

# **July 2018**

# Service user experiences of CNWL services

### **PART 2: RAPID RESPONSE**

Conducted by Healthwatch Camden on behalf of the Camden Clinical Commissioning Group.

#### Introduction

Camden Clinical Commissioning Group asked Healthwatch Camden to conduct service user research around two newly commissioned services: Discharge to Assess and Rapid Response. Rapid Response aims to reduce visits to A+E and hospital admissions by providing rapid short term care and support for the patient at home after an incident that may otherwise lead to a hospital visit. Rapid Response can also be deployed after discharge from hospital to provide short term support with the aim of avoiding re-admission.

#### **Aims**

The overall ambition was to learn whether the service/model is working well from the <u>perspective of the patients</u>.

We wanted to know what patients felt worked well or not so well about the support they were offered. In particular we wanted to know whether the patient felt that the care and support provided by the team helped them to feel able to stay at home and avoid a hospital admission.

**NOTE:** The aim was to gain insight into Rapid Response as distinct from other services. However, in practice, CNWL were not able to cleanse the samples of interviewees to ensure clarity between the different services. Many interviewees in the sample for Rapid Response were also recorded as Discharge to Assess and many had just returned from a period in hospital or were living with complex conditions that involved regular hospital visits or contact with other services.

While distinctions between commissioning intentions and names of services may be irrelevant to patients, this made it difficult for researchers to identify which line of enquiry to pursue during interviews.

Although the composition of the samples made it difficult to pursue the distinct research questions with the clarity originally intended, the interviews demonstrated the complex and interwoven nature of patients' experiences of Discharge to Assess, Rapid Response and wider services in general. The overall endeavour to understand the patient experience and the insight obtained from the interviews was not undermined by these definitional complications.

# **Summary of findings**

- All those interviewed were clear that they wanted to remain at home and were pleased that the Rapid Response team allowed them to do so.
- No one expressed anxiety at being encouraged to stay at home rather than go to hospital.
- The majority of those interviewed felt they benefitted from the support at home.
- Most patients had support needs that linked them into a wide range of medical or care services making it hard to identify feedback related to the Rapid Response service in isolation.
- In cases where patients were in contact with a range of different services the feedback was less positive.
- Generally there was positive feedback about Rapid Response team personnel.
- There were some cases of failure to follow up on commitments made to patients and actions that appeared to have been lost in the transition between teams.
- Many patients expressed some confusion around managing the complexity of their care needs and different appointments.
- Patients were frequently assisted by family members and carers which sometimes confused the picture.
- Ill health or injury made many patients feel dependent and lacking in control. This lack of agency played out in different ways for each patient.
- Several patients expressed conflict around a desire to retain independence while needing support. In some cases this led patients to refuse support that was offered.
- Very few patients reported a "seamless service".
- Only three patients reported having "no idea" who was meant to be doing what. But only five reported a full understanding. The sense of not being able to comprehend who is meant to be doing what causes stress.
- Patients expressed a preference for having a single named person and telephone number they knew they could contact if any aspects of their support and care did not go smoothly.
- Patients want good communication both with them and between the individuals caring for them.

# **Findings**

## a. Did the Rapid Response support at home work well?

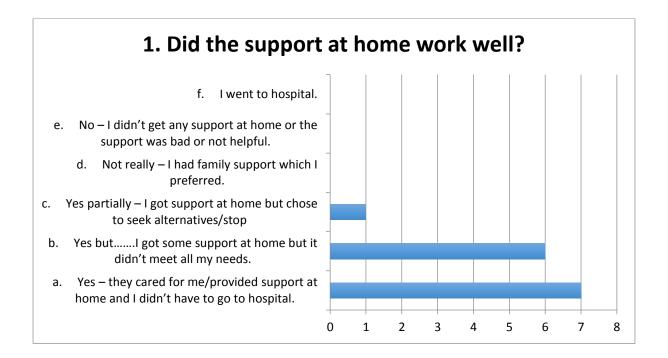


Chart 1 explores whether patients felt that support from the Rapid Response team worked well for them and helped them stay out of hospital. Half the sample of 14 patients reported a very positive experience. They felt the Rapid Response service had met their needs at home and said they avoided going to hospital.

"I was very pleased. It was good to have someone come to my home and check me over thoroughly. I was very impressed. It was nice to stay at home - more relaxed. I've had a lot to do with hospitals over the years and I much preferred to be at home."

<sup>&</sup>quot;I needed help and I got it."

<sup>&</sup>quot;Yes I was very pleased not to have to go into hospital. I don't want to be on a geriatric ward!"

<sup>&</sup>quot;It worked excellently. They were very calm and professional and reassuring."

<sup>&</sup>quot;Brilliant! Couldn't believe it! I was ill and they were there all the time."

<sup>&</sup>quot;They reassured me and I knew if I needed anything I could have asked and I would get it."

"For someone like me it was perfect. The GP said he would like someone to see me then someone turned up. They were good. They assessed me and monitored me for 72 hours and they only needed to come once."

"It was an excellent solution for this particular fall. I've spent so much time in A+E in the past is was good [to avoid it]."

"I was quite surprised! Here they were [at my home] in the evening, the day I came home from hospital."

However, only 4 of the 14 interviewed were patients for whom the Rapid Response intervention was not inextricably entwined with other support services.

An example of a straightforward case was Patient X who had a dizzy spell, called her GP who referred her to Rapid Response and explained that someone would come to see her at home. A health worker came as expected and checked the patient over and reassured her. The patient reported that everything worked smoothly, she avoided going to A+E, and did not involve any other services. She was extremely positive about the service.

In contrast, Patient y was a highly complex case. Here it was not possible to establish that the patient had any "Rapid Response" service to avoid admission because the patient reported a range of complex needs and a variety of support on a daily basis.

"I am not aware that I had any Rapid Response!"

In the case of several interviewees, Rapid Response was deployed after a hospital admission to avoid re-admission. For two patients this worked very well according to the patients and carers, achieving good longer term outcomes by introducing the family to a range of other support that they had previously been unable to access.

"We wanted to get her out of hospital as soon as possible. Mum was put well and truly on the way to recovery at home."

"I was pleased and surprised by the comprehensive nature of the service."

In one case the role played by the Rapid Response team in a coordinated response was a major factor in a positive patient and carer experience.

"We thought we would be left hung and dry but everyone got on the same page. Rapid Response were diligent and worked purposefully with social services and the GP to ensure it was all joined up. It was a conscious collaboration instead of hiding and gatekeepers. And the people on the front line were fantastic."

"No one can speak bad to me about social services any more. Social workers of Camden are fantastic!"

"When things are coordinated everything works well."

In a less positive example, the intervention of the Rapid Response team appears to have become mixed up with a wide range of other issues, predominantly housing

needs. It was not possible to clarify through the interview why the Rapid Response team had been deployed and it seemed that their intervention may have raised expectations and further confused the picture for the family. In one case, the patient's son, who was caring for the patient within the extended family home, reported being confused about the next steps after the rapid response team had become involved and then ended their support.

"I thought now that it's finished nothing is going to happen. Hope was gone and since then nothing has happened." Carer

We heard a few examples of failure to follow up on commitments made to patients and actions that appeared to have been lost in the transition between teams.

"The promised blood pressure machine didn't come and the pads came 8 weeks later so we had to buy them for ourselves."

One patient had been offered a wheelchair which he thought was a good idea. When it didn't materialise he asked his GP to follow up and was told that a "recommendation" had been made.

"Everyone says "we'll work on it" but it never seems to get anywhere."

On enquiry, Healthwatch Camden was informed that one referral had been made by someone who did not qualify to complete the referral form and that it was therefore declined. Subsequently a referral from an Occupational Therapist was processed. This serves to demonstrate the difficulty of eliminating cracks in the coordination of services which can leave a patient feeling confused and let down.

Despite some reports of shortcomings, the large majority of those interviewed felt that they did benefit from support at home. Among those whose reporting was more mixed, the reported problems related to the fact that they were in contact with a range of different services. This made it difficult to get a clear sense of the value placed on the Rapid Response service in isolation.

### b. Did the patient feel confident that they knew what to expect and why?

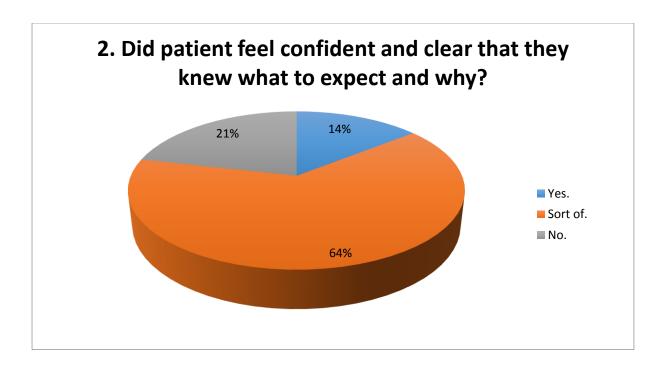


Chart 2 explores whether patients felt in command of what was happening to them. Here the results were less positive with only two patients out of 14 saying they felt confident and clear what to expect and why. A further three had little understanding of what they could expect from the Rapid Response service and the remaining 9 were fairly clear but not entirely so.

Patients also talked of feeling confused, vulnerable and lacking in confidence due to the circumstances of their ill health or injury. This produced a tendency in many to relinquish their desire to exert influence over their own care and support. But this lack of agency produced mixed emotions with many feeling conflicted between a desire to retain their independence and their need for support. Several of those interviewed asserted their desire for independence and in a number of cases it seemed that this had led them to tell the Rapid Response team or other services that they did not need or want some of the support offered.

"It's a mixed blessing. I don't want to feel totally dependent."

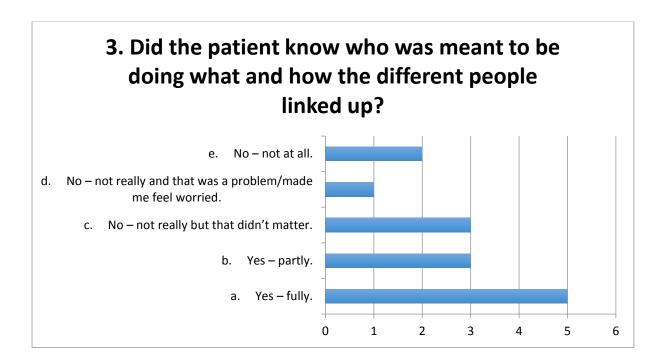
"I didn't fit the profile [for the care offered]. I didn't go to bed at 6pm or eat ready meals. But one of the carers turned out to be a brilliant cook."

"I was overwhelmed by how much care is actually available unsolicited although I haven't sought it."

<sup>&</sup>quot;I'm an independent man."

The complex emotions expressed by many of those interviewed indicate the need for the Rapid Response service to make every effort to respond sensitively and flexibly to the individual patient wants and needs.

c. Did the patient know who was meant to be doing what and how the different people linked up?



A common cause of anxiety for patients is a sense of confusion about the different roles and relationships between the multiple providers with whom they have contact. However, Chart 3 shows that the great majority of patients interviewed (11 out of 14) reported that they either fully understood who was who and who was meant to be doing what or that they partly understood or at least were not adversely affected by the whether or not they full grasped the different roles and relationships. Only three patients reported unwelcome stress caused by confusion around who was meant to be doing what. However, for these patient the level of stress appeared high.

<sup>&</sup>quot;There are so many people coming and going I really don't know who is who."

<sup>&</sup>quot;It would help me a lot to know more exactly who is who and why they are here and what can be achieved."

<sup>&</sup>quot;I've had visits when much of the visit is spent working out why they are here."

<sup>&</sup>quot;A lot of different people contact me ... they ask what do you need etc... but I don't always know which organisation is which and that's a problem."

"It's a small house and lots of people were coming and going. Sometimes it felt intrusive."

"I had an idea there was a social worker and carers - then there was a new team - palliative care - and two OTs, two physios and two nurses and I was still none the wiser."

"There were just so many - they just walk into the house - some days it felt like I could sell tickets!"

The majority of those interviewed expressed some confusion around managing the different appointments and strands of support. Very few patients reported a "seamless service". Many patients were also assisted by family members and other carers which further complicated the findings.

Overall, the interviews demonstrated the complex and interwoven nature of patients' experiences of Rapid Response and wider services in general. Annex 1 presents the patient experience as described by one interviewees in the form of a "mind map". (Annex page.)

### d. Did the patient know who to contact if needed?

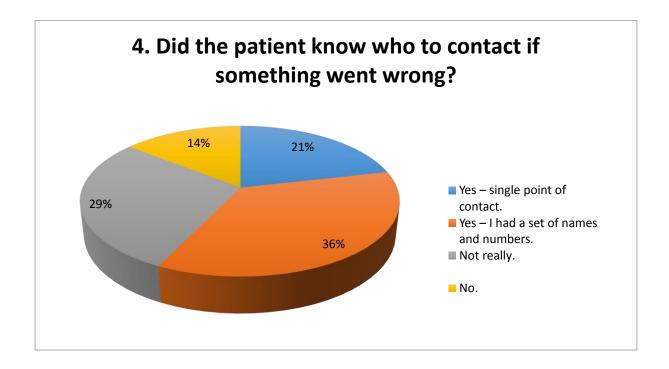


Chart 4 shows that eight of the total sample of 14 patients reported they were given contact names and numbers should they need to contact someone about their support needs although only 3 of these were confident they had one single point of contact. Six of the 14 patients did not have a clear idea who they should contact about their support needs around the time of the incident.

The patients expressed a preference for having a single named person and telephone number they knew they could contact if any aspects of their support and care did not go smoothly.

## e. Quality of carers

Although not the subject of our enquiry, the interviews elicited a range of views on the quality of carers deployed to provide support in the home. A common theme was a reticence among patients to criticise individual carers alongside frustration at a sense that the service was not always providing what the patient wanted and needed.

"Sometimes the carers do not stay as long as they are supposed to. I have not made an issue of it because I like them."

"The carers are very good. They were willing to do things outside their remit. The agencies are hopeless but the carers manage themselves."

Patients made it clear they prefer consistency and like to know who is coming and when.

"It would have been better if it had been the same person each time."

"They often didn't know how to get here."

"I would have liked to have somebody regular rather than somebody different every time."

"The people who came to help me get washed need a lot more training - one really didn't know what to do."

"I don't eat honey and marmite sandwiches!"

"We had one care company that turned up three hours late but the next company were amazing and dad was sad to see them go."

#### f. Communication

An overriding theme emerging from the interviews was patient's desire for good communication — both with them and between the individuals caring for them.

"Often people aren't very good listeners so then there's a miscommunication."

"When people say "we want to know how you are doing" I never really know how to respond to that question."

"I've no idea and there's been no communication. In desperation I rang the social worker - there's no one you can talk to - it's worrying."

"When they come they are very nice but I'm not entirely sure why they're here. They say "we just popped in to see how you are doing". Maybe they could be a bit more specific."

#### Method

The research used one-to-one in depth interviews. Interviews were structured with a set of open-ended questions. While responses to the pre-set questions were sought, free comment around the themes was encouraged. A maximum of 45 minutes was allocated per interview. Actual interview times ranged from 45 minutes to 80 minutes per interview. Responses were recorded using hand-written notes with effort made to capture direct quotations. These were then coded to ensure anonymity. The responses were reviewed and the commonly occurring responses were identified to create a reporting framework. Each interview was then analysed using the reporting framework.

Interviews were conducted with a total of 28 service users, 14 of whom had contact with the Discharge to Assess service and 14 of whom were supported by the Rapid Response service within the past 6 months.

Interviewees were identified by CNWL through their patient records. Patients were contacted directly by CNWL staff and invited to volunteer for interview. Volunteers gave permission to be contacted directly by Healthwatch Camden. Healthwatch Camden then arranged interview times and locations directly with the patients. Most interviews were conducted in patient homes with a small number in alternative public venues. Interviews were conducted by a team of three experienced researchers. Care was taken to ensure that no one was pressured to take part in an interview if they did not wish to do so. Those who volunteered for interview were given details of the scope and reason for the interview. Guidelines for the protection of the wellbeing of patients were observed at all times.

Although there was agreement between Healthwatch Camden and the CCG that patients with dementia or significant memory loss would be excluded from the interview sample, in practice, CNWL was not able to eliminate such patients.

#### About Healthwatch Camden

Healthwatch Camden is an independent organisation with a remit to make sure that the views of local service users in Camden are heard, responded to, taken seriously, and help to bring about service improvements.

Our duties (which are set out under the Health and Social Care Act 2012) are to support and promote people's involvement in the planning, running and monitoring of services; to gather views and experience and to make reports and recommendations for improvement based on those views; to offer information and advice on access to services and choices people can make in services; and to enable local people to monitor the quality of local services.

Our remit extends across all publicly funded health and social care in the borough. It includes statutory powers to enter and view any publicly funded health and social care service and to call for a formal response from the relevant bodies to any of the recommendations we make. Healthwatch Camden has a seat on the Health and Wellbeing Board and contributes to strategic thinking about reducing health inequalities across the borough.

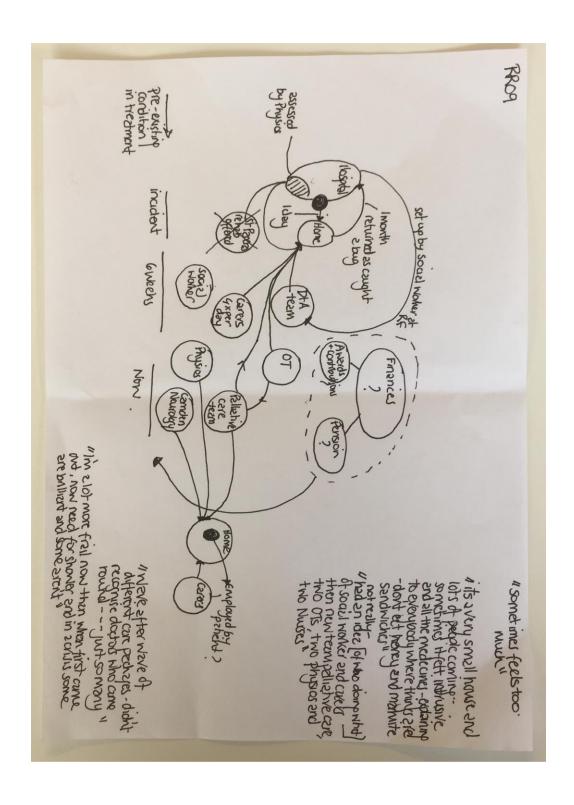
### **Acknowledgements**

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Project lead for Healthwatch Camden was Anna Wright, Policy and Insight Manager. Interviews were conducted by Eli Collis, Anna Wright and Connie Smith. Analysis and report writing by Anna Wright and Eli Collis.

Annex 1 - The mind map provides a visual representation of the patient experience described in interview by a patient in contact with the Rapid Response service.

Mind map: Patient RR09



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