

Access to GP services for people with communication support needs: Experiences of local people

June 2016



Executive Summary

Access to GP services is a topic under the national spotlight at present, and Healthwatch Camden, in common with other local Healthwatch, receives many queries and comments from people about their GP practice.

We conducted research around the issues for people who are d/Deaf or visually impaired or have learning disabilities¹. Difficulties happen if services do not adjust their usual ways of communicating to take account of the different communication needs of disabled people. Variations in equality of access result in increased disadvantage for some groups of patients. Furthermore, communication failures prevent the safe, effective and efficient provision of good quality primary health services.

This report presents the findings of our research with three different groups of patients who have communication support needs: people who are d/Deaf; people who are visually impaired; and people who have learning disabilities. The findings are presented in three sections. While many of the themes and recommendations are common across all three groups of service users, there are also some issues or concerns that are distinct to each group.

Overall, across the three groups of service users, our research suggests a need for three basic areas of adjustment: first, efficient and consistent systems for identification of patients with communication support needs across the entire staff team at every GP practice and in GP referrals to other services; second, greater attention to appropriate communication with use of clear and easily understood formats (drawing as appropriate on new technologies) for both verbal and written communication; third, greater sensitivity to individual patient preferences, especially regarding different patient's attitudes to their desire for independence and a focus on providing support without undermining patient self-esteem.

There are some good examples where GPs have provided appropriate support and made reasonable adjustments but our research suggests that good practice is neither consistent nor universal across Camden's GP practices. In sum, a positive experience of visiting the GP is too often dependent on a stroke of luck – particularly around which staff members happen to be on duty.

Our research suggests that many of Camden's GP practices are not yet meeting the Accessible Information Standard. This will be a legal requirement by 31st July 2016.

All our recommendations are compatible with the implementation of the Accessible Information Standard.

¹ People with other forms of disability may also experience access difficulties, but these have not been the focus of this particular study.

The views of local disabled people set out in this report will help local GP services to implement the Standard, through illustrating the sorts of action that will make the most difference to their disabled 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.

Introduction

Access to GP services is a topic under the national spotlight at present, and Healthwatch Camden, in common with other local Healthwatch, receives many queries and comments from people about their GP practice.

Disabled people face many of the same issues that will be familiar to other local people – for example, difficulty in getting an appointment. But the challenges can be greatly exaggerated if services do not meet their access needs as disabled people. This report focuses on the issues for people who are d/Deaf or visually impaired or have learning disabilities². Difficulties happen if services do not adjust their usual ways of communicating to take account of the different communication needs of disabled people.

Healthwatch Camden talked to people with the kinds of disabilities that mean they require specific adjustments to support their communication with services. We asked them about their experiences with GP practices in Camden. We wanted to

² People with other forms of disability may also experience access difficulties, but these have not been the focus of this particular study.

know more about the ways in which being d/Deaf or visually impaired or having a learning disability may make it more difficult to access the services to which they are entitled. We also wanted to hear what works well. Variations in equality of access result in increased disadvantage for some groups of patients.

Since the introduction of the Disability Discrimination Act (1995) and subsequent Equality Act (2010), providers of health services are required by law to make reasonable adjustments to make services accessible to people with a disability, including sight loss. Adjustments are not necessarily expensive, can benefit all patients, and can save time and money.

More recently, the Accessible Information Standard has been introduced with the intention of making health and social care information accessible. By 31st July 2016 it will be a legal requirement for all organisations that provide NHS or adult social care to follow the Accessible Information Standard. It tells organisations how they should ensure that disabled patients receive information in formats that they can understand and make sure patients receive appropriate support to help them communicate.

This report presents the findings of our research with three different groups: people who are d/Deaf or visually impaired or have learning disabilities³. The findings are presented in three sections. Recommendations are presented at the end of the report.

The views of local disabled people set out in this report will help local GP services to implement the Standard, through illustrating the sorts of action that will make the most difference to their disabled patients.

(NOTE: An Easy Read version of Part 1: Experiences of people with learning disabilities, is provided in Annex 2.

³ People with other forms of disability may also experience access difficulties, but these have not been the focus of this particular study.

PART 1: Experiences of people with learning disabilities

Methods: how we gathered the evidence

We conducted the research in partnership with Health Matters, part of The Advocacy Project for people with learning disabilities.

Back in 2012, Health Matters did some finding out work about what people with a learning disability thought about their family doctor services or GPs. In 2015, Health Matters agreed to work with Healthwatch Camden to follow up their earlier work with some new research. A research team comprised of 2 members of Health Matters spoke to 20 people in Camden People First, 8 people from Health Matters, 8 people from New Shoots and 10 people from Hopscotch. The discussions took place at group meetings held between May and June 2015.

Findings: what people told us:

Getting an appointment is difficult

Making an appointment to see a GP can be difficult for everyone. But people with learning disabilities say they find it particularly difficult because they may have to rely on help from a support worker or relative to make the phone calls or because the process can be confusing and demanding.

“There’s numbers to press, music as well. It can take an hour or two.”

“My mum calls. It takes 2 or 3 hours. Some days they don’t answer.”

“I have to go at 8 o’ clock and wait outside in the road. They open at 9. Then I go to see the doctor. There’s 20 people standing in the road.”

“My support worker can’t make GP appointments with me. I have to go to the key worker. I can’t always get hold of them [the keyworker].”

“When I get sick someone rings up for me. It’s hard at first to ask someone to help me make an appointment. The people that support me... floating support... they are all different people. I don’t know who is going to support me.”

“It’s hard to find a time when we are all free: me, my mum and the doctor.”

Seeing a doctor who knows you feels very important

People with learning disabilities feel very strongly that they benefit from seeing a doctor who knows them and is aware of their support needs. Repeating information to a new listener can be very stressful for someone with a learning disability and it's also hard to understand new people who may speak fast or in a different accent.

“My doctor understands me. He knows what my needs are. He knows me since I was 15. He slows down.”

“I feel uncomfortable with someone I don't know.”

“When you see a GP you don't know you have to say things over and over again.”

“I see lots of doctors I don't know. There's two thousand people in our practice.”

“When I see a new doctor they talk really fast and they rush you.”

“When I ask for my regular doctor the receptionists say ‘why? Go for another doctor’. They don't understand.”

“They have these screens but my doctor always comes and gets me because he knows I can't read the screen.”

Support is needed to ensure people can access the same services as patients who are not disabled

People told us that they need the right support when visiting the doctor. The right support might mean help to find where to go, being accompanied by a support worker, more time to talk to the doctor or other staff, or just being spoken to more slowly and clearly. We heard that not all health professionals seem to know what good support looks like.

Lots of people don't know about their rights to a good service. People with a learning disability told us that they don't usually feel able to challenge or complain if they are not getting the right support and it's often hard for them to ask for what they need. Complaints systems vary and are often hard to navigate.

The Equality Act 2010 places on some people and organisations a duty to make reasonable adjustments for disabled people to remove the barriers they face because of their disability.

“I don't think they all understand what support people with a learning disability need.”

“The doctors are in a hurry to kick me out. They’re not patient with me to understand I need extra time.”

“They want me to go [to the doctor]. I said I couldn’t – I need my sister to go with me. I can’t go alone. I think the doctor doesn’t know that my sister supports me.”

“It’s so big and I get lost.”

“I saw a doctor and she kept saying ‘Do you understand? Do you understand?’ It was the way she said it that wasn’t nice.”

“I’ve only just started on a new brown pump [for my asthma]. She [the practice nurse] asked me how to do my peak flow. I said how I did it but she said I did it wrong. I didn’t tell her I had a learning disability. I should have when she explained it the first time she ran through it really quickly. I’m not sure my doctor knows. My file has a brown/yellow sticker with a ‘d’ on it. Maybe that’s it.”

“When I went to the hospital the clinic was hard to find. A man said ‘no – you’re not supposed to go there’. I don’t think the doctor knew how to get me support.”

“I’m not sure the support workers know how to ask for reasonable adjustments.”

Practice staff don’t always know or understand the needs of patients with learning disabilities

People told us that other members of staff at the practice, such as receptionists, are often not informed that the patient has a learning disability and appear unaware that considerate communication is essential. As a result, receptionists often don’t do as much as they could to make sure people get the support they need during their appointment.

“I don’t know if the receptionists know I have a learning disability. They just handed me a little slip to fill in.”

“I don’t think the receptionist knows you have a learning disability. I don’t think the doctor tells them. When I came in she just said ‘Oh go upstairs’.”

“The receptionists rush you, they don’t say please.”

“Some of the receptionists get to know you but when they are new they aren’t sure what to do. They are dealing with other people and don’t like to be disturbed.”

“They didn’t tick the box to say I had a learning disability.”

“Sometimes I don’t understand and I would like them to help me understand. I ask if they could go a bit slower but this nurse I see is very fast. I did ask her to but she didn’t do she. Sometimes they have new receptionists. This new lady they have doesn’t understand.”

Getting excluded from the conversation or being talked across is common

When people with learning disabilities are accompanied by a support worker or a friend or relative they often find that the doctor or other staff address everything to the person they are with instead of including them.

Patients with learning disabilities told us that they don’t want people to ignore them or talk over them. A number of interviewees mentioned that ambulance staff set a good example by speaking in a way that can be easily understood.

“Talk to us – not over our heads to our support worker or parents.”

“When you don’t talk to me it makes me feel sad and angry.”

“It’s good sometimes when they speak to me. Sometimes it’s difficult to understand so I like them to speak to my mum.”

“I used to go with my mum but she would tell them too much and take over.”

“They always talk to the support worker. It always happens.”

They talk to my sister. That’s how she [sister] likes it. They always know my sister.”

“Doctor knows me, knows what I need. Talks to my mum. I like it that way. Would be nice to be able to talk to them more.”

“I’ve got a good doctor now. Sometimes the doctor talks to me and sometimes to my sister. When there are things I don’t understand my sister helps me.”

Easy read communication is essential

Most people with learning difficulties need people to communicate in clear and simple language. They need information in formats that they can understand – like short words and pictures – and they need people to understand that they may not be able to read or write well.

Easy Read refers to the presentation of text in an accessible, easy to understand format. Sentences will be short with pictures to represent each sentence where possible. Language is simplified and any necessarily complicated words are explained.

Letters and other information from the doctor can be hard to understand. People told us that Easy Read would help them to process the information they receive from their practice.

“The doctors should do the letters in Easy Read. It’s all in jargon. There’s no pictures in it. They should have it on the computer.”

“I would like letters with pictures in.”

“The doctor sent me the results but I couldn’t understand it. I had to go back to ask what it meant. My appointment letter wasn’t in Easy Read. I don’t think they know how to do them.”

“I get texts from the GP and the hospital. My phone can read them out but the GP ones come out funny. There are jargon words in it.”

“I got sent to Great Ormond Street – my GP sent me. The letter I got was in Easy Read. The doctor there knew about my learning disability and made it easy. My GP must have told them.”

“Please use easy words and pictures to help us understand.”

In Sum

People we spoke to said they felt the common barriers are “a hundred times more” for people with learning disabilities. People also told us that these barriers are not hard to overcome with a bit more awareness and understanding. For example, communicating clearly and slowly and using Easy Read for written correspondence can solve many of the problems this group of patients encounter. There are some good examples where GPs have provided appropriate support and made reasonable adjustments but our research suggests that good practice is neither consistent nor universal across Camden’s GP practices.

PART 2: Experiences of local people who are visually impaired

Methods: how we gathered the evidence

We conducted the research in partnership with Visually Impaired in Camden who were able to introduce us to visually impaired people willing to be interviewed as part of our research.

The scoping phase involved meeting with individuals who have a role in coordinating networks of visually impaired people to identify key themes and to seek advice on appropriate research methods.

Next, Healthwatch Camden attended a meeting of Visually Impaired in Camden at which we presented the plans for the research, sought feedback and comment on the research questions and requested volunteers for one-to-one in depth interviews.

Subsequently we conducted six one to one interviews with visually impaired volunteers - four of whom were identified through Visually Impaired in Camden and two of whom were identified through other community engagement activities conducted by Healthwatch Camden.

Initial draft recommendations were prepared. These were presented and discussed with the group at a second meeting of Visually Impaired in Camden. At that meeting, additional one to one conversations were conducted with two further visually impaired individuals.

Findings: what people told us:

People told Healthwatch Camden about their experience of visiting the GP and trying to communicate with both administrative and clinical personnel. A key issue that emerged was the conflict many visually impaired people experience between their need for communication support and their desire to retain their independence and self-esteem.

Support needs are not always recognised on arrival at the practice

Once practice staff have been made aware of the patient's support needs they are usually very responsive and helpful. However, people told us that it can be

difficult and can feel bad when they check in at the practice but their support needs are not recognised. Quick and efficient identification of a visually impaired patient's support needs can help ensure that these can be met sensitively and appropriately without causing embarrassment.

“There should be something that flags up my support needs when I check in and give my date of birth at the reception desk. But it all depends on the member of staff.”

“There is no flagging system of my support needs when I check in at reception.”

“If they had some system to flash up that I am visually impaired it would help a lot.”

“They don't realise how limited my sight is.”

“I am also hearing impaired. So when I go to the reception desk I use physical gestures to indicate my need for people to speak up.”

“Sometimes I'm in the queue waiting to see the receptionist. I can't tell whether or not the queue is moving. Then it gets to my turn but the receptionist doesn't respond to my blindness. I wave my stick.”

“At my GP there is a complete lack of awareness training among the reception staff.”

“Flagging about my support needs should also be clear on my case notes for referrals to hospital.”

Some people prefer not to be identified because the responses are not sufficiently well judged to be welcome

We heard that some people value their independence very highly and much greater sensitivity is needed in providing support without undermining patient self-esteem. There needs to be greater sensitivity to individual patient preferences, especially regarding different patient's attitudes to their desire for independence.

“When people realised I was blind their whole attitude to me changed and they frogmarched me to the bus!”

“I'd prefer not to be identified as having special support needs. I don't want to be helped all the time and I don't want people to make a fuss. I like to be treated normally.”

“I don't like to advertise my poor sight. I have a white stick but I keep it folded in my bag.”

“People say “but you don’t look blind!””

“Once they understood I was blind then I’d lost my independence.”

“If you take out the magnifying glass then all of a sudden everyone wants to help you.”

“I want to retain my independence - it’s a big adjustment.”

“They need to take into account the individual person and their lifestyle requirements.”

“We’re all different.”

GP practices rely heavily on visual communication

People told us that self-check-in systems and electronic display boards in the waiting room don’t work for visually impaired patients. So these patients find their own solutions. Staff members are often helpful but the level and type of help is inconsistent and highly dependent on specific individuals and circumstances. This doesn’t help visually impaired people to feel confident and welcome at the practice premises.

“I need to sit in a certain place so I can see them [the reception staff] in case I am called.”

“When it’s my turn the name and room comes up on a screen but I can’t see it. So I look around to see if anyone else gets up and moves. Then I have to ask another waiting patient and say “did you see that name because no one moved?””

“If it’s a receptionist who knows me then they will call me.”

“There’s an indicator board which I can’t see but the GPs do come out and get me. I don’t know if this is because they know me but I have never found myself left sitting.”

“There is one receptionist who knows me and that is helpful.”

Communicating with the practice

We heard that visually impaired people can struggle with inaccessible systems to make and confirm appointments and that this may put people off attending. It can also be hard to access other information from the GP such as reports and test results. Different people have different support needs depending on their disability and also on their personal preferences. Many of our research participants

experienced a lack of flexibility from the GP practice in responding to their requests for alternative forms of communication.

A range of new technologies are now available to help those who have communication support needs but it seems these are not being widely adopted among Camden's GP practices.

Inaccessible communications can lead to errors in reading appointment times with consequent possible delays in diagnosis and treatment.

"It's essential that I can use the telephone [because I have no useful vision]. But when I call for a repeat prescription they say no I have to come in or send an email."

"I can't read print and I can't access emails independently - I have to have a computer assistant. That's difficult for private matters."

"Staff can read test results over the phone to me by my agreement. I've asked for information to be sent to me on audio CD but they can't implement that."

"If I am sent a text message via landline I have technology that will vocalise the text in digital speech. So it can be done."

"I would like text to speech via telephone."

"Appointment letters are not provided in large print. Text messages are good as I can enlarge them and I can also enlarge emails. But I prefer traditional text in hard copy."

"Reports and test results are not in large print."

"I can always manage to read my appointment letters. I use my magnifying glass."

"My support worker helps me or my daughter helps if I can't see."

"Telephone calls are best please. I can't read the letters and I don't use braille."

"Menu options on phones are a big bug bear as manipulating the options can be hard when you can't see well."

Managing medications

People told us that they struggle with the instructions that accompany medications because these are usually in small print formats that are inaccessible for people who are visually impaired. Inaccessible communications can lead to errors in reading instructions for medicines with consequences for health.

“I have to check and ask them to confirm what is on the prescription.”

“A major problem for people who are severely sight impaired is that, although the name is in braille, neither the expiry date nor the instructions on the medications is in braille.”

“There is no applicator for liquid medicines anymore. There used to be a 5ml cap [which I could use] but with the syringe I can’t see the measurement. So I can’t take my medication independently.”

“Instructions are hard to read.”

“Medications in blister packs work well and help avoid getting mixed up.”

Appointment length

People with communication support needs require more time to communicate. This can be difficult at the GP practice where doctors are busy and other patients are waiting. People with visual impairments are often self-conscious about their support needs.

“There’s a trade-off between being a good doctor and keeping people waiting. I feel guilty about keeping others waiting - it spoils the interaction with my doctor as I am feeling bad.”

“I would like staff to be able to spend a little more time with me.”

“Older people and people with disabilities need longer appointment times.”

Expectations, preferences and experiences vary

While some visually impaired patients expressed frustration that their communication support needs are not sufficiently well met, others were keen to stress that they are happy with the services provided at their GP practice and have no wish to make additional demands.

“I have adjusted and can generally make my own adjustments and manage.”

“I have no problems with the service at my GP practice.”

“My GP practice understands my needs.”

“The people that need to know about my support needs do know.”

In Sum

A key finding emerging from our research was the conflict experienced by many visually impaired patients between their need for communication support and their desire to retain their independence. A wide range of preferences were expressed across the research participants indicating that a combination of standardised and efficient alert systems combined with a well-informed, flexible response to the individual preferences of each patient will be the best way to address the wide variety of needs.

PART 3: Experiences of people who are d/Deaf

Methods: how we gathered the evidence

Healthwatch Camden held community forums in which d/Deaf services users participated (along with other community members) and raised issues that were important to them. Drawing on these initial conversations we then conducted some more in-depth research in partnership with the British Deaf Association. We were also assisted by Action on Hearing Loss who provided information about the experiences of people with hearing loss.

We held initial scoping discussions with d/Deaf representatives on the basis of which we designed focus group questions. We issued an invitation to attend a focus group discussion which was distributed across the British Deaf Association network and further distributed through the various communications channels of Healthwatch Camden. Nine people participated in the focus group. These included people who used British Sign Language and people who use English Speech to Text Translation. The findings from the focus group discussion were distributed among participants as an interim report and comments were invited.

The findings from the focus group were subjected to “sense-checking” in five one-to-one conversations with d/Deaf service users and at a question and answer session with d/Deaf attendees at the Camden Deaf Awareness Day.

Findings: what people told us:

On average, one in every six patients registered at each of Camden’s GP practices will be Deaf or deafened or hard of hearing. Many of the issues faced by d/Deaf patients are the same as those experienced by Camden residents who are not

d/Deaf, for example, having difficulty making an appointment to see their own doctor. However, there are some particular challenges for d/Deaf people.

NOTE: we use the term d/Deaf to refer to people who are Deaf, deafened or hard of hearing.

Making an appointment with the doctor is difficult

People who are d/Deaf told us that their disability makes it very difficult to use the telephone to make an appointment at the GP practice. Consequently, waiting times for appointments can be even further extended.

“I have to get someone to make the phone call - my daughter - which leads to delays.”

“Text and email to make an appointment is a good system for me.”

There are communication barriers at the check-in desk

When d/Deaf patients arrive to check in for an appointment they find that there are physical barriers that hinder good communication.

“The glass screen in front of the reception desk and the glare from the lights makes it hard to see. I need to be able to see the receptionist’s face to be able to lip read.”

“Switching off the light helps. And non-reflective glass would help too. But they don’t think about this when they put the glass in.”

“I write notes and give these to the receptionist. But they give back notes that are not clear. The notes get pushed back and forth.”

“Kentish Town Health Centre is a good model. There is a good reception desk.”

Communicating with reception staff can be difficult

People told us that they often find it difficult to communicate effectively with staff at the reception desk. This makes them feel uncomfortable and unwelcome.

“The receptionists are low down and look down at their computers which means you can’t lip read.”

“Receptionists need to change their facial expressions.”

“They turn their face away.”

“Gesturing is not okay. They think it’s the same as sign language but it’s not.”

“It would be good to have receptionists who know how to sign.”

The environment at the practice does not feel welcoming

d/Deaf people told us that they feel isolated and ignored when sitting waiting for their appointment.

“Deaf people have to be like owls - sitting there staring at people trying to lip read.”

“They just come in and shout your name lots of times.”

“I feel ignored”

“The dot matrix board does not put you name up.”

“The electronic board signs that alert you when it’s your time are too hard to read and it’s not always working.”

“I need to feel safe.”

Systems to flag communication support needs are not consistent or efficient

People said that many problems could be solved if GP practices had consistent and efficient systems for flagging the patient’s disability and related support needs to all staff and at all stages in the referral process to hospital or other services.

“They don’t know what I need or want.”

“It’s okay if someone recognises me but otherwise I have to go through it all and explain that I am Deaf.”

Support needs during the appointment are not always well met

Clear communication is essential during a doctor or nurse appointment. But people said that their support needs are not sufficiently well met. Sometimes people are left unclear about their diagnosis or the advice they should follow after visiting their GP. Understanding written information on prescriptions can also be hard. Seeing someone who they know, and who knows about their support needs and medical history, makes it easier. But it’s not always possible to get an appointment with the same doctor.

“There is often an assumption that everyone wears hearing aids and there is also an assumption that everyone is English first language. But British Sign Language (BSL) is not English and BSL users don’t use hearing aids.”

“Foreign language speaking doctors or nurses can be harder to understand because of an accent.”

“Hearing loops don’t help if you use BSL.”

“I’m using a hearing aid but it doesn’t mean I can hear easily.”

“There is not enough general awareness about the different variations of d/Deaf needs.”

“GPs sometimes ask people to come with a family member to sign (BSL) for an emergency appointment. But this is not appropriate - matters may be sensitive or private and it’s not fair on children to have to do this and miss school.”

“I can’t understand the jargon in the information they provide at GPs.”

“Reading English, like on the medicines, can be difficult for Deaf people too.”

Deaf communication services are not efficient or flexible enough

A major area of concern is around access to British Sign Language (BSL) interpreters and other deaf communication services. A standard GP appointment booking should trigger the GP practice to book a BSL interpreter (and this usually works well). The problems arise with emergency appointments when interpreters may not be available. People also told us that patients who are not profoundly deaf may not be recorded on the GP file as being Deaf and therefore an appointment booking will not trigger a request for a BSL interpreter despite the fact that the patient may need communication support.

“If you can speak they often don’t think you need an interpreter.”

“Sometimes there is a last minute cancelation of an interpreter. These things happen but a good example was when they sent me a text alert and gave an explanation of why. In this case they did manage to get a replacement. But sometimes they just don’t show up and then it’s all a waste of time.”

“Deaf patients need to have a way of contacting their interpreter. For example, if you have to cancel an appointment you can’t contact them to apologies and explain. Instead you just get recorded as a DNA (did not attend) which is embarrassing as you feel bad for wasting their time.”

“It would be good to know in advance who your interpreter is going to be.”

“They need to involve the d/Deaf service users in consultation about contracting for interpreting services.”

“I don’t understand the system for booking interpreters. There’s all sorts of different systems.”

Deaf communication services for hospital referral are also a major area of concern

One participant told of how he turned up at the Royal Free Hospital and the receptionist could sign and the doctor had basic sign too which he really liked. But others raised the concern that limited BSL can be dangerous in a clinical conversation.

“When you get referred to the hospital or to other specialist the GP often doesn’t put it clearly on the letter that you need an interpreter.”

“If patients were to get a copy of the referral letter then they could check and follow up if interpreting services haven’t been flagged as needed. Why not copy the letters to the patient?”

“The Royal Free is improving in deaf awareness - they are trying to do things to improve.”

“Why can’t they share the contact details for who is making the interpreter bookings at the hospital? If the patient had this information they could control it and follow up as needed. But this doesn’t happen.”

“You can contact PALS and request a specific interpreter for your appointment if you want to.”

“If I got a copy of the referral letter I could check that my needs are correctly flagged up. But I don’t get to see it.”

The overall level of Deaf awareness is low

The research participants all agreed that the general level of Deaf awareness among staff at GP practices is low. They felt strongly that everyone needs d/Deaf awareness training to encourage a change in attitude.

“I have seen Deaf people in tears because we feel like we are hitting a brick wall. And they look at you like you’re nuts.”

In Sum

A key finding emerging from our research with d/Deaf patients was their desire to feel in control and for systems and processes to allow the exercise of that control rather than undermining it.

Improvements in communication and a change in attitude from service providers and others in the community could help to improve this. A positive experience of visiting the GP should not be dependent on which staff members happen to be on duty.

Deaf communication services emerged as a major cause for concern. People told us they want greater investment in flexible and efficient d/Deaf Communication Services that take advantage of new technologies to ensure interpreters can be available across extended hours and at short notice.

Recommendations:

Overview

When it comes to GP services, people with communication support needs face many of the same issues that will be familiar to other local people. For example, the difficulty of getting an appointment with a busy GP is in no way unique to people with disabilities. However, the challenges are greatly exaggerated for people who have communication support needs related to their disability. This must be addressed because people with disabilities should have the same level of access to health services as other people and their communication support needs should be anticipated, assessed and met in order to avoid poor health outcomes.

Overall, across the three groups of service users, our research suggests a need for three basic areas of adjustment: first, efficient and consistent systems for identification of patients with communication support needs across the entire staff team at every GP practice and in GP referrals to other services; second, greater attention to appropriate communication with use of clear and easily understood formats (drawing as appropriate on new technologies) for both verbal and written communication; third, greater sensitivity to individual patient preferences, especially regarding different attitudes to their desire for independence and a focus on providing support without undermining patient self-esteem.

Our research suggests that many of Camden's GP practices are not yet meeting the Accessible Information Standard. This will be a legal requirement by 31st July 2016.

The findings from our research support a series of formal recommendations to those who provide GP services (the GP practices) and to those who commission and

performance manage GP services (NHS England and the Camden Clinical Commissioning Group). Most of the recommendations are common to all three communities of services users

We make ELEVEN recommendations for adjustments that could be made by Camden's GP practices and TWO recommendations to the commissioning bodies (Camden's Clinical Commissioning Group and NHS England). All our recommendations are compatible with the implementation of the Accessible Information Standard.

RECOMMENDATIONS TO GP PRACTICES

Recommendation 1: Alert systems

GP practices should introduce or improve consistent and standardised alert systems for instant identification of patients with communication support needs. The alert should appear on screen at appointment booking and check-in and on the patient's electronic record.

Evidence: The research suggests that many problems arise from a failure to recognise the communication support needs of the patient at the start of the interaction – whether with staff at the reception desk, those answering the phone, new clinical staff or temporary staff or in referrals to other services. Ensuring that all staff members who are interacting with the patient know that they have a communication support need (learning disability, visual impairment or d/Deaf) is the essential first step towards ensuring that any support needs can be met at every stage of their experience with the GP practice.

Recommendation 2: Single Page Profile

GP practices should institute a standardised single page profile summarising the support needs and preferences of any patient who has a learning disability or is visually impaired or d/Deaf. This should be developed in partnership with the patient and should be kept on file and attached to all referrals, ensuring that the patient's support needs and preferred method of communication can always be quickly recognised and understood without the need for repetition.

Evidence: There needs to be greater sensitivity to individual patient preferences and the needs of patients to retain their dignity, be treated with respect, retain

their independence and to remain in control. Simple and efficient systems that help avoid the need for repetition or misunderstanding will improve the interaction between patient and all GP practice personnel.

Recommendation 3: Reasonable adjustments

All clinical and administrative personnel, including temporary and new personnel, should be instructed to take note of the support needs of the patient (as indicated by a systematic identification system and single page profile) and to make reasonable adjustments in their methods and tone of communication to help improve two-way understanding.

Evidence: Failure to ensure that patients with learning disabilities, or those who are visually impaired, or d/Deaf, have appropriate communication support causes communication failure between GP service providers and patients. Communication failures prevent the safe, effective and efficient provision of good quality primary health services. By 31st July 2016 it will be a legal requirement for all organisations that provide NHS or adult social care to follow the Accessible Information Standard.

Recommendation 4: Appropriate communication formats

GP practices must use Easy Read formats for all text-based communications with patients who have a learning disability. GP practices must use Large Print or screen reader-friendly formats for all text-based communications with patients who have a visual impairment. This should include letters, emails, forms, medication instructions, and text messages. Each patient's individual needs in terms of preferred formats (including font size, braille or audio) should be identified, recorded and adhered to. Patients who are d/Deaf should be able to make an appointment via an alternative method to a telephone. Online booking will be useful to some but other should also be available. Practices should extend the use of technology that can help improve the patient experience for d/Deaf patients, such as visual display screens and induction loops or infrared systems, VRS or video relay online (VRI) which can be used on a smartphone and options such as TextRelay, SMS and email for booking appointments.

Evidence: Ensuring that patients can understand the information being shared with them and can engage in a meaningful dialogue with health care personnel is essential to providing good care and ensuring compliance with health care advice. Sharing information in ways that reduces the reliance of patients on a third party support worker improves the experience of the patient and could contribute to better health outcomes. GPs need to ensure that they meet the new Accessible Information Standard which will be a legal requirement from end July 2016.

Recommendation 5: Seeing a familiar doctor

Where possible, people with communication support needs should be able to see a health professional who they know. Where it is not possible for a patient to see a doctor who knows them well, extra time should be scheduled for the appointment with an alternative doctor and that doctor should be well briefed on the support needs of the patient and make efforts to communicate clearly and slowly including listening carefully to the patient.

Evidence: people with communication support needs feel strongly that a doctor who knows them can understand them and support them better than a doctor who is not familiar with their needs. However, it is not always possible to see your own doctor, especially for an emergency appointment. Greater investment by GP practices in ensuring that all doctors communicate well with patients with communication support needs will help to reduce the importance of seeing one doctor rather than another.

Recommendation 6: Disability awareness

All staff should receive training on disability awareness and be competent to assist patients to ask for the right support by using appropriate questions like “Do you need more time? Do you need me to speak more slowly? Do you need information in large print or with pictures in? Can you find your way to the clinic in the hospital? Do you need a support worker or friend or relative to come with you? Shall we check that you know what to do?”

Evidence: It is sometimes hard for people with communication support needs to know in advance what help they need. Not everyone finds it easy to ask for what help they need. People tell us that it can help if they are asked directly if they need a specific type of support. Health care personnel need to be aware of the types of support that might be needed in order to assist patients to ask for appropriate help. Often staff members are not aware of the different types of needs and find it difficult to know how to respond and engage appropriately with patients with support needs. For example, people may not be aware that lip reading is easiest if people speak clearly but not too slowly, do not exaggerate their lip movements and use natural expressions and gestures. They may not understand that shouting distorts lip patterns and makes it more difficult to understand - not easier to hear. Familiarising staff with effective communication tips is not difficult or resource intensive.

Recommendation 7: Lead responsibility and meeting legal obligations

One member of frontline staff should be identified to take lead responsibility for disability awareness and patient care throughout the practice and ensure that legal obligations to make reasonable adjustments are being met.

Evidence: GPs need to ensure that they meet the new Accessible Information Standard which will be a legal requirement from end July 2016. A positive experience of visiting the GP is too often dependent on a stroke of luck that depends on which staff members happen to be on duty.

Recommendation 8: Respect and inclusion

All staff should focus their communication primarily on the patient and not speak across them to the support worker. Even in cases where the patient appears to have limited capacity for communication, they must be respected as the primary participant in any interaction around their healthcare wants and needs.

Evidence: a common complaint from patients with communication support needs is that they are ignored and that healthcare personnel direct communication across them to their support person. This is disempowering and makes the patient feel that they have no control over their own health needs. Even where the patient may need the help of a support person, they must be afforded the respect due to any patient and must be assisted to exercise control and independence to the extent that they chose.

Recommendation 9: Referrals to other services

Referrals from the GP practice to other care services should include clear flagging of the patient's support needs so that all staff, including those making first contact, are aware in advance of any reasonable adjustments that will be required to ensure that the patient is properly supported.

Evidence: patients with communication support needs report that it can be very difficult to manage a visit to hospital or an appointment at a secondary care clinic where they are unfamiliar with the environment and the staff do not know them or are not aware or sensitive to their support needs.

Recommendation 10: Deaf communication services

GP practices should have policies and procedures in place to enable d/Deaf communication services to be booked as and when required using only

communication professionals who are fully qualified to deliver interpreting services in a healthcare setting.

Evidence: People told us of their concerns around interpreting services, particularly about processes for booking BSL interpreters and around standardisation and quality. People experience frequent difficulties getting communication support services for emergency appointments.

Recommendation 11: Two way understanding

Encourage a dialogue to improve two-way understanding between patients with communication support needs and GP practice staff so that providers have a fuller understanding of what these patients need and want AND so that the patients can better understand how and why systems work the way they do so they can make things work better for them.

Evidence: Improvements in understanding are needed in both directions. Much frustration and negativity could be avoided if patients with communication support needs were given clear explanations of systems and process and treated as partners in helping to improve services. For example, greater transparency about the procedure for booking deaf communication services would empower d/Deaf patients to do more to help themselves by checking if interpreters have been requested and their support needs understood. Similarly, if d/Deaf patients received a copy of all referral letters they could check themselves to ensure their support needs are correctly specified and follow up if needed, thus avoiding problems which waste time and resources at the appointment.

RECOMMENDATIONS TO COMMISSIONERS

Recommendation 12: Contract and performance management

The Camden Clinical Commissioning Group and NHS England should ensure that the communication support needs of patients are recognised and addressed in contractual arrangements for the delivery of primary care services in Camden and that progress towards implementing needed adjustments is monitored within performance management arrangements.

Recommendation 13: Promoting and supporting improvement

The Camden Clinical Commissioning Group and NHS England should promote improvement by providing support to Camden's GP practices to implement the recommendations outlined in this report.

Thank you.

Annex 1: RESPONSES TO THE RECOMMENDATIONS

Healthwatch Camden has statutory powers 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 majority of the recommendations in this report (No. 1 to No. 11) are addressed to GP practices. Recommendations No. 12 and No. 13 are addressed to those bodies with responsibility for commissioning primary care services for Camden's residents and for managing the performance of the GPs through those contracts (the Camden Clinical Commissioning Group (CCG) and the National Health Service of England (NHSE)).

We shared our report and recommendations in final draft with all the GP practices in Camden and asked them to respond. We also shared the recommendations with the Camden CCG and with NHSE.

a) Response from the Local Medical Committee representing Camden GPs

Local Medical Committees (LMCs) are statutory bodies which are in place to represent the interests of all local GPs and their teams. The Camden Local Medical Committee is made up of practising GPs and practice staff elected by local GPs.

Dr Claire Chalmers-Watson, Chair, Camden Local Medical Committee, sent the following response on behalf of all the general practices in Camden:

"Thank you for giving us the opportunity to respond to your recommendations in this report, and please accept this letter as providing a view from Camden practices.

One of the most salient points to come out from the body of the report is the variability of need, not just between the areas of disability, but from individual to individual and the ranges of expressed preferences.

Obviously, as GPs we are committed to providing the best quality of care we can for our patients. We already have care plans in place for patients with specific and complex needs to support an integrated care approach, and these include the needs of carers. There are currently more developments coming into place with access via IT systems, which will improve access across appointments, clinical information including correspondence and results, and there will be further developments in this area. There is also on-going development of integrated care records across health and social care providers, but all of this has to be within in terms and requirements of confidentiality, consent and secure access. However, the context in which we seek to provide NHS general practice services is one in which we have significant resource implications. This is not just in terms of

challenges in recruiting and retaining practice staff and practice nurses but with fewer GPs. Further hurdles include increasing workload, both with the range and expectations of what general practice is to be able to provide within the NHS Five Year Forward View and the secondary to primary care workload shift.

Many of your recommendations have significant resource implications in terms of staffing levels, training and availability of workforce. A prime example is your recommendation to increase the consultation length, which would be welcome both for patients and GPs. We would also seek to include not just those patients with disabilities, but also those patients with long term conditions and/or mental health problems. However, in the current climate we just do not have the resources available to be able to provide such appointments.

We note that you only have two recommendations for CCGs, one of which is that, and this includes NHSE, that there should be further contract performance management for GPs. GPs have their performance already extensively managed, both contractually, monitoring service delivery against performance indicators and by CQC. Recognising that the accessible information standard has to be implemented by 31st July, and although commissioning organisations are not required to implement the standard themselves, they must support compliance by organisations from which they commission services. The guidance sets out that this could be done by, for example by incentivisation. Where it therefore would have been more helpful is within the recommendations for practices that resource implications, and the part the CCGs could play in supporting and resourcing practices to meet the standard, may have been considered further. For example, individual GP practices do not have the resources to provide Equality and Diversity training for their staff and this is best done in collaborative multidisciplinary educational events. Similarly, provision of adequate interpreting services or management of transport or secondary care hospital appointments to meet the needs of the patient(s) are not within any GPs control, but within the remit of the commissioner who contracts for these services-that is the CCG.

Finally, and where we do feel that there is work to be usefully done, is in conjunction with the CCG, discussing how practices can be best supported in implementing the accessible information standards which, as you know, is not just about being able to access services independently or making choices about treatment, but also being able to make decisions about health and wellbeing and self-managed conditions.

We would also welcome the opportunity to take this work forward in consultation with yourselves, ensuring that we offer the best service that we can for Camden patients.”

Yours sincerely,
Dr Claire Chalmers-Watson
Chair, Camden LMC

We were pleased that Dr A T Agrawal and Dr A Zahan from the Museum Practice and Dr Lim from Primrose Hill Surgery and Dr Chalmers-Watson from Parliament Hill Medical Centre also chose to send us an individual response.

b) Response from the Camden Clinical Commissioning Group (CCG)

The CCG is a group of General Practices that work together to plan and design the local health services. The CCG commissions many of Camden's NHS health and care services. Healthwatch Camden therefore asked for a specific response to Recommendation 12 and Recommendation 13 which relate to commissioning primary care services.

Dorothy Blundell, Chief Officer, Camden CCG, sent this response on behalf of the CCG:

“Thank you for sharing the report with the CCG with the opportunity to comment.

At present, NHS England, in their role of the commissioner, has overarching responsibility for ensuring standards around service accessibility, equality and diversity are met in general practice. We have therefore taken the opportunity to discuss your report at our regular meetings.

The newly introduced Accessible Information Standard (AIS) for health and social care organisations will help all service providers to consistently meet the communication needs of the population we serve. We recognise that Camden CCG has a role to play here - including ensuring:

- *Any engagement activity we undertake is inclusive, including producing information in accessible formats and meeting individuals' communication needs accessibility.*
- *We reflect individuals' communication needs when managing complaints, including providing information in accessible formats.*
- *We promote national policy requirements around general practice accessibility standards to general practice, reflecting we are a membership organisation.*
- *We are assured that the providers of any services we commission meet national equality, diversity and accessibility requirements.*
- *We work closely with local authority colleagues to ensure our jointly funded services, any joint events and meetings take into account the needs of disabled patients and carers.*

We will ensure therefore that the recommendations included in your report are reflected in our relevant policies, including our equality analysis and annual equality and diversity action planning under the AIS. We anticipate that all Camden CCG commissioned providers will address these issues, as they are also required by the AIS to meet the communication needs of patients and carers.

Finally, I wanted to let you know that a comprehensive accessible information policy for North Central London CCGs is in development, to help ensure we meet all communication requirements of our patients, carers and stakeholders.

We would be happy to share the draft policy with you, and would welcome your input.”

*Yours sincerely
Dorothy Blundell
Chief Officer*

cc: Caz Sayer, Chair, Camden CCG

c) Response from NHS England

NHS England is responsible for commissioning primary care services and manages the contracts for these services with the GPs in Camden. Healthwatch Camden therefore asked for a specific response to Recommendation 12 and Recommendation 13 which relate to commissioning and contractual arrangements for GP services.

Dr Henrietta Hughes, Medical Director for London North Central and East at NHS England responded as follows:

“Thank you for sending this report. The issues facing deaf patients were discussed at the Quality Surveillance Group yesterday. I have copied in Ruth Thomsen, Chief Scientist for London at NHS England, who is leading on this work and will be able to give you more information.”

No further response has been received to date. Healthwatch Camden is pursuing this matter with NHS England.

Easy Read

We also have a separate Easy Read version of this [report](#) on our website.

