part of your care?
  - a. If yes, what were your experiences with the service?
  - b. *Possible probes if relevant:* Do you still have any equipment from the service? Have you arranged for collection of any equipment you no longer need?
6. To what extent do you feel that the care provided met your specific health and care needs?
  - a. *For patients who are no longer receiving care:* At the end of the care, did you feel independent or ready for the care to end?
  - b. Were you readmitted to hospital for the same health concern?
7. What would you recommend services do to improve the quality of intermediate care?

## Appendix 2 – Demographics of patients









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