NHS
Wessex
Cancer Alliance

Improving prostate cancer diagnosis across Dorset, Hampshire and Isle of Wight

The views of patients, care-givers and the public

December 2023

Key messages

- There needs to be clearer, more consistent public messaging about prostate cancer; all prostate cancer diagnostic tests, especially PSA tests; the benefits and risks of tests; and the prostate cancer pathway end to end. This should be aimed at encouraging men to seek help earlier.
- Overall feedback was that the prostate cancer diagnostic process needs to ensure the maximum number of people can benefit from a speedy diagnosis; whilst being mindful some people may need more time or steps in this process for a variety of reasons.
- It was felt that GP testing could be better streamlined to speed up time to hospital referral and therefore diagnosis.
- Most people preferred the proposed one stop option (see below) because of its convenience; with options 2 and 3 stage pathway being available to accommodate those who may need more time. An alternative option was offered.
- Any good patient journey will be predicated on clear and accessible patient information delivered in a variety of ways, including being able to speak to a person, from the GP and throughout the diagnostic pathway.

Background

An inaugural focus group of 16 plus[1] patients, care-givers, family members and the public was held in December 2023 to discuss how prostate cancer diagnosis could be improved across Dorset, Hampshire and the Isle of Wight. Feedback was also received by email and during an information meeting from 3 other people.

Discussions focused on the part of the cancer pathway from the point a GP referral is received by the hospital to diagnosis; although people highlighted important concerns about issues related to steps prior to a referral for diagnosis, and around treatment.

Three diagnostic pathway options were presented and people were asked their views on the pros and cons of each of them. They were also asked about what patient information would be useful to them at each part of the different pathways, and how and in what format they would like to receive it.

This report provides some key messages, as well as more detailed findings. These will be shared at a 'Pan-Wessex Prostate Cancer Deep Dive' workshop with clinical teams involved in improving how prostate cancer will be diagnosed across the area.

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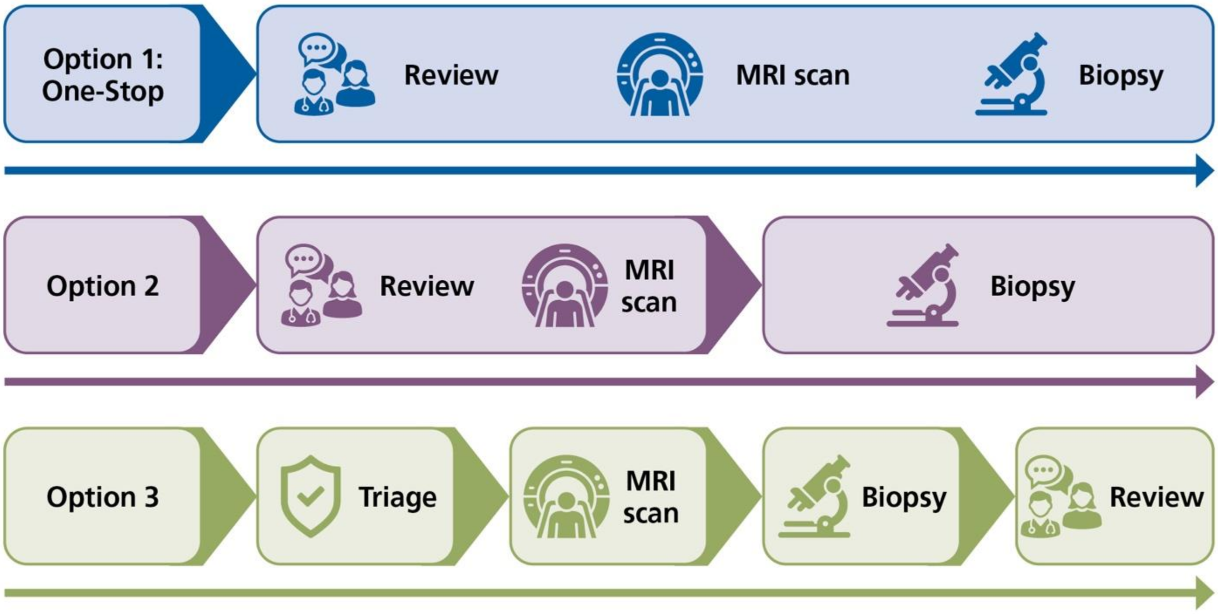
[1] Two more were unable to stay for the full event

An introduction to the prostate cancer diagnostic pathway review

The Faster Diagnosis Team have been meeting with colleagues from Hampshire, Dorset and the Isle of Wight to understand what happens to people when their GP writes to the hospital to carry out further tests for a suspected prostate cancer. This is to find out the different steps in the processes, how they run and how they are currently working across the area.

Figure 1. Options for the potential prostate cancer diagnostic journey



Three potential options for people suspected of having prostate cancer are being considered. Option one being a one stop shop; two a two staged process; and three having more stages (shown above).

Each of the options include a review of any tests undertaken by the GP. In the first and second model, the GP test results and next steps will be explained to the person by a clinician. The clinician will assess people to ensure they are fit enough for the tests, arrange the tests and ensure they are not put through unnecessary ones.

In the third model the clinical team reviews the results and plan the next steps and this is communicated to (rather than discussed with) the person with suspected cancer.

The next steps in terms of diagnosis is an MRI scan, which allows identification of suspicious parts of the prostate. Then if needed, a biopsy is undertaken, which samples of this tissue.

Detailed findings

Participants were keen to ensure the maximum number of people benefit from a speedy diagnosis, and a good patient experience for anyone going through a prostate cancer diagnosis. Consideration of these findings will support this outcome.

Awareness of prostate cancer

There needs to be more prostate cancer awareness – including that there are different types and therefore treatment may vary. Men, trans women, non-binary and intersex people should be encouraged, including through their partners, to seek help from primary care. The higher risk of prostate cancer for Black men should be communicated, both to those likely to be affected and to GPs.

GP testing

Questions were asked about whether GP processes could be streamlined and sped up, as this currently requires multiple trips prior to getting a hospital referral. Someone asked if greater priority is given to referring a person who has delayed seeking advice/ a PSA test.

People's experiences of GPs granting PSA tests varied widely, especially if people didn't have any symptoms and for Black men who are at higher risk. This was a key concern to participants.

People shared that Digital Rectal Examinations (DREs) are not routinely conducted. For some people, a DRE is a barrier to seeking help. For others it had been useful to determine that there was an issue and helped with the decision to proceed to biopsy.

More information is needed to clarify men's rights to request PSA testing, as well as greater awareness of the tests undertaken by GPs, when they are deployed and why, how useful they are, and the benefits and risks of undertaking them.

People should be encouraged to use the NHS app so they can check their own results and follow up if necessary. This would need to be supported by clear patient information about what the results mean.

Preferred diagnostic pathway options

The preferred option for most people was the 'one day (4-6 hour), one stop option'.

People felt that the more that can be done in one appointment the better. This includes people from racially minoritised communities. Seeing the same set of clinicians on one day would also provide consistency of care.

This option would lower the burden around practical issues for people. It would require less time off work for those who are working. Weekend appointments would be welcomed too. The cost of travel and parking for multiple trips, especially from the Isle of Wight, is expensive. It may also reduce any potential 'excuses' people could use to not engage or to miss additional appointments. People also saw it as much more efficient for the NHS.

The group did however feel that the 'two stop option' may be preferred by some who may need more time to digest information and make informed choices; recognising that this is a lot for people to take onboard and do. People with a Learning Disability may need even more steps in the process (option 3).

A frailty screening prior to referral should be built into processes to ensure people receive the right care for them. People could be asked to complete this online, by phone or in person prior to hospital attendance to save time.

There was some concern that option 1 will not be deliverable in terms MRI capacity. People asked about what happens for those who do not need a biopsy, as well as whether the service could be delivered in community settings closer to people.

With options 2 and 3, it was recognised that with more stages there may need to be more follow up with people to support them to stay engaged in the process. It should be noted that some people said they would choose services a local town/city even if there are more stages to the process rather than travel to a town/city further away.

In each of the options, carers should be facilitated to support the person throughout.

An alternative option

One participant suggested that a concerning PSA test result would automatically trigger a referral for an MRI scan rather than having to go back to the GP for another consultation. An MRI would be arranged and undertaken and then there would be a review conversation with the person. This would include a discussion about a biopsy. This could all be done as a one stop option – or if needed have more steps in the process.

Information

Participants felt that there needs to be clear, jargon free and accessible information provided at each stage of the diagnostic pathway – from the GP all the way through to diagnosis.

Giving reliably sourced information in the right way early in the process will allow people to know what to expect in terms of timeframes and processes, ask questions and consider their options. This would clearly need to explain the different approaches across the area to allow people to choose.

Some people will want more detailed information than others at the different stages so the approach should be tailored. Some felt that GPs would be key in this process, as well as be good judges of how much information to give people. Those with partners or care-givers recommended having another 'set of ears' at appointments to help digest the information and ask questions.

Information should be given in a variety of formats – verbally, written, subtitled videos (including stories from people with lived experience), alternative formats (BSL, Easy Read) and in different languages. Information needs to be culturally informed.

People would value speaking to a 'specialist' and having someone to ask questions of, where necessary with the use of interpreters, once referred to the hospital. Some would like to see all their imaging alongside these conversations.

All information needs to provide reassurance and encourage people to participate.

Other support needed

It was recommended that emotional support was provided through the process, especially at the point of diagnosis.

Next steps

Once this report has been discussed with the clinical review group, an improvement action plan will be produced and shared with the focus group participants.

Further public facing conversations need to be arranged to inform the review, including:

- With people with learning disabilities, and other disabled people, about how to make this process accessible to them
- How people want to receive the results of the hospital tests
- How people can make informed decisions with clinicians about treatment options
- PSA testing and its role in diagnosing prostate cancer

It is also recommended that the Review Team discuss with colleagues how primary care prostate cancer diagnostic processes can be streamlined.

Contact details

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