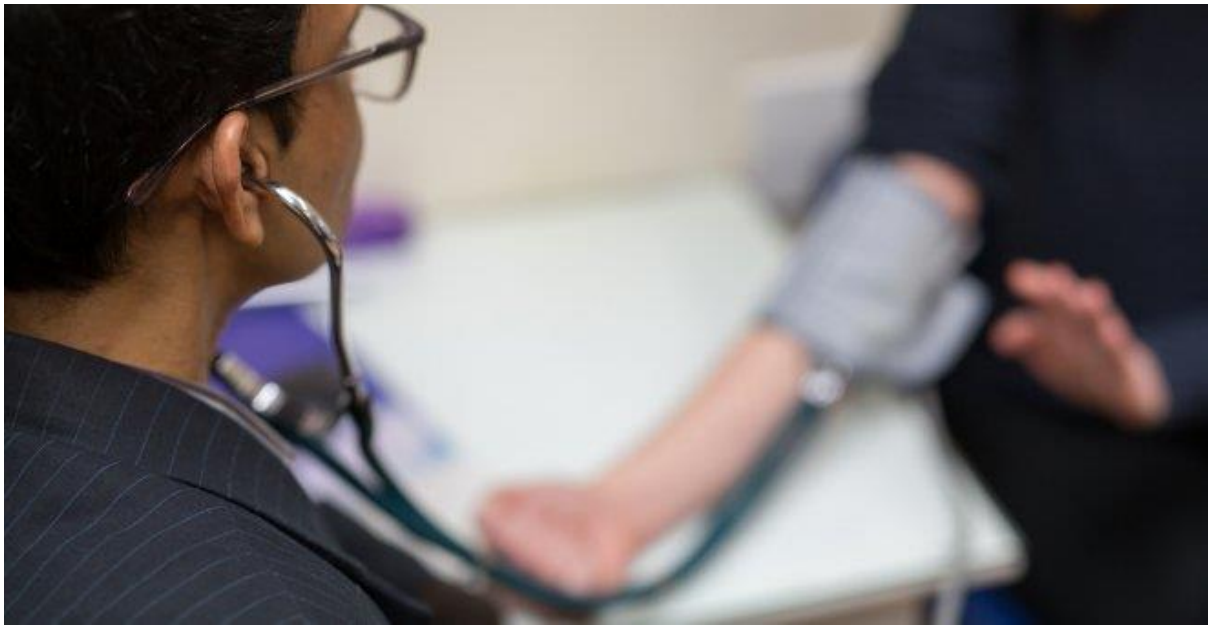
# Experiences of Camden patients attending the Royal Free Hospital or University College Hospital for outpatient appointments

February 2020



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## Introduction

Healthwatch Camden often hears anecdotal reports about poor patient experiences of hospital outpatient appointments. We wanted to better understand the patient experience starting with a GP referral right up to the day of the hospital appointment. Over three weeks in spring 2019, we interviewed Camden patients in the outpatient clinic waiting areas at both the Royal Free Hospital (RFH) and University College Hospital (UCH). We asked patients about booking their appointment, how they were informed about the appointment and about whether things went smoothly for them up to arrival at the clinic on the day of interview. We also spoke with NHS staff to explore the challenges they face in organising appointment bookings. We explored one patient case in detail, matching their experience against the experience of the NHS administrators who were handling that appointment booking (see case study, Annex 1, on Page 25.)

Healthwatch Camden interviewed a total of 153 patients who had been referred by Camden GP practices — 81 at the RFH and 72 at UCH. We interviewed patients in a wide range of clinics but the largest numbers or responses were from patients in orthopaedics, rheumatology and dermatology clinics. (See Method section on page 23 for details.)

## Aims

- To learn about the experience of patients referred by Camden GP Practices for a specialist outpatient appointment at Camden's major hospitals.
- To hear from patients about the utility of that appointment from the patient perspective.
- To understand how challenges and complications arise in the systems for outpatient appointments.
- To identify areas for improvement.

## Summary

The great majority of the patients we interviewed had a fairly straightforward experience of referral from their GP to a specialist hospital outpatient appointment. Although long waits were common, most patients were offered an appointment which was not cancelled or changed, were content with the communication about the appointment and were pleased with the appointment itself. However, in the minority of cases where complications had arisen, these had often been serious and were highly frustrating with potential impact on patient wellbeing.

Although there are reasons for variation in the systems and processes by which appointments are made and patients are informed, these are not well understood by patients. Being unclear how your appointment will be made, by whom, and how you will hear about it can cause unnecessary anxiety.

The majority of patients reported that communication around their outpatient appointment was clear and simple. However, in the cases where communication had gone wrong, patients reported that things had gone very wrong.

While the appointment booking system is designed to offer patients a choice of time and date, less than half of patients experienced any choice in scheduling their first outpatient appointment.

Our interviews exposed a striking gap between what patients had been told during their appointment and their ability to recall, understand and act on that information immediately afterwards. There are many reasons for this. It is easy for those who are familiar with a system and the environment in which they are working to assume this understanding in others. Patients, on the other hand, are often unfamiliar with how things work and are stressed by the hospital experience which further hinders their capacity to understand and act on information given. This failure of "information prescribing" by hospital doctors creates stress for patients and inefficiencies for the hospital following the appointment.

Patients reported very high levels of satisfaction with their specialist appointment immediately after seeing the specialist (usually a consultant or registrar). Although our interviews were not designed to test this theory, the responses indicated that patients place very high value on direct contact with a senior clinician and the reassurance this provides. Our findings suggested that this high regard for specialist clinicians is not always fully rational (for example, a significant number of patients reported full satisfaction with their clinician despite also reporting contradictory evidence of poor experience). Although reports of complications around outpatient appointments usually appear to relate to administrative functions we heard some evidence of the contribution clinicians can make to poor patient experience and to system errors (for example, through poor information prescribing). However, the patients that we interviewed were inclined to blame the administrators.

Follow up appointments represent a large proportion of available hospital outpatient appointments. Pressure on outpatient appointments could be eased by reducing the number or regularity of follow up appointments with consultants and registrars. However, patients will continue to need ongoing reassurance. Any replacement mechanisms for offering patients follow up reassurance will need to be mindful of strong patient preferences for appointments with people who they recognise as senior clinicians.

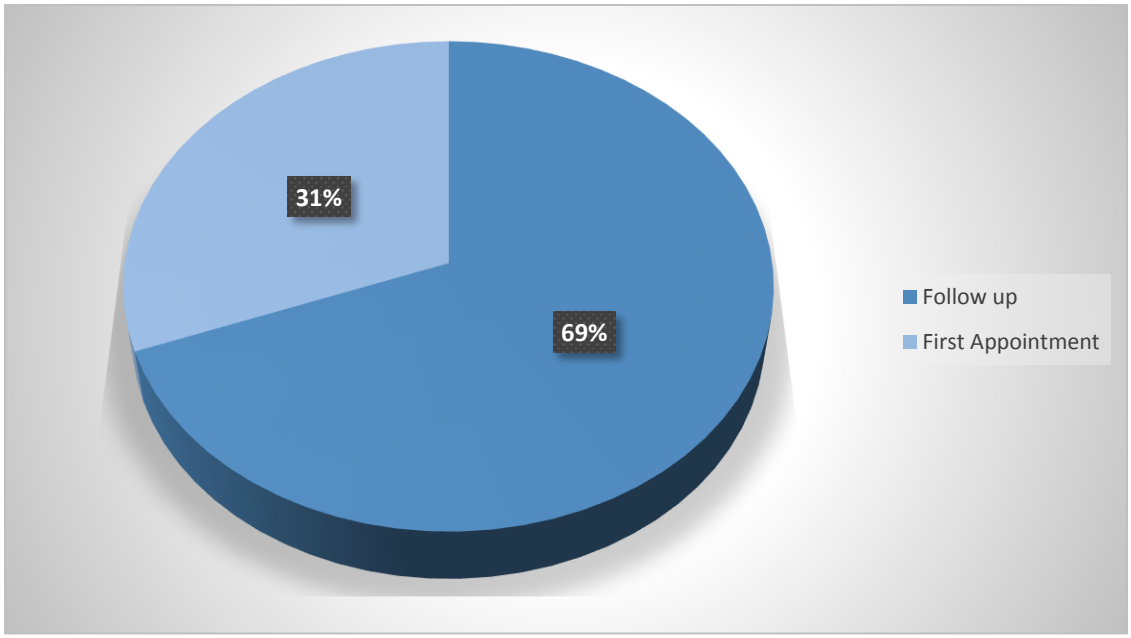
For recommendations see page 21.

## Findings

### a. The majority of outpatient appointments are for follow up

Among those we interviewed, only one third of the outpatient appointments was for a first consultation. The majority of patients were attending follow up appointments. This was roughly the same at both hospitals and across all days and clinics. UCH had a slightly higher proportion of follow up appointments (71%) compared to the RFH (68%).

**Figure 1:** Patients attending first appointments compared to follow up appointments (totals - RFH and UCH combined)

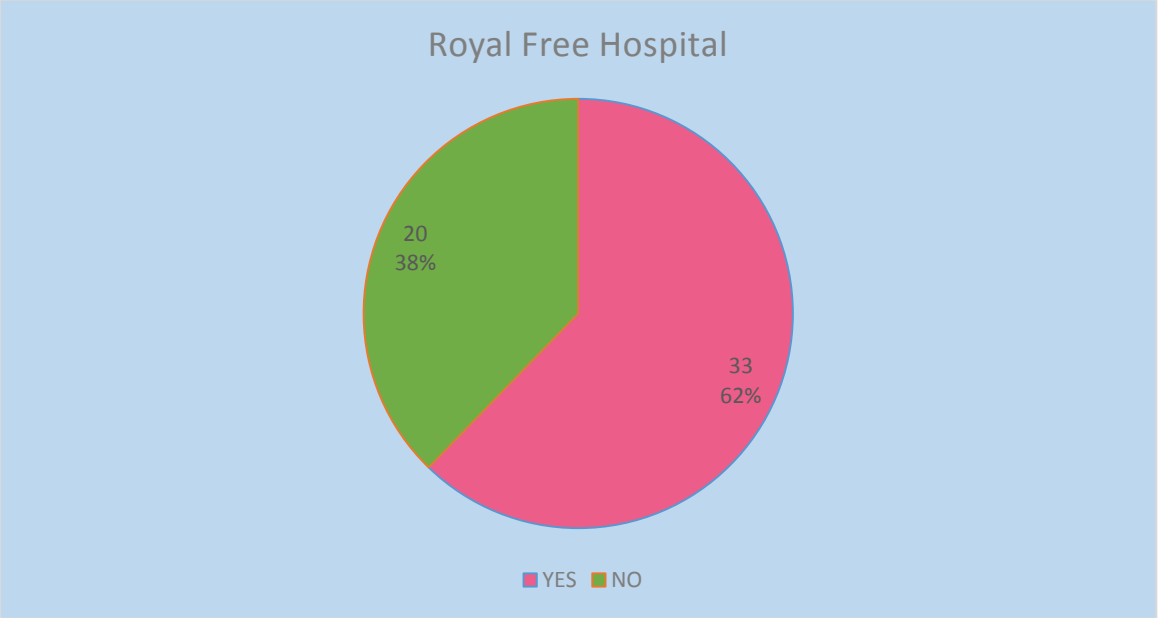


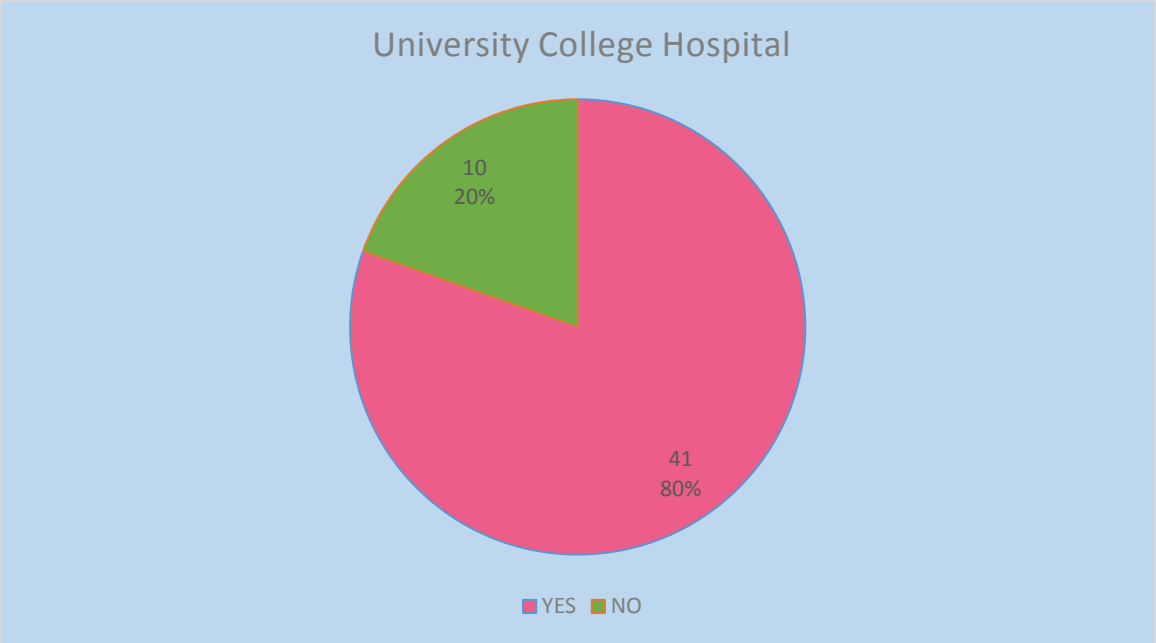

We spoke to patients before they were called in to see the specialist and then again when they came out of the meeting. Out of the total sample of 153 patients, 105 were available to answer the post-appointment questions. Among these, the majority had been instructed to make a follow up appointment. The number was significantly higher at UCH than at RFH. Out of 53 patients at RFH, 33 had been asked to book a follow up appointment at the same clinic (62%). At UCH, 41 out of 51 patients had been asked to book a follow up (80%). (Note: one patient did not answer this question.)

*"I went to another hospital where they discharged me. At UCH I have had regular follow ups. The follow ups give me confidence that if I need any help I can just come back."*

Although patients clearly value follow up appointments, we noted that such a high rate of follow up appointments must contribute to pressure on the availability of outpatient appointments and be a factor explaining long waits for a first appointment following GP referral.

**Figure 2.** Were you instructed to make a follow up appointment? (The chart below shows the number and the percentage of patients at each hospital instructed by their clinician to make a follow up appointment.)



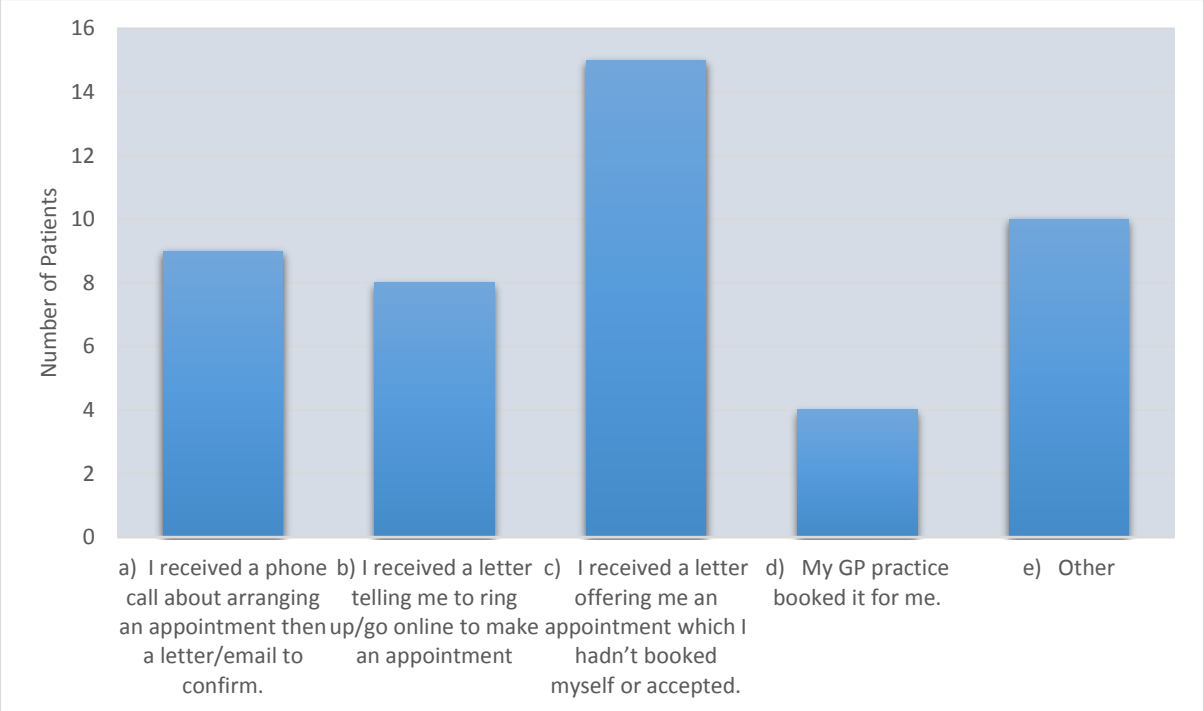
### b. Outpatient appointments are booked in a variety of ways

We heard about variations in the process and systems for booking and communicating with patients about their appointment. Among the 47 patients who were attending a first appointment, 17 said their booking had involved some choice. (Note: one patient did not answer this question.) These patients had either received a phone call to organise an appointment in discussion with them or they had received a letter inviting them to book an appointment to suit them. Fifteen patients had simply received a letter with a pre-allocated time.

*"I got a letter giving me an appointment time that I hadn't chosen or agreed. The time is not good for me and I would have chosen a different time if I could have chosen."*

*"I wish I could have had a choice about what time to come. It's very important to me not to have to travel at busy times."*

**Figure 3.** How was your appointment booked? (Patients attending first appointments only)




Patients reported inconsistencies and inefficiencies in the systems for bookings and appointment reminders for both first and follow up appointments.

*"Sometimes they ring you to ask if you'd be okay with the time and sometimes they just send a letter with a fixed date and time. It's very inconsistent with UCH and I would prefer if I was always asked my preferred availability."*

*"The letter only arrived the day before the appointment"*

*"The letter got delivered to a neighbour and by the time I received it I had missed the appointment date."*

*"I usually receive a text message to confirm but that wasn't the case this time."*

*"When I tried to change appointments over the phone I got letters saying I missed my appointment. That makes me feel annoyed."*

*"When you want to change your appointment you often have to stay on the phone for an hour or more."*

*"The phone line to change my appointment at UCH was not being answered - not for four days!"*

*"I was ill on the day so I tried to reschedule my follow up appointment at the RFH. I couldn't get through on the phone - it was a huge call waiting queue. So I rang the clinic who told me to come in today. There's no systems for people being ill on the day of the appointment."*

*"You make a follow up appointment when you are here and it's for ages in advance and then often a few weeks before you get a letter saying it's cancelled which is frustrating."*

*"I got a text to remind me. It's always good to have a reminder and you can cancel so that's good."*

Generally patients did not understand the complexities of the different routes via which their appointment may have been booked and this added to the sense of confusion and inefficiency about which some patients complained.

*"It feels like there may be more than one system involved in making appointments."*

*"When you get to the right person you get treated very well but I get fed up with all the muddle with these outpatient appointments."*

*"The process isn't clear."*

We noted a small but significant number of similar cases (5) in which patients reported difficulties around their referral and specified that their referral had been via the Camden MSK service.

*"The Camden MSK service is clumsy. No one got back to me and I was not sent to the correct specialist. In the end I had to go back to my GP and start again."*

*"The MSK service is a black hole."*

We noted that the system for booking follow up appointments works more smoothly than for first appointments. Most of the patients we interviewed who were attending follow ups had either made the appointment at the clinic reception desk at the time of their previous appointment (and had then received a confirmation letter) or they had been sent a letter following the previous appointment. Some of these patients had experienced frustrating cancellations but because they were already "in the system" they were more confident about what to do or who to ask when things went wrong with scheduling a follow up appointment.

*"Once you're in the loop it's not so bad."*

In the example below, the patient was able to resolve the issue directly with the hospital despite the complications:

*"I got an appointment at UCH for follow up. Then they cancelled it and gave me a date I couldn't make. I called and after some trouble got another. Then they sent me a letter saying I had missed an appointment (which I had never done) so they said I should go back to the GP for a new referral. I managed to call and they told me to ignore that letter."*

However, in some cases, follow up systems failed and patients got lost in the system.

*"The consultant asked that I see him again in one month but that never happened — I wasn't put on the list."*

We also heard from patients who had taken matters into their own hands. In some cases this hurried things up and got the patient the answers they needed but in others it introduced further inefficiencies.

*"The consultant wanted me to have an appointment in one month but I didn't hear anything so I emailed the consultant to get an appointment. I got one but somehow I got put on a different consultant's list by mistake and then I wasn't put on the list for a follow up and the treatment requested was not booked. Then I went to book online and the system didn't recognise me so I had to speak to the desk."*

*"My son called the number on the appointment letter just to confirm as we had no trust that it would be correct. Our fears were justified. He was told they didn't know anything about it. Then he was passed around and someone else told him the date was wrong or had been changed and also that the letter had been*

*sent out wrongly by the automated system. I was given a new date. On that date I came to UCH but on arrival was told it was the wrong day. Their computer was showing a different appointment date to the letter in my hand."*

*"I booked via the consultant's secretary directly."*

*"Because we know how the system works we know to speak to the secretary – they are the ones with power. You need to know where to go and who to speak to."*

*"My tip to other patients is do not give up or put the phone down until you get what you need."*

We heard many complaints about long waits between GP referral and first hospital appointment.

*"Waiting times are a pain but the referral is overall pretty good."*

*"My GP said I'd have to wait 6-8 weeks but I've waited 5 months."*

### c. From appointment confirmation to arrival at the clinic

Once patients had been given a hospital outpatient appointment (either first or follow up), the majority went on to attend the appointment as scheduled without any changes or complications.

*"It's always been really straight forward and I've never had any problems."*

*"I think the process is really good. I'm really pleased."*

However a significant number (39 out of 152 interviewees who answered this question) did experience changes being made to the appointment arrangements prior to attending the appointment on the day of interview. Some of these changes were made by the patient themselves. Others involved a cancellation and re-booking.

*"I missed the appointment this morning but they rescheduled me immediately for this afternoon. It works smoothly and easily."*

*"I received the appointment letter after the appointment date so I missed it. I felt guilty."*

*"I had an appointment last week but when I arrived it was cancelled. The receptionist said they'd sent me a letter which was probably true."*

*"It's very difficult to navigate. In today's age sending lots of letters is not the most efficient way of doing things."*

*"I went online to get an appointment – a long way ahead. Then got a letter cancelling. I phoned the number on the letter and got another appointment. Then last week that was cancelled. I phoned and got the appointment today."*

Half of those cases in which there had been a change to the original scheduled appointment experienced very severe disruption, confusion and delays. (See Figure 4 "*It was more complicated*".)

*"I had to follow up with UCH myself. I was ringing everywhere to chase the results. It wasn't clear who to call. I was on the phone for 2 hours last week just trying to find out who to call. Then they rang and said there was an appointment today but we didn't know where. I rang them and couldn't get any information. I spent so much time on this and I am someone who knows the system. I am a GP!"*

*"I had a scan and the doctor at UCH said I needed another appointment. I waited 10 days thinking they'd arrange it. Then I called my GP to follow up and was told I had to make the appointment myself and they gave me the number."*

*"My first referral to the RFH was about 2 years ago. It was cancelled with no explanation. Then it was rescheduled and cancelled five times and each time I had to go back to the GP."*

Among patients who had a poor experience, many associated the failings with the administrative system, not the clinicians.

*"I do have the feeling that the clinicians are brilliant but the admin side sometimes lets them down."*

*"The hospital doctors apologise for the system – you see it's ridiculous!"*

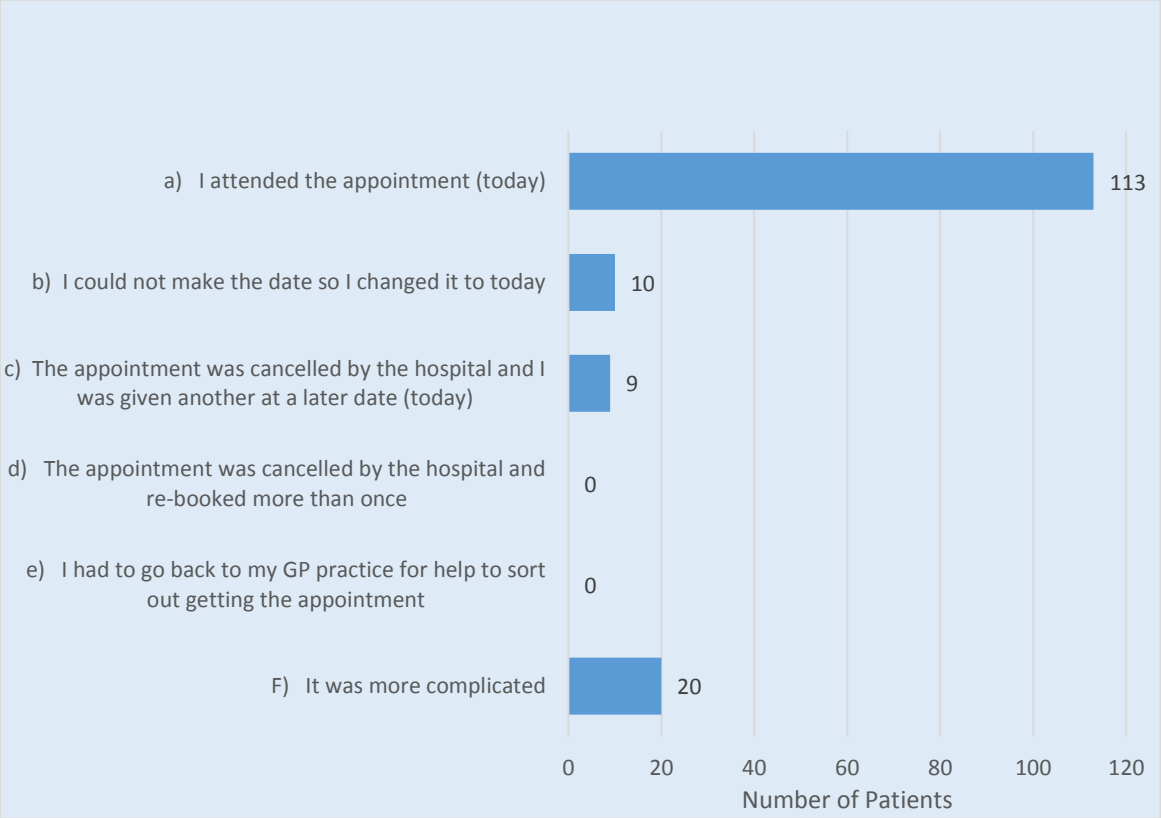
*"It's just disorganisation in the administration. They are constantly making mistakes."*

However, responses to our later questions to patients after seeing the clinician did indicate that there are cases where clinicians (including GPs and hospital specialists) may play a role in contributing to administrative or other inefficiencies.

*"They all passed me back and forth. One consultant wanted me to go back to the other speciality consultant and tell them they had made the wrong diagnosis. It's absurd that the patient should be the go-between between two clinical services. What seems to be lacking at UCH is a multi-disciplinary approach to services."*

*"If they had read the notes at the last appointment they might have reached this decision earlier but it has taken a further appointment."*

**Figure 4.** What happened after the appointment was given?




### d. Patient satisfaction with their appointment

Ninety-three out of 105 patients (over 90%) who talked to us after their appointment reported that it had been useful in getting them the care or treatment they needed.

*"The whole process is smooth, reassuring and carried out in a confidential manner which I think is important."*

*"I've been a patient for a long time so the staff at UCH know me and there's a kind of warmth."*

*"Everything about the NHS has been spectacular! I can't tell you how glad I am I'm not still living in the USA."*

*"Since I've been coming here to the RFH I've had no problems."*

*"Everything went smoothly. I do not speak English but they found an Arabic interpreter for me."*

There were some exceptions:

*"It feels rushed. I can't think of what I need to say until after I get home."*

*"It was a waste of time. I waited for 3 hours to see him for 10 minutes."*

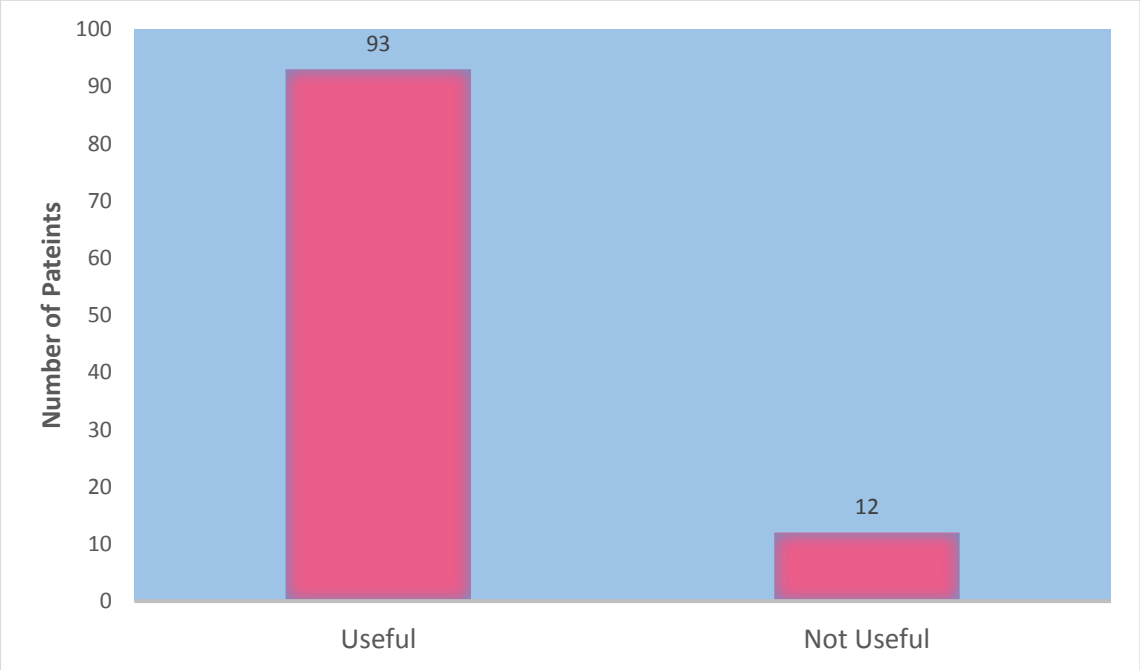
*"Why was I sent to the wrong place? It's careless. There's a disengagement with the patients."*

*"I should have been sent to take a test instead before seeing the consultant so the appointment was a waste of time."*

*"When the doctor arrived he said "When were you last here and what can I do for you?" It seemed as if we were starting from scratch! It made me lose confidence."*

*"The doctor gave us a piece of paper for 3 tests. We went to the place for the first one but they said "oh no not here anymore they have used the old referral slip". So they sent us somewhere else. We traipsed round the RFH. I'm exhausted!"*

**Figure 5.** Was your outpatient appointment useful?




As a supplementary line of inquiry, we were also interested to know whether patients attending appointments found they were seeing the specialist or clinic

that they had expected and whether, after the appointment, they felt they had seen the appropriate person to provide the care or treatment they needed.

While waiting to go into the appointment, about 90% of the patients we interviewed told us that their appointment was with the clinic or specialist they were expecting (RFH 88%/UCH 92%). Among those we talked to afterwards, almost all reported that they felt they had seen the right specialist.

There were a few exceptions. One interviewee told us *"I haven't seen my actual consultant for ages. I don't know how to get to see him now. The clinic is so busy."*

Another said *"I came because of chronic back pain but the doctor just spoke to me about my hand (I'd had a slight problem with my hand previously) but that wasn't main reason I was here."*

"I expected to see a consultant but it was a senior nurse."

For another patient their appointment appeared to have been booked in error.

*"I was seeing the wrong person so the appointment wasn't useful at all."*

We noted that some clinics kept patients waiting up to 3 hours or more in chairs. In the orthopaedics clinic at the RFH, some patients had to leave before being seen.

Some patients commented on a poor patient experience in the waiting room:

*"My appointment was at 8.45am. I saw the doctor arriving after 9am – he was all relaxed as if he didn't know what he was doing. It gives a bad impression. I am always kept waiting at UCH."*

*"When I came I sat waiting for an hour before they came out and sent me for an X-ray. When I got back I had to wait again. The X-ray could have been done while I waited before but the nurse said they don't get the notes enough in advance to plan ahead for the patients."*

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| Interviewer comment: At the UCH dermatology clinic based at Mortimer Market we noted that the environment was calm and positive. There were plenty of chairs and not too many waiting with the waiting time being short. There was help and advice offered by the duty nurse including drinking water offered to waiting patients. |

Overall however, the responses indicated a very high level of satisfaction among patients with their meeting with the specialist. We noted that even those who had reported poor experience leading up to the appointment nevertheless reported high satisfaction with the appointment itself, further evidence of the tendency of patients to place very high value on contact with senior clinical specialists.

*"He's really excellent so sometimes the appointments run a bit late. He makes you feel like a person."*

*"I've waited 7 months for the appointment but I'm relieved and so pleased. I've been very happy with the care and treatment I've had."*

One patient at UCH had been misdiagnosed and given an operation he did not need. There was miscommunication between different specialists and clinics and he was given incorrect or cancelled appointments several times. *"I kept being sent between different clinics and there were miscommunications."* Despite all this, the patient reported the appointment with the consultant that day as "*very useful*" and rated communication received about his outpatient referral and appointment at a 5 (meaning "clear and simple").

### e. Communicating with patients

We explored two specific areas of communication between patient and provider. The first was around the communication received by the patient related to organising their outpatient referral and appointment (i.). The second was about the communication during the appointment about next steps (ii.).

#### i. How would you rate the communication you have received about your outpatient referral and appointment?

We asked patients to rate the communication on a scale with 1 being "unclear and confusing" and 6 being "clear and simple". Relatively small numbers gave a poor rating (see Figure 6). However, we heard several reports of poor communication.

*"I turned up today at UCH to be told my appointment had been cancelled. We hadn't been told - unless it was one of those phone call press buttons which we don't understand. You can't understand anything and you can't speak to a person."*

*"Our only complaint is that we'd rather have a letter or someone speak to us. We can't even work our phones!"*

*"The automated phone system is so confusing. They want me to confirm my date of birth but if I put it in the wrong way it gets cut off. I did complain to the RFH about it but they said they couldn't change it."*

*"This letter is confusing. It sounds like it's the appointment for the operation but it's just with the doctor."*

*"The phone number for changing my appointment was not being answered for four days."*

*"There's a lack of communication overall."*

*"I don't want to slip through the net and have someone tell me it's my fault."*

*"I have lots of appointments to keep up with so I'd like the system to be smarter in terms of reminding and showing all the appointments."*

We noted that the number of interviewees who gave examples of poor communication exceeded the number who allocated a low communication score on the 1-6 scale question. This may indicate a tendency among NHS patients to feel grateful and positive about the service they receive even when they have some complaints.

*"They are doing their best."*

*"I'm so impressed with everyone who works in the NHS clinically but they can fall down on communicating with the patient."*

We heard a number of reports of poor communication between GPs and the hospital or the GP and the patient regarding the referral process.

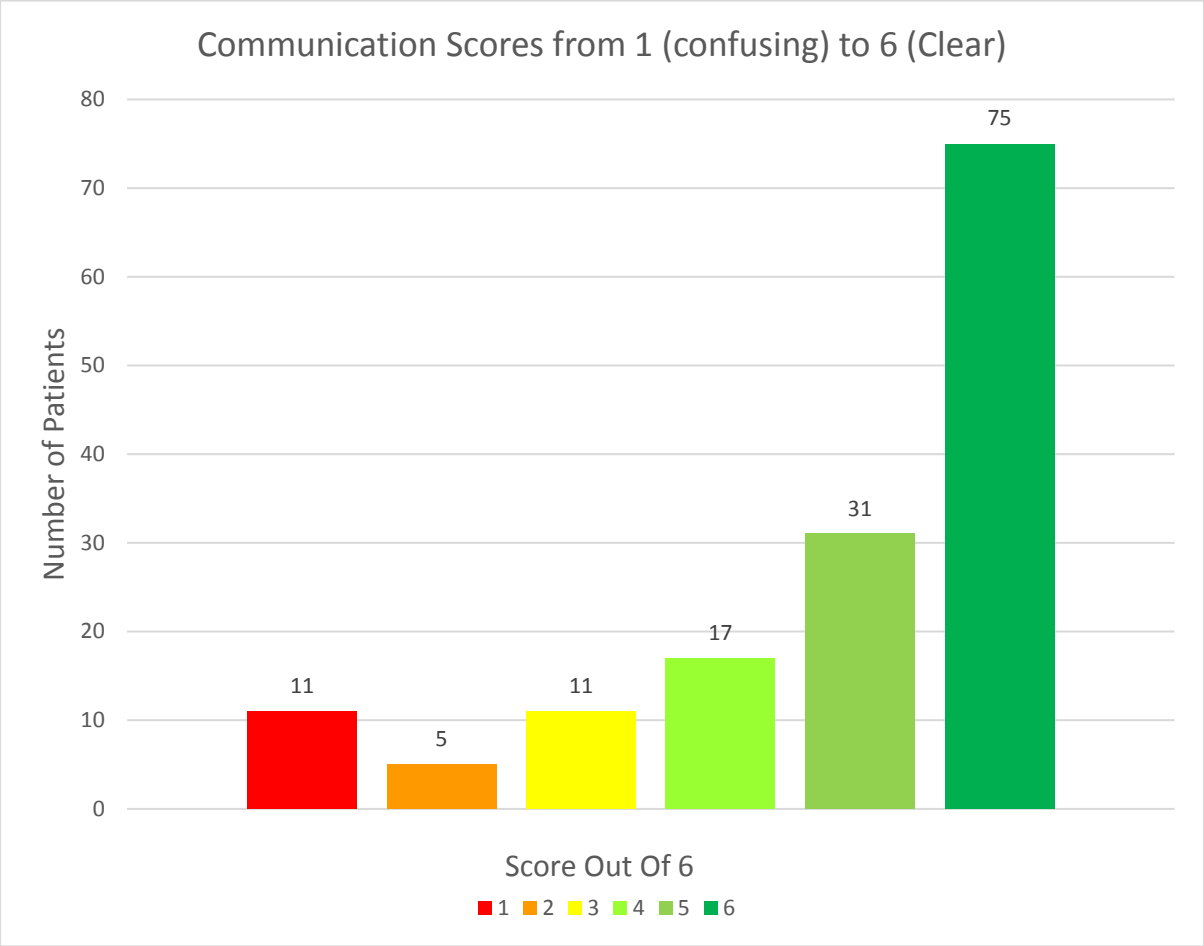
*"It was a little confusing. My GP wasn't clear with me about the process of getting the outpatient appointment and I wasn't clear how I would hear about it."*

*"When I was in recovery (I was feeling very out of it) they said they'd send the report with test results to my GP and they said "if they haven't got it tell them to email us". But my GP didn't get it. They had to email UCH to get it. Should it be my job to tell them that?"*

*"I saw two GPs at my practice. One has sent me back to the original surgeon at UCH but the other must have sent me to MSK and from there to the RFH and now they say I shouldn't be here. It's a bit of a mystery."*

*"I've had conflicting advice between the GP and the hospital consultants about medication and dosage. They should communicate."*

**Figure 6.** Communication between patients and providers




### ii. On leaving your appointment, do you know what will happen next?

Only 5 patients out of the 105 we interviewed as they came out of their appointment said that they did not know what would happen next. However, on further questioning, the responses of some patients who had answered "*yes - I know what will happen next*" became less clear.

*"Until I got out I thought it was clear but now I'm not so sure. I am confused.com!" RFH*

*"I don't know what to do now and the girl at reception didn't know either. The doctor didn't specify where to go about the injection or the blood test." UCH*

*"Yes I feel confident I know what will happen….. it's something about…….I had a thing…..they will look at me again in a year…..I didn't quite understand what she was saying." RFH*

*"I have a piece of paper. I can't remember what she [the consultant] said. There is somewhere else I have to go now to make a different appointment for something else." UCH*

*"I think I have to go to physiotherapy but I don't know who makes the appointment – whether it's supposed to be me or the consultant. He didn't give me a form so I suppose he's going to do it." UCH*

*"It all seemed clear but when I got out I realised I didn't know what I was meant to do next." UCH*

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| Interviewer comment: At 5pm, the reception desk in Clinic 5 at the RFH closed and all administrative staff disappeared. As the clinic was running late, patients continued to emerge from appointments clutching papers having been instructed by the clinicians to make follow up appointments "at the desk". A passing nurse advised the patients to leave their pieces of paper on the counter and that an appointment would be sent to them in the post. |

## Key Findings

- Almost all patients report finding the hospital outpatient appointment itself useful in getting them the care and treatment they need.
- Patients place very high value on contact with a senior clinician and the reassurance this provides.
- Many patients are confused about next steps following their outpatient appointment and have not fully absorbed or understood the information given during the appointment.
- There is a wide range of different systems and methods for hospital appointment bookings and communication about hospital appointments. Patients do not understand the systems which can add to anxiety in cases where things don't work smoothly.
- While the appointment booking system is designed to offer patients a choice, less than half of patients experienced choice in scheduling their first outpatient appointment.
- In a significant number of cases (slightly over 25%), things go wrong with bookings and appointment arrangements contributing to complex and stressful experiences.
- Poor communication between GPs and hospitals can contribute to poor patient experience.
- Communication around hospital appointment scheduling is often poor and points of contact for patients (such as phone numbers to call to reschedule or resolve problems) are unclear and often unresponsive.
- The challenges faced by the administrators (including CCAS, Camden MSK and GP practice staff) who are organising bookings contribute to poor patient experience.
- A significant majority of patients are attending hospital outpatient clinics for follow up, not first appointments, and the majority are asked to make a further follow up appointment.

## Recommendations

**RECOMMENDATION 1:** Medical directors at University College London Hospitals NHS Foundation Trust and at the Royal Free London NHS Foundation Trust should work with clinicians, administrative staff and patient groups to improve the clarity and consistency of written and verbal instructions given to patients (and their carers) during outpatient appointments.

***Why?*** *Significant inefficiencies are created for the system and unnecessary stress is created for patients as a consequence of confusion around instructions given during outpatient appointments for immediate next steps.*

**RECOMMENDATION 2:** Outpatient clinics should designate a clear "check out" desk for all patients to report to at the end of their appointment. Check out staff or volunteers should actively support patients to take the correct next steps (e.g. where to go for the blood test, which piece of paper is for what, how and when the patient will hear about the appointment for a scan etc.)

***Why?*** *While much attention has been given by NHS leadership to the management of patient flow into outpatients, the "check out" function appears neglected. This contributes to inefficiencies for the system and a poor experience for patients.*

**RECOMMENDATION 3:** Ensure all new or temporary clinicians are briefed on the systems relevant to that outpatient clinic (e.g. a one-page handout for all locums).

**Why?** *At the RFH and UCH, outpatient clinics are often staffed by locum physicians who may be unfamiliar with systems that vary between hospitals. This can contribute to patients being misdirected or misinformed about procedures for the next steps.*

**RECOMMENDATION 4**: The University College London Hospitals NHS Foundation Trust and the Royal Free London NHS Foundation Trust, with the Camden Clinical Assessment Service and Camden's GPs, must review, improve and standardise patient letters and electronic messaging about outpatient appointments.

A guidance leaflet for GPs to give patients, covering what to expect along the referral pathway and how to get what they need and want from their hospital appointment, should be developed as part of the above process.

The requirements of patients with communication support needs must always be met.

***Why?*** *For patients, confusion and anxiety is created by poor communication. This in turn introduces extra demands on the system as patients struggle to get a response or seek reassurance. Appointment letters in particular are often confusing with illogical or convoluted presentation of essential information.*

**RECOMMENDATION 5:** The University College London Hospitals NHS Foundation Trust and at the Royal Free London NHS Foundation Trust must ensure that any phone numbers issued to outpatients are correct, are correctly directed and are sufficiently resourced to provide patients with an appropriate response.

***Why?*** *Phone calls to numbers that are unanswered, misdirected, or answered by someone who gives out confusing or misleading information create inefficiencies and add to poor patient experience and loss of confidence in the service.*

**RECOMMENDATION 6**: The University College London Hospitals NHS Foundation Trust and at the Royal Free London NHS Foundation Trust partners should review and address the wide range of systems factors that contribute to poor patient experience and inefficiencies around outpatient appointments including:

- Multiple appointment bookings that are not smoothly coordinated;
- Hospitals replacing appointment slots in e-Referrals (online booking system) with internally booked triage services (limiting availability and choice through eRS);
- The hospital trusts holding incorrect or inconsistent patient contact details;
- Late notice or failure to notify patients of changes to appointments;
- Insufficient investment in administrative functions and insufficient support for administrative staff.

***Why?*** *Reducing variation in the outpatient system will increase the numbers of patients who can obtain a first outpatient appointment that suits their needs leading to fewer "Did Not Attend" and a better patient experience. It will also reduce the number of cases in which things go wrong. When things do go wrong, the system needs to be flexible enough to respond well. Good administration systems and staff are essential to making outpatient appointments efficient.*

## Method

Interviews were conducted with a total of 153 patients – 81 at the RFH and 72 at UCH.

Interviews were conducted by a team of researchers comprised of Healthwatch Camden staff members and volunteer researchers who were Masters students at University College London.

With the agreement of both hospitals, research teams were on site at RFH and UCH at random times over two full weeks. Interviews were conducted with patients who were waiting in the following clinics:

Trauma and Orthopaedics (52 interviews); Rheumatology (28 interviews); Dermatology (19 interviews); Ophthalmology (15 interviews); Cardio (10 interviews); Gastro (5 interviews); Vascular (5 interviews); General Surgery; Thoracic; Endocrinology; Colorectal; Hepatology; Bariatric; Diabetes; Haematology; Cardiology (all fewer than 5 interviews).

(With guidance from hospital staff, the research team avoided conducting interviews in clinics where patients were likely to have been referred via the fast track "2 week wait" pathway.)

Every patient waiting in the clinics was approached by an interviewer. Each person was first asked if they had been referred by a Camden GP practice. If the patient was not registered with a Camden GP the interview did not continue. Every patient from a Camden GP was invited to participate in the interview. 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.

Because we interviewed every waiting patient from a Camden GP, our sample included patients from a range of backgrounds including some for whom English was not a first language, patients with disabilities and those with caring responsibilities. However, the research did not seek to explore factors related to equality and diversity and information on protected characteristic was not collected. In cases where the patient required a translator, these patients were often accompanied at the clinic by a friend or relative who had come to translate for them. In these cases the interview was conducted with the help of the translator.

Our in depth case study (Annex 1) interviewee was selected in cooperation with the Camden Clinical Assessment Service (CCAS) who sought permission from the patient to be contacted by Healthwatch Camden for interview and for permission to share information held by CCAS on the administration of the appointment.

The interview included two sets of questions, the first of which was designed for patients waiting in chairs prior to their appointment and the second of which was designed for the same patients on return to the waiting area after their appointment. Of the 153 patients who completed the first part of the interview, only 105 also completed the second part as many needed to leave immediately.

The research used one-to-one in depth interviews. Interviews were structured using a combination of multiple choice and open-ended questions. Free comment around all the questions was encouraged and recorded. A maximum of 45 minutes was allocated per interview. Actual interview times ranged from 30 minutes to 50 minutes per interview. Responses were recorded using hand-written notes with effort made to capture direct quotations. Interviews were then coded to ensure anonymity. The responses were reviewed and the commonly occurring responses and themes were identified to create a reporting framework. Each interview was then analysed using the reporting framework.

See Annex 2 for the questions used to structure our interviews.

## 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.

## Annex 1: Case Study – an outpatient appointment for Ms LB

**This case charts the experience of the patient, Ms LB, alongside the experience of the Camden Clinical Assessment Service (CCAS) as they worked to book the appointment for the patient.**

**Ms LB**: *I attended a GP appointment as I was experiencing light-headedness. I was sent away but my symptoms persisted. A further GP appointment (with a different GP) resulted in a referral to neurology. The GP told me that I would receive communication about booking an appointment.*

*I then received a letter inviting me to call to make an appointment. I called the number on the letter. On the call "they" (CCAS) asked me for my preference of hospital and I chose UCH. The call handler did not offer an appointment time but said they would make an appointment for me and that I would be informed.*

**CCAS**: *Having received the referral from the GP, we contacted Ms LB on 28th November 2018. We offered a choice of hospital and the patient asked for UCH.*

*The University College London Hospitals NHS Foundation Trust (UCLH)/National Hospital for Neurology & Neurosurgery (NHNN) service on e-Referrals (eRS) is a 'Triage Service' which means that UCLH do not put their available appointments on the system. Instead, we send referrals to them via -eRS and the hospital books the patient an appointment.*

*On 5th December 2018, UCLH/NHNN state in email correspondence to us that a letter was sent out on the 5th December 2018 to the patient to inform them of the appointment booking for the 12th February 2019.*

**Ms LB:** *Then I waited, hearing nothing, for several months.*

*Finally I made a call direct to the appointments line at UCLH using a number I found on previous correspondence from another matter. I explained that I wanted to know whether I had been given an appointment. They checked while I was on the phone and confirmed that an appointment had been made for me. They told me the date which I noted down but they didn't have a time. I still received nothing in writing nor any further details. So I had the date but not the time of the appointment.*

*I then rang CCAS so ask for the time of the appointment. They gave me the time and place. They said it would be at the Hospital for Neurology in Queen's Square. I called CCAS again a couple of days before the appointment to double check and confirm.*

**CCAS:** *We received a call from Ms LB asking for clarification about the time and location of her appointment as she had not received a letter from UCLH. The operator Ms LB spoke to when she called us found the details that UCLH had*

*inputted into the e-Referrals system which at that time was their Queen's Square location.*

**Ms LB**: *On the day I arrived early for the appointment time at Queen's Square. I was sent upstairs but, after some waiting, was told the appointment was at a different location. They said I was in the wrong place and that I needed to get to Cleveland Street. Travelling to the correct location would mean I would be late, despite having arrived early. I noted that from the reactions of the staff at Queen's Square that they had experienced similar mis-directions before.*

*I asked the Queen's Square staff to call ahead to the Cleveland Street clinic to explain that I was on my way and would be late. I also called CCAS to ask for clarification. The CCAS call handler was apologetic but confirmed that Queen's Square was the appointment address they had been given. He offered to also ring Cleveland Street to explain the mistake and ensure I was expected.*

**CCAS:** *We received the call from Ms LB who was distressed that she had reported for her appointment at Queen's Square only to be told she should be at Cleveland Street. The team leader called and emailed UCLH staff to try explain the address was incorrect on the letter and that the patient was on their way.*

**Ms LB:** *On arrival at Cleveland Street, I stood in the queue and when I reached the front I was told I must see the Manager. The manager confirmed they had received a call to say I was on my way and then I was sent through to a waiting room. In the waiting room a nurse noted that the consultant was running late and commented that they would not even be aware that I had arrived late so not to worry. However, apparently the manager had informed the consultant that I was late so he was in fact aware of the situation. When the consultant came out he refused to see me on the grounds of late arrival. Witnesses in the waiting room were shocked.*

*I called CCAS again to tell them what had happened. CCAS said they would make a new appointment. The new appointment was for a month later.*

**CCAS:** *We made a complaint on behalf of the patient and managed to get UCLH to give her an earlier appointment on the rescheduling. The initial one they offered was a couple of months away.*

**Ms LB:** *At my appointment one month later the doctor referred me for an MRI. He gave me a form to take to the reception desk on leaving the consultation. The receptionist said they would contact me with an appointment date.*

*[At time of interview] I still haven't received any communication about a date for an MRI (it's now 2 months later). I have received a copy of a letter sent by the consultant to my GP to explain that he has assessed me and referred me for an MRI.*

## Annex 2: Interview questions

Interviews were structured using the following questions:

NAME:

DATE:

HOSPITAL:

OUTPATIENT CLINIC:

(NOTE: depending on clinic may need to confirm speciality.)

INTERVIEWER NAME:

1. **Were you referred by a Camden GP practice?**

   If yes, which practice?

   If no – do not proceed with interview

2. **Did you have to come to hospital for tests before your GP could refer you?**

- Yes/No

  If yes, did that go smoothly?

3. **Is this your first appointment or are you returning for follow up?**

- First appointment (go to question 4)
- Returning for follow up (go to question 5)
- Not sure (go to question 4)

4. **Once your GP made the initial referral, how was the appointment booked for you?**

a) I received a phone call about arranging an appointment then a letter/email to confirm.

b) I received a letter telling me to ring up/go online to make an appointment.

c) I received a letter offering me an appointment which I hadn't booked myself or accepted.

d) My GP practice booked it for me.

e) Other

**5. If this is a follow up appointment, how was today's appointment made for you?**

a) I made the appointment at the desk when I was here last time.

b) I was sent a letter/text/email following my last appointment.

c) Other

**6. Was this what you expected to happen based on what the GP told you?**

- Yes/No

  If No – please tell us what the GP told you would happen and how that was different.

**7. When you got the appointment, was it with the clinic or specialist that you were expecting?**

- Yes/No

If No, any further comment?

**8. Once you had been given an appointment, please choose from the following options to describe what happened next.**

a) I attended the appointment (today)
b) I could not make the date so I changed it to today
c) The appointment was cancelled by the hospital and I was given another at a later date (today)
d) The appointment was cancelled by the hospital and re-booked more than once
e) I had to go back to my GP practice for help to sort out getting the appointment
f) It was more complicated……. If so please explain (free response – interviewer to gather as much detail as possible about the individual case story)

**9. On a scale of 1 – 6 (with 1 being unclear and confusing and 6 being clear and simple), how would you rate the communication you have received about your outpatient referral and appointment?**

1 2 3 4 5 6 (circle)

**10. Any other comments you would like to make about your outpatient referral?**

***Would you be willing to talk to us again when you come out of your appointment today and tell us a little bit about it?***

On coming out of the appointment…….

**11. How was your appointment?**

a) Useful in getting me the care or treatment I need
b) Not useful

**12. Do you think you were seeing the right specialist to provide the care or treatment you need?**

- Yes/No

**13. Do you know what will happen next?**

**14. Have you been asked to make a further appointment?**

- Yes/No

Would you like us to send you a copy of the report when it is published? If so, please give us your email address or a postal address if you would like a hard copy.

Email:……

Postal address:……

Would you like to be added to the Healthwatch Camden mailing list to receive our newsletter and other updates?

- Yes
- No

## Annex 3: Responses to Recommendations

Healthwatch Camden has statutory powers (under the Health and Social Care Act 2012) to make recommendations to those bodies that are responsible for policy or for commissioning or providing health and social care services across Camden. In accordance with regulations, those bodies are required to respond formally and in public to any recommendations made by Healthwatch Camden.

The recommendations in this report are addressed to the Royal Free London NHS Foundation Trust and the University College London Hospitals NHS Foundation Trust. Recommendation 4 is also addressed to the NHS Camden Clinical Commissioning Group (the body with responsibility for commissioning health services for Camden's residents).

We convened a meeting between these bodies and other stakeholders to discuss a draft of this report. Those discussions contributed to the formulation of the recommendations to which we subsequently requested a formal response. The formal responses are set out below in full.

Healthwatch Camden thanks both Trusts and the Clinical Commissioning Group for their constructive responses and their commitment to collaborative efforts to improve experience for patients.

## 1. Response from University College London Hospitals NHS Foundation Trust

We would like to thank Healthwatch Camden for the excellent and systematic work to develop this report, and we welcome the important findings within. It is particularly powerful to see the quotes and the direct views of patients come through so clearly.

The report is very timely, as we work towards the development of a transformation programme for UCLH around outpatients and administration. The important issues identified will underpin the work we do to make significant improvements to the way we work in the coming year, as well as more structured long-term improvements.

One significant change since the research was undertaken is the introduction of Epic, our new electronic record system, replacing numerous paper systems and over 150 separate computer systems. This has been both a significant challenge to deliver, but which now allows major opportunities for much better patient communication, bookings and clinical care, which is already delivering positive results. Patient involvement has been part of the development of Epic, to ensure that we respond to their priorities, including the patient portal.

We were pleased to see the positive feedback around the experience of the appointment itself, and the quality of clinical support. However, a significant part of the findings relate to cases of poor experience relating to administration of appointments including lack of booking choice, errors, communication challenges and problems with telephones. Other problem areas include waiting times and the usefulness of some appointments.

We are happy to work with Camden Clinical Commissioning Group ('the CCG') and the Royal Free ('RFL') to agree common principles and joint work where appropriate.

- Recommendation 1 – We are very keen to improve the clarity of information and instructions during and after consultations. With the introduction of MyCare, our patient portal and app for phones, patients can see all of their administrative and clinical information in one place. This includes appointments and clinical information such as letters after their clinic visit. Over 16,000 patients are now using the portal. The introduction of a clear 'After Visit Summary', as standard has been made possible with the introduction of Epic. Also our clinic outcome letters in Epic are now designed to meet the Patient Records Standards Body ('PRSB') best practice standards in terms of consistent, reliable, high quality information between clinicians and patients. These standards also improve continuity of care by helping clinicians to communicate relevant information more quickly, reducing transcription errors by enabling re-use of key data into GP systems.
- Recommendation 2 – We will discuss with our outpatient managers how staff and volunteers can better support next steps and checking out. Patients should no longer be given bits of paper to carry round now as we have moved to a fully digital system.
- Recommendation 3 – All new or temporary clinicians now receive training on Epic, our system used in outpatient clinics and throughout the hospital. We are also scoping the development of a Standard Operating Process ('SOP') to support and guide clinicians in outpatients who are new to Epic.
- Recommendation 4 – We will work with the CCG and RFL on this, as Camden have indicated. We have previously undertaken a significant amount of work to

develop simple and clear appointment letters, and with the introduction of Epic we have already introduced new standards for clinical letters and have introduced improved text messaging around outpatient appointments. But we are happy to collaborate further to develop a set of principles for patient correspondence (that meets any relevant professional standards) and communication, which helps foster consistency but allows for the specific needs of individual patient groups to be considered, where a one size would not necessarily fit all.

- Recommendation 5 – We will undertake a project over the next six months to ensure that are telephone numbers are accurate on letters and that alternative, convenient means of contact are available including text, email and MyCare messaging. A key aim will also be to improve the responsiveness of our telephone service.
- Recommendation 6 – As suggested, we will review the systems that contribute to the poor experience and inefficiency that can occur in the areas outlined.

Responsibility for this work will sit with Henry Wilson as Head of Admin Transformation, Lisa Anderton as Head of Patient Experience, Luke O'Shea as the director leading work on admin and outpatient transformation, and Dr Gill Gaskin as our Board level Medical Director.

## 2. Response from Royal Free London NHS Hospitals Trust

Each year we have approximately 600,000 out-patient attendances at the Royal Free Hospital (RFH). We are committed to ensuring that all our patients receive the very best care and recognise the importance of working with partners in health and care across North Central London to improve the care, treatment and experience for out-patients.

We play a leading role in North London Partners in health and care, the North Central London Sustainability and Transformation Partnership, Planned Care Work Stream's out-patient transformation programme. In 2019, we aligned our trust's internal out-patient transformation board with this programme to help make sure actions and decisions made are taken forward in a timely way.

We know that we do not always get it right and that our out-patients sometimes experience difficulties when they visit us and we are working hard to improve this. Our responses to the recommendations in this report are below.

We would also like to take this opportunity to thank Healthwatch Camden for putting this report together and for all their support.

**Recommendation 1: Medical directors at University College London Hospitals NHS Foundation Trust and at the Royal Free London NHS Foundation Trust should work with clinicians, administrative staff and patient groups to improve the clarity and consistency of written and verbal instructions given to patients (and their carers) during outpatient appointments.**

We would be happy to work with University College London Hospitals NHS Foundation Trust and other partners across North Central London to improve the written and verbal instructions given to patients, their carers and families during out-patient appointments.

The RFH's medical directors are actively engaged in the North London Partners out-patient transformation programme. Through this, we are working to standardise out-patient pathways across North Central London which includes how we communicate with our patients. At the Royal Free London NHS Foundation Trust (RFL), we are implementing patient co-design in several areas of this work to help ensure that proposed changes result in meaningful improvement for our patients.

**Recommendation 2: Outpatient clinics should designate a clear "check out" desk for all patients to report to at the end of their appointment. Check out staff or volunteers should actively support patients to take the correct next steps (e.g. where to go for the blood test, which piece of paper is for what, how and when the patient will hear about the appointment for a scan etc.)**

We will be considering the introduction of "check out" desks in our clinics and exploring whether this is something we may be able to implement in some of our clinics.

To help patients understand the next steps following their out-patient appointment, we:

- Have patient navigators across the RFL who guide patients through the process of booking and attending appointments and also organise the patients' follow up.
- Will continue to standardise out-patient pathways through the North London Partners out-patient transformation programme and RFL's clinical practice groups (CPGs). The aim of CPGs is to work in partnership with patients to co-design new pathways of care and establish what outcomes matter to our patients the most.
- Are working with colleagues at North London Partners to establish how patients can receive more care and treatment in primary care so that they do not have to come to hospital for out-patient appointments.

**Recommendation 3: Ensure all new or temporary clinicians are briefed on the systems relevant to that outpatient clinic (e.g. a one-page handout for all locums).**

We agree that all clinicians need to be properly briefed before carrying out clinics at our hospitals independently. All new clinicians, including locums, undergo trust and departmental inductions at the start of their posts.

**Recommendation 4: The University College London Hospitals NHS Foundation Trust and the Royal Free London NHS Foundation Trust, with the Camden Clinical Assessment Service and Camden's GPs, must review, improve and standardise patient letters and electronic messaging about outpatient appointments. A guidance leaflet for GPs to give patients, covering what to expect along the referral pathway and how to get what they need and want from their hospital appointment, should be developed as part of the above process. The requirements of patients with communication support needs must always be met.**

We would welcome the opportunity to work with Camden Clinical Assessment Service and Camden Clinical Commissioning Group to improve and standardise letters and electronic messaging about out-patient appointments.

**Recommendation 5: The University College London Hospitals NHS Foundation Trust and at the Royal Free London NHS Foundation Trust must ensure that any phone numbers issued to outpatients are correct, are correctly directed and are sufficiently resourced to provide patients with an appropriate response.**

It is important that our patients are able to contact us when they need to. We will update and review the contact details for our services on the trust's website over the coming months.

**Recommendation 6: The University College London Hospitals NHS Foundation Trust and at the Royal Free London NHS Foundation Trust partners should review and address the wide range of systems factors that contribute to poor patient experience and inefficiencies around outpatient appointments including:**

- **Multiple appointment bookings that are not smoothly coordinated;**
- **Hospitals replacing appointment slots in e-Referrals (online booking system) with internally booked triage services (limiting availability and choice through eRS);**
- **The hospital trusts holding incorrect or inconsistent patient contact details;**
- **Late notice or failure to notify patients of changes to appointments;**
- **Insufficient investment in administrative functions and insufficient support for administrative staff**

We agree that multiple factors influence patients' experience of out-patient services and are committed to reviewing and addressing these factors alongside colleagues at University College London Hospitals NHS Foundation Trust through North London Partners Planned Care Work Stream, and through RFL's out-patient transformation board.

We will share this report with the North London Partners out-patient transformation programme team and the relevant Planned Care Work Stream delivery groups.

We have also recently developed a non-clinical practice group. This group is looking at improving RFL's administrative systems and processes for patients and aims to address some of the issues identified above.

## 3. Response from NHS Camden Clinical Commissioning Group (Recommendation 4 only)

Firstly, we would like to thank Healthwatch for their work to compile this report.

We recognise that outpatient care comprises a large proportion of the interactions our patients and residents have with our acute providers, and therefore ensuring a positive experience when attending an appointment, and that the interaction provides genuine

clinical value, is vital. As such, we were pleased to see the majority of patients report that they felt their outpatient care had been positive and that they had received a good service.

We also acknowledge the challenges highlighted in the report and the frustrations felt by some with regards to outpatient services or the processes that surround the appointment. There are areas we note would benefit from further attention including:

- Confirmation re the service or clinic someone has been referred to
- Waiting times between referral and a confirmed outpatient appointment
- Difficulties liaising with departments when appointments need to be changed or someone is seeking additional information
- Confusion about which organisations / departments do what, and therefore who a patient should contact with queries and how to do that
- Waiting times when attending an outpatient appointment
- Varied experiences in the 'usefulness' of the appointment, e.g. test results not ready, differences in understanding of situation between patient and clinician, lack of clarity for next steps, etc.

Although this report focuses on the experiences of Camden patients using services at these two local Trusts, we recognise these outpatient experiences are relevant to patients across North Central London (NCL).

Outpatients is included in the NHS Long Term Plan as an area of the health system that would benefit from review and major reform. Local insights into outpatient services are therefore extremely valuable, as we develop and progress system-wide work to improve and transform outpatient services at pace.

We particularly acknowledge the importance to the overall patient experience, of clear and consistent communications. We recognise that improving communications between all parties, will in turn improve not just patient experience, but also help reduce inefficiency and waste in the system. Below we pick up the particular action in relation to recommendation 4.

**Recommendation 4**

Our NCL response to the NHS Long Term Plan, our NCL Medium Term Financial Strategy (MTFS) and the NCL-wide Planned Care Outpatient Programme (delivered jointly with providers within our STP) all include a focus on improving outpatient services and care. We will ensure report insights and findings are shared internally and picked up in relevant work plans so opportunities for improvement are identified and realised. This will include the following activity to deliver against recommendation 4:

NHS Camden CCG, which includes the Camden Clinical Assessment Service (CCAS), will develop a leaflet for GPs to share with patients when they are being referred for specialist treatment:

- The leaflet will be developed in collaboration with people from CCG patient networks and Healthwatch patient engagement groups/networks.
- We will also reach out to work with Trust communication teams and their patient / public forums to get as broad an input as possible.
- The leaflet will focus on two areas:

- Information for patients and carers that would help them navigate the system (e.g. who to contact with specific queries or problems)
- Generic information or 'top tips' that might help patients get the most from their appointment.
    - Different formats will be produced to ensure the information is accessible to those with different communication and support needs.

We have also received an invite from Cllr Kelly's office for a Health Scrutiny discussion on the 11th February. The CCG will be sending a commissioning lead and we hope this will be an opportunity to further consider how we might work together locally to draw on your findings and progress actions that respond to the recommendations within for the health and care system.

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