



Impact report: Better support for people on the NHS prostate cancer pathway in Birmingham and Solihull

June 2024





Executive summary

People in Birmingham and Solihull will benefit from improvements made to the NHS prostate cancer pathway by University Hospitals Birmingham NHS Foundation Trust (UHB), following Healthwatch Birmingham and Healthwatch Solihull's joint report [*Experiences of the NHS prostate cancer pathway in Birmingham and Solihull*](#) in July 2023. The report highlighted the importance of the service being responsive to the needs of users alongside patients' concerns regarding the lack of information about treatment options, the slow pace of treatment and limited post-treatment support.

After changes made in response to the report, people seeking care/support should now experience:

- Improved access to appointments and diagnosis
- More holistic needs assessments being undertaken
- Improvement in the post-treatment support they receive
- Improved experience of care and support

Background

When people seek help for prostate cancer, a quick diagnosis, treatment and post treatment support are vital. However, this is not always swift, appointments are not always available, and choice is hampered by a lack of information on treatment and potential side effects. There is also a lack of post treatment support and often support does not meet people's needs as holistic needs assessments (HNA) are often not carried out.

In July 2023, Healthwatch Birmingham and Healthwatch Solihull's investigation examined local people's views of screening services, treatment and care and support services for prostate cancer. Although a majority have a positive experience of the prostate cancer pathway, variability of experience exists and increases within the post-treatment support pathway.

Among the issues identified 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.
- Poor referral to support services for post treatment side effects.
- Low numbers of HNA carried out which meant that care and support was often not informed by people's needs.

Using the findings of the report, UHB has made important improvements to the diagnostic, treatment and support pathway for prostate cancer.

These include:

- Ensuring availability of appointments through staff recruitment.
- Carrying out more HNA to enable choice and understanding of needs.
- Offering more support with the side-effects of prostate cancer.

We would like to thank Healthwatch Birmingham and Healthwatch Solihull for conducting this valuable piece of research into local people's experiences of the prostate cancer pathway. We would also like to thank the 93 people who gave their time to participate in the research.

The value of hearing the voices and thoughts of people who have used our services cannot be underestimated. It is very reassuring to see that the majority of people who participated in the research had a positive experience of the prostate cancer pathway.

It is clear from the research, however, that there are areas that need to be further improved to support people who are in a prostate cancer pathway, specifically around empathetic communication, post-treatment follow-up, and side effects.

We will use the findings of the research to focus on and improve the specific areas that need attention, whilst we continually work to improve the services that we offer to local people."

- Jonathan Brotherton, Chief Executive, UHB

In May 2024, we wrote to UHB requesting evidence that the actions they committed to have been implemented, including details of the impact on patients. We requested evidence of:

- Empathic communication.
- Post-treatment follow-up (e.g. how many more people are being followed up since the publication of our report, what difference is this making etc.)
- What has been done to improve access and availability of services that provide support to those experiencing side-effects including post-treatment side-effects?
- Has a review been carried out to understand staffing numbers and can the Trust assure us that numbers are adequate thus providing the highest standards of care and treatment?
- How many clinical support workers (CSW) have been recruited and what improvements have been seen in the numbers of HNA carried out?
- What action has been taken to actively encourage patients to flag any concerns with the team? Has this improved the way patients raise concerns or engage with the Trust when concerns occur and has this enabled the provision of appropriate and timely support?

Progress and outcomes

UHB has provided the following details:

Improved access to appointments and diagnosis

Faster diagnosis is one of the NHS Long Term Plan ambitions and an accurate diagnosis is important to determine the stage of the disease and make sure the appropriate treatment is offered (NICE, 2020). UHB has:

- Revised the **GP referral form** and continues to work around primary care decision support tools to guide referrals.
- Transformed the **prostate cancer faster diagnostic pathway** so that it is much more streamlined. This has significantly brought down waiting times.
- Invested in additional **MRI and LATP (biopsy) capacity**.
- Started to recruit additional **surgeons, prostate oncologist and clinical nurse specialists (CNS)**, to further improve the pathway, and now have patient coordinators and training specialist biopsy nurses.
- Committed to increase the **Solihull Elective Hub** capacity for robotic prostatectomy and is also ensuring the urology service has optimised resource and capacity.

I recently attended a number of appointments here as part of an ongoing prostate cancer investigation. I am very happy with this service, the doctors and nurses have been great.

- Patient feedback provided by UHB, March 2024

Thank you [UHB staff] for your time yesterday and the clarity in which you delivered the results of my tests for prostate cancer and the treatment options available to me.

- Patient feedback provided by UHB, May 2024

I left feeling very positive of a successful resolution to my current diagnosis.

- Patient feedback provided by UHB, May 2024

More holistic needs assessments being undertaken

A Holistic Needs Assessment (HNA) enables good supportive care for people going through the prostate cancer pathway. Prostate Cancer UK notes that carrying out an HNA is associated with improved quality of life and outcomes. A HNA supports patient centred and collaborative care, and enables early intervention. Specialist nurses and high-quality patient information play a key role in providing supportive care.

- UHB now has two support workers that contact all new prostate cancer patients. They offer a HNA, provide support and signposting to other areas. Any concerns that are identified during the assessment are fed back to the patient's keyworker to address. This has had a huge impact, ensuring support is offered to patients across all sites.
- Patients can access cancer information services across the hospital sites at any point in their pathway. A HNA will be offered at any point in the patient's pathway if appropriate.

I have received outstanding care, treatment and support throughout my prostate cancer diagnosis and treatment. I have attended a number of various appointments with consultants and specialist nurses, and I have felt well informed and supported. I really cannot fault the services offered. – Patient feedback provided by UHB, February 2024

Many thanks for the clear and detailed information you gave me yesterday about my prostate cancer diagnosis and the treatment I'll be getting. – Patient feedback provided by UHB, May 2024

Improved post treatment support

Having a named specialist nurse who is easy to contact for information, advice and support can help people feel reassured that they are well informed and involved in decisions about their care. NICE's quality standard on prostate cancer says people with prostate cancer should discuss their treatment options and possible adverse effects with a named nurse specialist. UHB has told us it has made the following improvements:

- **Empathic communication:** cancer 'fail safe' officers and cancer support workers (CSW) support people on the prostate cancer pathway, acting as a point of contact for the patient, alongside the patient's named cancer CNS. Colleagues are supported and receive training to ensure that their communication is appropriate and empathic. We (UHB) strive to provide holistic needs assessment to all patients.
- **Review of staffing:** we (UHB) continually review our staffing numbers, to ensure that we are able to meet the needs of patients and that we are able to provide the highest standards of care and treatment.
- **Clinical Support Workers:** two clinical support workers have been recruited to support personalised stratified follow up and personalised care.
- **Encouraging patients to flag concerns:** patients are actively encouraged to make contact with their named cancer CNS, or via the admin team that support the service, with any queries or requests for support they may have. Patients who are on stratified follow up are offered a treatment summary which includes red flag symptoms and who to contact if they experience any. Patients on chemotherapy are provided with an alert card with the signs and symptoms during chemotherapy/immunotherapy; this includes contact numbers.

My experience has been very good. I have received good care from the prostate cancer team, having regular check-ups. The staff have been great, they are very informative, and communication is good. – Patient feedback provided by UHB, December 2023

Thank you for your time, guidance and sensitivity delivering the news of my prostate cancer. – Patient feedback provided by UHB, May 2024

I would like you [UHB staff] to know how very much I appreciate the care the team is giving me. – Patient feedback provided by UHB, May 2024



Next steps

Healthwatch Birmingham and Healthwatch Solihull welcome the details of change being made by UHB. However, some feedback we have heard since the publication of our report shows that these changes have not, or are yet to have, the desired impact on those on the prostate cancer pathway. People have shared concerns around choice and treatment options, follow-up post treatment, support from specialist nurses, information and communication.

I have recently been diagnosed with prostate cancer and they don't give you options at all. They just want to castrate you and send you on your way to dribble. I have asked them for other treatment options and if I hadn't done my homework they wouldn't have given me any options. I don't want to feel debilitated, and I feel that all options should be explored as it is affecting my mental health with the worry of the options from having the treatment.
- February 2024

I had care here when I had prostate cancer. Urology was good. I was referred quickly, and they helped me as much as they could. The follow up has not been the best and sometimes they don't explain everything to me. I need to sort out a GP to make sure I'm getting help for when my prostate flares up. - November 2023

My husband had prostate cancer and had surgery at the QE hospital but when he was transferred to Heartlands he had problems. When he had a meeting with the consultant they didn't even know he had surgery and spent the whole time in the session reading the notes not allowing time to ask questions. The integrated nurse that was supposed to be following my husband through his treatment never saw him again - October 2023

Healthwatch Birmingham and Healthwatch Solihull will continue to liaise with UHB to ensure that improvements made become business as usual leading to a positive impact on patients and their outcomes. We recognise that change will take time as evidenced by some of the experiences of the pathway people shared during the write up of this impact report.

To ensure positive progress, we will continue to listen to the experiences of patients seeking or receiving care and support for prostate cancer from UHB. All experiences shared with us will be shared with UHB to inform continued improvements to the prostate cancer pathway. We will also share these with other stakeholders such as the Care Quality Commission, BSOL ICB, HOSC, and Birmingham City Council.

Healthwatch Birmingham and Healthwatch Solihull would like to thank UHB staff, users of prostate cancer services in Birmingham and Solihull, their families and carers for their participation and involvement in this investigation.

Birmingham residents can share experiences by:

- Visiting the Healthwatch Birmingham online [Feedback Centre](#).
- Calling Healthwatch Birmingham on 0800 652 5278
- Emailing info@healthwatchbirmingham.co.uk

Solihull residents can share experiences by:

- Visiting the Healthwatch Solihull online [Feedback Centre](#).
- Calling Healthwatch Solihull on 0808 196 3912
- Emailing enquiries@healthwatchsolihull.org.uk

About us

Local Healthwatch were established in every local authority area across England following the Health and Social Care Act 2012. Our key role is to ensure those who commission, design and deliver health and social care services hear, and take into account, the public voice. Healthwatch Birmingham and Healthwatch Solihull listen to and gather public and patient experiences of using local health and social care services such as general practices, pharmacists, hospitals, dentists, opticians, care homes and community-based care. We hear these experiences via our Information and Signposting services, our online Feedback Centres and through our community engagement activity led by staff and volunteers.

Read more about the work of [Healthwatch Birmingham](#) and [Healthwatch Solihull](#).

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Birmingham






Healthwatch Birmingham
PO Box 16875
Birmingham, B16 6TN

-  www.healthwatchbirmingham.co.uk
 -  0800 652 5278
 -  info@healthwatchbirmingham.co.uk
 -  @HWBrum
 -  facebook.com/HealthwatchBirmingham
-

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Solihull

Healthwatch Solihull,
Enterprise Centre, 1 Hedingham Grove,
Chelmonds Cross, Chelmsley Wood,
Solihull, B37 7TP

-  www.healthwatchsolihull.org.uk
-  0808 196 3912
-  enquiries@healthwatchsolihull.org.uk
-  @HealthwatchSol
-  facebook.com/HealthwatchSolihull