



July 2018

Service user experiences of CNWL services

PART 1: DISCHARGE TO ASSESS

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. The first, referred to by the title “Discharge to Assess”, aims to replace the practice of assessing patients in hospital to determine home support needs (equipment and services) and instead to conduct this assessment at home very soon after discharge. Evidence suggests that assessment at home is likely to be more accurate and ensure a better match between patient needs and the prescription of both equipment and other support.

Aims

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

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 support in terms of equipment and care was what patients felt they wanted and needed on return from hospital.

NOTE: The aim was to gain insight into “Discharge to Assess” as distinct from other services and the intention was that interviewees should be selected and interviews conducted with this in mind. 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 “Discharge to Assess” were also recorded as “Rapid

Response” and many had, in fact, been assessed and issued with equipment prior to leaving hospital.

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

- The majority of interviews did not identify a consistent or distinct service that matched the CCGs description of “Discharge to Assess” (patient discharged and then assessed at home with consequent prescription of suitable equipment or services). Instead, the interviews produced evidence on what seems to be a highly varied set of support measures provided in a highly varied way. The ways in which individual patients experience or perceive the services is also highly varied and individualised.
- Where the range of different support is well coordinated the patient experience is more positive.
- Cases where the support is well coordinated and works smoothly seem to correlate with cases where the patient is cooperative and dependent.
- For patients who draw on other resources (family support or personal problem solving), or express a greater desire to exercise control over the support offered, the patient experience is less positive.
- Overall, the level of satisfaction with the services being provided at home is high for most patients interviewed.
- Many patients offered high praise for care staff.
- Most patients were very grateful for the support and several expressed feelings of guilt. This suggests patients did not feel a sense of entitlement to services.
- Most patients did not feel in command or control of the services they were receiving. Most did not express a strong sense of being able to shape whether or not those services met their expectations or needs.
- Only one patient out of 14 interviewed expressed anxiety at the fact they were discharged home and none said they would have preferred to stay in hospital.
- The link between hospital and community services appears to be mostly but not always clearly explained to patients before they leave hospital.

- Some patients reported a lack of clarity about what people visiting home were briefed to do or how they linked up but this was not a cause of concern for most patients.
- Reporting on whether patients felt confident they knew who to contact if things went wrong are mixed. Some were clear that they had a name and phone number while others talked about contacting their GP or thinking there was something on a letter somewhere.
- In some cases, patients have showed paperwork to the interviewer. Often the paperwork is unclear with several services listed, care plan incomplete, no discharge date. In some cases patients do not have any paperwork as service providers had reportedly taken this away. In these cases patients appear to have been left with no details for reference including no contact details/phone numbers.
- In the majority of cases it was clear that the patients were living with multiple pre-existing conditions aside from the specific episode that had led to recent hospitalisation and discharge. This contributed to a complexity of response and varying degrees of confusion for the patient between different services and personnel with whom they were in contact. The desire for a single and well known human point of contact who could help the patient navigate between the different visitors and service offers was keenly felt by some of those interviewed.
- These findings indicate the need to ensure that services in the community are flexible and can respond to and accommodate the highly individual needs of each patient while remaining coordinated and reliable. Meeting this challenge also requires that personnel are able to adapt and accommodate the preferences and coping strategies of each patient on a case by case basis. The interview responses suggested that this flexibility and responsiveness was present in some cases but not in all.
- Overall, the interviews demonstrated the complex and interwoven nature of patients' experiences of Discharge to Assess and wider services in general. Annex 1 presents the patient experience as described by one interviewee in the form of a "mind map". (Annex page 12)

Findings

- a. On leaving hospital, did the patient feel confident they knew what was going to happen?

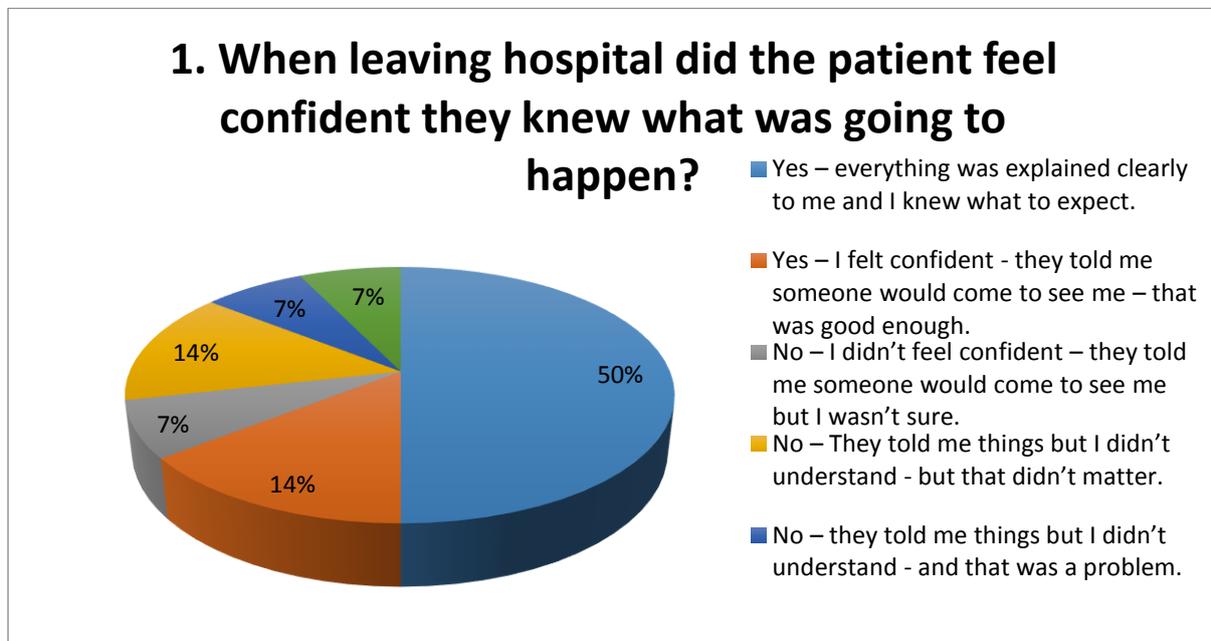


Chart 1 shows that only a very small proportion of patients (1 patient in a sample of 14) were explicitly unhappy about the experience of being discharged for assessment at home. This unhappy experience was attributed to a lack of clear information or an inability on the part of the patient to sufficiently comprehend information provided about what was going to happen and this caused significant anxiety. Interesting to note, a larger number of 2 patients did not feel they understood the information given before leaving hospital but this did not concern them. These patients were willing to trust that things would fall into place and did not feel a need to understand more. Another patient recalled being told what would happen once home but did not feel confident that things would happen as described. Half of all those patients interviewed reported that everything was explained clearly to them before discharge and that they knew what to expect once home. A further two patients reported understanding the headlines of what would happen and felt this was enough to make them feel confident and supported.

“The doctors talk in their own language and I was dosed up with morphine and in pain so I couldn't remember or absorb most of what they said.”

“When I left hospital I felt confident if I needed the support it would be there.”

“The ward sister told me that the district nurses would be coming round to my home to see what help I needed.”

“I suppose I must have known someone would come. I wasn’t surprised when the Red Cross lady turned up.”

“I came home feeling fairly confident that things had been set up for home.”

b. On arrival home, did everything happen the way the patient expected and had been told?



Chart 2 shows what patients experienced on arrival home from hospital. The majority (9 out of 14) reported that everything happened the way they had been told it would. This is higher than the proportion of patients who reported feeling clear about next steps before leaving hospital and suggests that these patients felt less anxious once home. A further two reported that support did not transpire in the way they had expected but was nevertheless welcome. No patients reported a bad experience.

These findings show a high level of satisfaction with the support services provided at home but also suggest that some patients do not expect to fully understand or feel the need to be in control of the services being provided for them. In the small number of cases where carers participated in the interviews alongside patients, it was often the carers who expressed greater frustration at poor communication and not knowing what the patient could expect.

“I would have liked it to have happened as they said it would happen.”

“I was anxious that I was not ready to leave hospital but I was okay about it afterwards.”

“I don’t remember there being an “assessment” but I did get a visit from someone to arrange things.”

c. Did the patient get the care and support (including equipment) they felt they needed and wanted?

No one reported that they did not get the care and support they needed. Eight patients were fully satisfied with a further three partly satisfied. Two of those interviewed explained that they did not want or need what was offered so did not use the service fully.

“Yes I got everything I needed and wanted.”

“The care was good and the equipment was helpful. I got a cushion for my chair, a stool for the kitchen a rail by my bed and a step in shower. And each was most useful. I was comforted.”

“The service was simple and good.”

“When you are in a state of semi-dependence and need to work up your self-confidence it was wonderful to be supported.”

It was clear during interviews that, from a patient experience perspective, there is little patient understanding of the complex network of different services that contribute to their care and support. In cases where patients report good experiences these different services are working together seamlessly and distinctions are unnecessary for the patient.

“It was a seamless service.”

“I don’t know who ordered the equipment but I was pleased to have it.”

“There was a smooth handover from the carers and physio to visits from the local district nurse and physios from Gospel Oak.”

However, where lack of coordination exposes the cracks and therefore the complexity of the system, patients feel disempowered by a lack of influence or understanding and a sense of “being done to”. Some patients accept this while in others it provokes anxiety.

In a majority of the 14 cases studied, patients reported taking action for themselves (or action by family members) that either confused or disrupted the planned care and support offer. For example, in the case of occupational therapy equipment, some patients reported finding they did not need the equipment provided and they wished to return it but were unable to do so. In several cases, patients had secured equipment for themselves from other sources.

“They asked me what I needed but I already had a lot of stuff I had saved from my own mum. I had a pick up stick of my own and a perching stool and walking pusher.”

It was interesting to note that the cases where the service appeared to have worked most smoothly, in line with the pathway as theoretically described, were those where patients and carers had not made any efforts at self-care nor had sought solutions or support of their own.

Several patients interviewed were keen to stress their independence and to argue that they did not need the support offered.

“I told them that I did not need them. They came anyway.”

“They gave me a frame and two walking sticks. I came home from hospital with these. No additional equipment appeared once I was home.”

Another emerging theme was the disposition of the patients to be very grateful for the service offered and to feel guilty about drawing on public resources. None of those interviewed communicated a sense of being clear about their entitlement to services and this was accompanied by high levels of gratefulness to service providers and high praise for individual staff.

“I was reluctant to take on an expensive service I didn’t need. I said I’ll just have a wash down.”

“Personally I think the service was very good. I don’t think they could do more actually. It’s up to the person to ask for more isn’t it? I’ll know next time I go into hospital that I just have to ask for it... the help’s there if needed.”

“I was told a perching stool would be delivered. It never arrived. But I did not mind.”

“They treated me awfully well.”

“It seemed to me that every single person in the team was professionally on the ball.”

Carers were more demanding in their expectations:

“How do people manage where they don’t have family support?” Carer - patient’s daughter

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

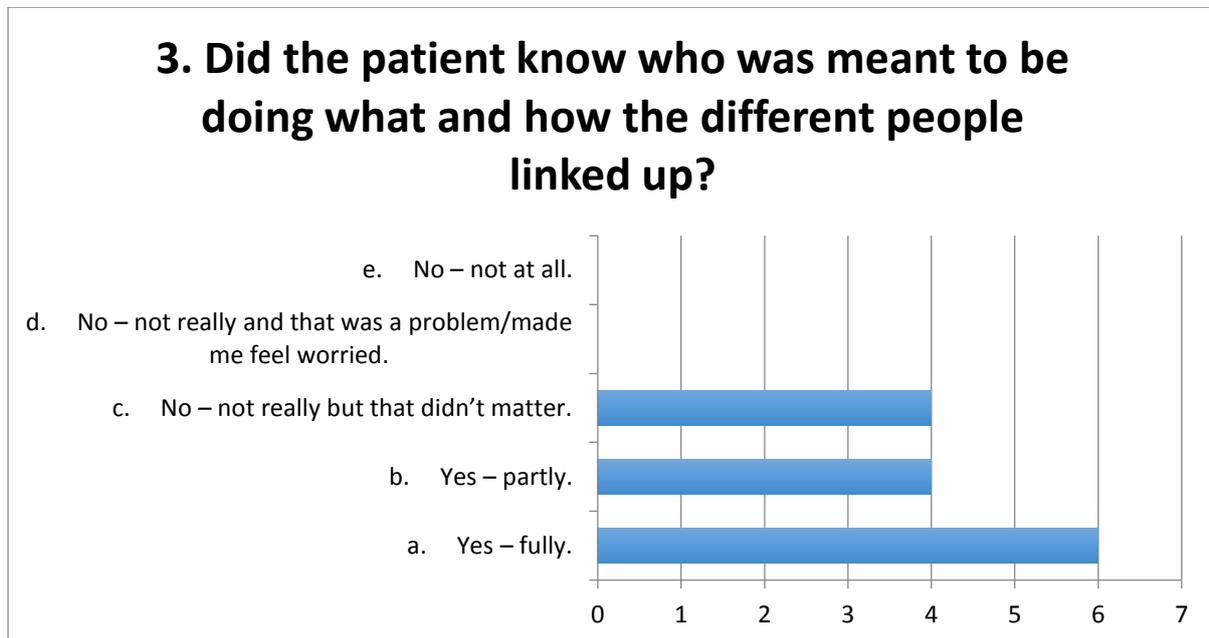


Chart 3 shows that that six of the sample of 14 patients felt they fully understood who was who among those who visited their home after discharge from hospital. A further eight either partly understood or did not feel they needed to understand.

“They told me who they were and what they were tasked to do. The team all knew each other and worked well together.”

“It felt to me like it was a tight knit group that worked well together.”

However, several interviewees made comments that were contradictory during interview.

“When they came round after I got back from hospital – what were they here for?”

“They told me that somebody was coming to see methey didn't say why.”

“I thought they were very good but I didn't know how to use them.”

e. Did the patient know who to contact if something went wrong?

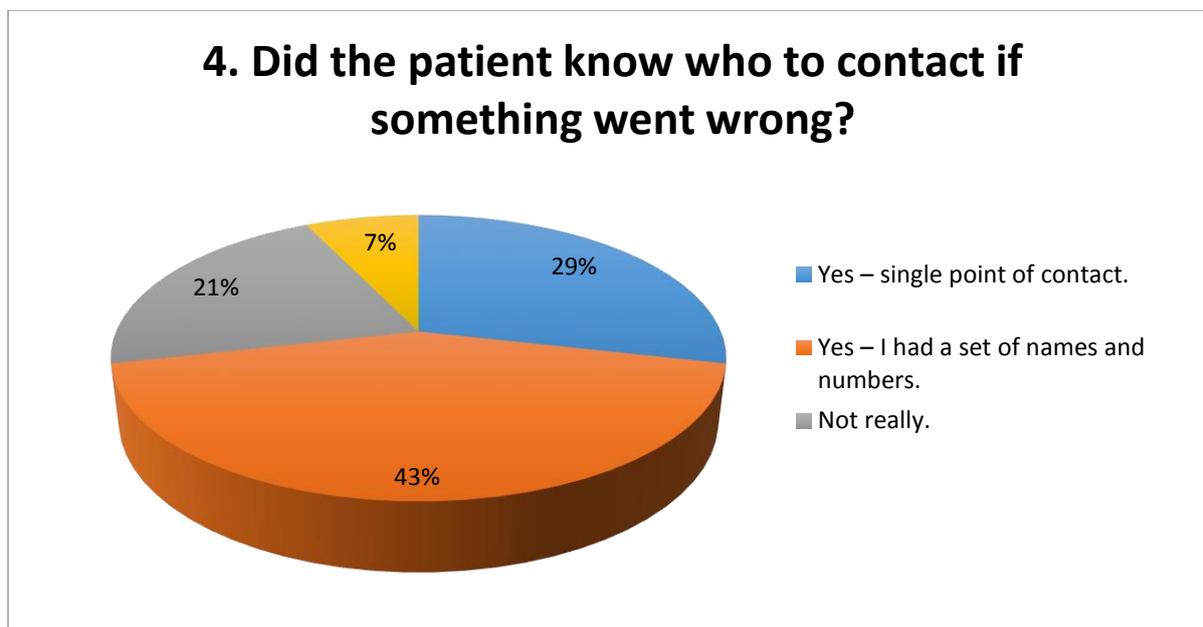


Chart 4 shows that nearly three quarters of patients reported they were given contact names and numbers although only 29 per cent were confident they had one single point of contact. A further 21 per cent said they just tried to get in contact with whoever they thought best - often their GP. One person said they did not have any idea who they should contact.

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. In cases where patients reported they had a set of names and numbers (43%) there were several examples given where telephone calls had not been answered or the patient did not know which name or number to ring. This was a cause of frustration and in some cases caused anxiety and confusion.

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.

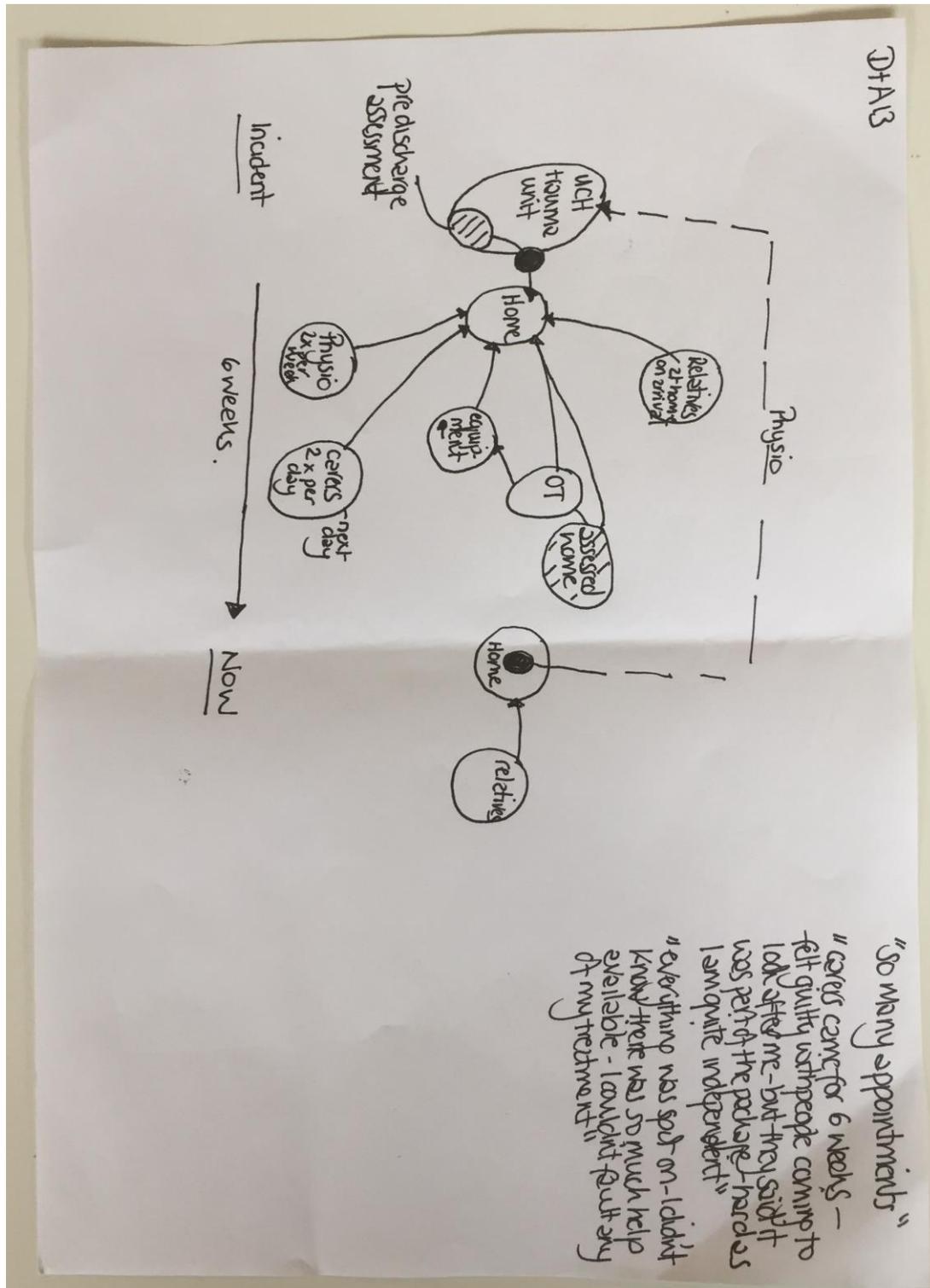
Acknowledgements

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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 under Discharge to Assess.

Mind map: Patient DtA13



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