Healthwatch Birmingham and Healthwatch Solihull’s response to Health and Social Care Committee Call for Evidence: Men’s Health

Healthwatch Birmingham and Healthwatch Solihull welcome the opportunity to respond to Health and Social Care Committee Call for Evidence: Men’s Health Women and Equalities Committee Call for Evidence: Women’s reproductive health. Our key role is to make sure that patients, the public, service users, and carers are at the heart of service improvement in health and social care across Birmingham.

We welcome that the Health and Social Care Committee are looking into this important topic, as we have heard feedback on it from many men across Birmingham. We monitor the demographics of the people we hear feedback from, to ensure our feedback is representative of all of the communities of Birmingham and Solihull.

We are focussing our comments on two main areas that we have heard about from the people of Birmingham and Solihull, prostate cancer care and use of general practice services.

Prostate cancer

Healthwatch Birmingham and Healthwatch Solihull sought to understand people’s experiences of using NHS prostate cancer services in Birmingham and Solihull by listening to their views of using screening services, care and treatment, and support services. We also sought to identify and understand barriers or challenges faced when using these services. Our full report can be found here: Experiences of the NHS prostate cancer pathway in Birmingham and Solihull

The feedback we heard from 81 people shows that overall, a majority have a positive experience along the prostate cancer pathway. However, variability exists and increases within the post-treatment support pathway. Within the diagnostic pathway, participants were satisfied with the:

- Information they received about prostate cancer services and what to expect following referral (62.5%).
- Way the service communicated with them (61.6%), and support that was offered to them (58.3%).
- Interaction and support from healthcare professionals, with 72% indicating they had a named Cancer Nurse Specialist.
- Speed of diagnosis, support, and information.

Key concerns with the treatment pathway were:

- Lack of information about treatment options and content of information leaving some people unprepared for the post treatment effects.
- Timing of information making it difficult for some people to make informed decisions.

- Slow pace of treatment, which meant that at the time of treatment for some people the stage of the cancer had changed, which can potentially impact outcomes.
- Lack of post treatment support, especially after discharge.
- Delays in follow-up appointments.
- Lack of information about side effects following treatment.
- Lack of parity with other cancer services.

The doctor and nurse were kind, but the process was about information sharing about the cancer, treatment and support. It didn't take into account the fact that after you hear the word cancer, you can't really hear anything else. It all becomes blah, blah, blah.

A letter arrived detailing an appointment with a prostate oncologist, but other than this there was no communication, no offer of support, no communication about what might happen. Had I not researched things myself, I would have been completely in the dark, sitting for two weeks knowing nothing and fearing the worst. After I had an appointment with the oncologist, life was more certain, as he was extremely professional, explained likely outcomes, what probable treatments I would undergo, and set the process of scans in train.

Ended up going to A&E for tests because of symptoms. Didn't wait long and at [hospital] they did the test and needed further tests. Was there for 4 days. I felt like I did not get much information. Would say they will discharge me and then would decide to keep me in. ended up in tears, felt they didn't explain an awful a lot. I was not getting any satisfaction at all. They said it had not spread and it was only small and have not checked it since.

I expected that the conversation with the consultant would discuss the options available, but it was more a this is what happens with a robotic prostatectomy. He did discuss side effects of the robotic prostatectomy but no others. It would have been nice to be able to have a discussion soon after diagnosis that covered all options and been given both the Prostate Cancer Organisation's booklets and the Tackle Prostrate Cancer booklets, I've only been given these recently

Apart from the sexual function advice and bi-monthly assistance of incontinence pads from the incontinence nurse there appears to be nothing available. The overall impression was very much that "you are on your own". One memory that stays with me since being discharged after my prostatectomy was being handed a few incontinence pads and being told to use children's nappies when the few pads were used up. It was for me, or rather my wife, to stop at supermarket on the way home and purchase packets of children's nappies.
I also managed to find out for myself where to obtain a limited supply of incontinence pads from the community incontinence nurse and have spent, over the years, several thousand pounds to supplement the limited supply.

> *Like everywhere it needs better promotion within primary care. It feels as though all the communication and awareness is being done through Prostate Cancer UK. Even in the GP surgery only their publications are on the information racks. I appreciate there is no reliable screening service - but nothing comes from the GP surgery to highlight prostate cancer and to signpost to the PCUK survey or to suggest taking a PSA test may be a first step for any men over 50. Women's cancers, breast and cervical have comprehensive programmes in place - but for men there is nothing even though prostate cancer diagnoses are similar at national level to breast cancer. It feels as though once you get a diagnosis help is there - but getting the diagnosis is the difficult part. Often found by accident - like myself.*

General Practice

We have heard from people across Birmingham who have experienced great difficulties accessing care and support from their GP practice. We have previously reported these difficulties, which showed that people with long term conditions, and people living in more deprived areas encountered more barriers to care : People's views on access to GP services in Birmingham.

We have also heard from people in Solihull about their experiences accessing GP services via technology. People told us they needed clearer instructions on how to access and use digital services and more assurance that these systems are confidential: People's experiences of accessing GP services via technology

Men told us further about the difficulties they have with GP services.

Problems accessing appointments

We heard from men about issues they had in getting appointments at their general practice. This includes problems with telephone systems, lack of face to face appointments and digital technology

> *My partner is disabled and has trouble with mobility, he is also hard of hearing and virtually deaf in one ear, and the pain medication he is on affects his memory and the ability to process what he hears accurately. As a result, when he needs to see a Doctor he can spend ages on the phone in a queue only to be told that there are no appointments left for that day and to call again at 8am the following morning. This is a huge issue as again, because of his medication, he often doesn't wake up until closer to lunchtime and is then extremely groggy for an hour, so any chance of making an appointment is almost zero. And all appointments tend to be callbacks, and again he either cannot hear the doctor, doesn't understand what is being said, and because of his typical male pride, he won't ask for something to be repeated.*

> *Difficult to get appointments. Admin and receptionist are not bothered and not friendly. Can't get through on the phone. Keep getting told to go to a walk in centre. Feels like surgery has too many patients and can't see everyone. Doesn't use smartphone so not confident booking online.*

> *Recently suffered a heart attack and need to able to access healthcare quickly. Downloaded the app to avoid the stress of phoning at 8am. No appointments available through the app. I tried to send them a message through the app but the practice has disabled messages. I'm quite tech savvy and believe that they deliberately making it difficult for patients to contact them. No email address supplied for practice manager.*

> *Trying to get a phone call from your doctor is a marathon task turning that into an actual face to face meeting is like scaling Mount Everest, totally inept receptionists*

> *My husband received a text from the surgery asking him to call make an appointment the doctor wants to see him, he phoned explained & got told he has to phone every day at 8 am to try & get an appointment receptionist was not helpful conversation ended with my husband saying ok doctor wants to see me not the other way round*

> *Sick of using phone running out of credit, can't get an appointment so go down and make it known I need appointment.*

> *They're terrible. Can't get through to them and can't make appointments. I can be calling for days. I was really poorly one time and my wife had to call NHS 111 because I couldn't get through to them. They ended up telling me to go to A&E.*

> *Can call GP and can be on phone for 20 / 45 minutes. They don't see you and tell you to go to NHS 111 service. Why can't I see my own GP. Don't want to discuss issues with someone I don't know. GP relationship is not the same. It costs us to hold on. The old system used to work, you are ill today and they ask you to come in a few weeks.*

Receptionists

Men told us about their experiences with receptionists at GP practices. We have heard concerns about confidentiality and privacy when speaking to receptionists.

> *[…]can't get appointments, receptionists are like dragons. I don't want to discuss things with them. I phone up and all appointments have gone. I ask to make an appointment for another day and they say no. I don't want to speak to a receptionist, I want to talk to a doctor.*

> *It is almost impossible to get an appointment and you can never see the same doctor. I do not like having to disclose my medical symptoms to a receptionist, and staff can be very rude and abrupt when I explain this. I just feel that it's a complete lack of privacy expecting patients to divulge sensitive information to a*

> *receptionist over the telephone. Referral times can be slow and there is a lack of communication keeping patients updated.*

> *Hard to get through, can't get past the receptionist. Receptionists don't pass the messages to GP when I call them for my medicines and as a result I have to go to hospital. I have just called to order the medicines and they said I can't do it over the phone and I should do it online or go into the surgery.*

> *Struggle to get an GP appointment. Invasive and intrusive asking from telephone receptionist.*

> *Could never ever get an appointment. The receptionists are like rottweilers, if you can get past them - great. I say it's personal and that I want to talk to a doctor. The doctors were brilliant.*

> *Couldn't talk to anyone. Fobbed off by receptionist, want to know what's wrong with me but I don't want to disclose this to someone who wasn't a doctor.*

> *I have kidney failure and do dialysis three times a week and trying to see a doctor all you get is a receptionist who knows nothing, it's a doctor you need to see not a receptionist*

Delays in getting further treatment or diagnostics

We have heard about delays in referrals from GP practices, and in some cases leaving men to feel they have to access private healthcare instead.

> *I noticed I had an irregular pulse. Ten days wait for an appointment with nurse not doctor. Heart tracing was abnormal, no doctor available, nurse clearly out of her depth. Another long wait to next GP appointment. But was able to arrange a private Specialist appointment the same week. The Practice refused to give me a copy of the heart tracing. Had to pay for another privately as well as for the consultation. Amusingly, an NHS Cardiology appointment arrived nine months later.*

> *Having issues with stomach, asked to see a doctor. Doctor said he would refer onto gastroenterologist through NHS. Still having issues and no appointment offered in months. So went private and had an phone call next day and appointment the following day at [hospital].*

> *Don't answer phones. Can't get appointments. I have issues with shoulder and arm/hand. They said they'd refer me to hospital but I have not heard from them, It's taking a long time.*

Sometimes get appointment and sometimes don't. start calling at 8am and wait a long time but they didn't answer. They have too many patients. I give up with those people. Went to the GP for mental health issues and they prescribed me medication but I would like to do counselling. They said they would refer me on but they have not done anything yet.

Required a referral for shoulder operation and been ringing since Sept 22 no response at all and the worst 2 phone calls it took 140 and 204 calls before got though and then call was dropped, even walked into practise at 8.01 to be told we don't take appointments face to face, and rang in front of the staff only for call to be constantly dropped

I contract the surgery to report abdominal discomfort. I was sent for blood tests and an ultrasound. The clinician I spoke to said 'when the results come back we will be in touch' to arrange a gastro referral as a potential next step. I heard nothing for 3 months.

Lack of support or follow up for conditions

Men told us about times they felt their GP should have supported them more, or followed up on conditions they have.

Had a heart attack few weeks ago, Not even a phone call to see if I'm ok, or if any problem with tablets supplied.

The consultant told me that the doctor at the surgery would get a letter that I was to ask for a repeat prescription from them. I rang last week told no letter has come. I rang Friday the day my husband received his letter, no letter arrived. I rang this week got letter there but cannot get prescription but the doctor has got to read letter and then do the prescription. Phone back in the afternoon. I phone back but what they did not tell me they were closed in the afternoon. My husband needs these tablets. But I will run out before I get a supply. That is a disgrace.

I can't get appointments, I have to keep asking and need to chase them. It's not even easier to get an appointment for children and then they don't follow up after an appointment.

I had to change GP as it was clear they weren't going to give any support for my health crisis, life-risking condition, urgent referral or the pandemic.

Lack of interpretation services

We have heard from men with sensory disabilities about problems accessing an interpreter for GP appointments.

> *I went for diabetes and heart review and booked interpreter 2 weeks before going for an appointment but when I reached for appointment there was no interpreter. This has happened 3 times.*

> *I go for fit and health assessments. They are good and provide interpreter but if it is emergency than it's difficult to get interpreter.*

> *I went for appointment for my twin daughters and interpreter was not booked and I needed interpreter for myself because as a father I want to know what's going on.*

We look forward seeing the further work of the committee on this subject.

Yours Sincerely,

Sarah Walmsley

Data & Insight Officer