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How and under which circumstances does a rapid diagnostic pathway for prostate cancer work to reduce anxiety for patients? A realist evaluation based on patient, caregiver and staff perspectives

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ABSTRACT

Introduction Referral to a cancer diagnostic pathway is a stressful life event, yet distress may be exacerbated by long waiting times, miscommunications or other avoidable challenges. A model prostate cancer (PCa) rapid diagnostic pathway (RDP) called Prostad has been developed and trialled to reduce the time between referral or diagnosis. This realist evaluation asks how, for whom and under which circumstances this model RDP may reduce anxiety for patients.

Research design and methods We conducted semi-structured realist interviews with staff, carers/ partners of patients and patients exploring how, for whom and under which circumstances the PCa RDP produced intended and unintended outcomes. We also attended monthly programme development meetings and had access to documentation regarding the pathway and its development, which we used to produce theories regarding the contextual and mechanistic factors influencing patient experience of the RDP.

Results We interviewed staff (n=12), patients (n=15) and partners or carers of patients (n=3) to produce five programme theories regarding how patients interact with Prostad to produce outcomes. These theories are organised under five themes: rapidity; communication and virtual consultations; communication and continuity; disempowerment and distress; agency mitigating anxiety.

Conclusions Earlier diagnosis is viewed positively by participants; however, in a context where patients have low expectations of health services, the speed of RDPs needs to be adequately communicated at the time the pathway is introduced to the patient to avoid unnecessary concern regarding the rapidity. Patients value regular and consistent communication, which may help mitigate illness uncertainty and offer a sense of control.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Health providers are increasingly experimenting with rapid diagnostic pathways (RDPs), particularly for cancer diagnosis.
- ⇒ Research and evaluation on RDPs for prostate cancer diagnosis generally suggest that this approach does decrease time to diagnosis, which is viewed favourably by patients and medical professionals.

WHAT THIS STUDY ADDS

- ⇒ To our knowledge, this is the first realist evaluation of a prostate cancer RDP.
- ⇒ Our focus on patient voices adds crucial information regarding how patients experience these pathways and highlights areas where simple adjustments—like consistent communication—can have important benefits to patients.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The evaluation of this pathway will inform and support the development of this and similar pathways through opportunities to ‘scale up’.
- ⇒ This evaluation may be used to inform practice and pathway design elsewhere.
- ⇒ It will inform local practice and contribute to a growing body of evidence that may influence policy regarding diagnostic processes.

INTRODUCTION

Referral to a cancer diagnostic pathway is a stressful life event. Patients often feel a conflict between appreciating the medical advantages of swift action and their need for time to reflect and process what they are going through.[1] The time between referral and diagnosis or discharge constitutes a period of illness uncertainty. Illness uncertainty can occur at any time from the onset of symptoms and may remain with a person even when they become well, as the knowledge of illness and fear of recurrence remains. As a concept, illness uncertainty is defined broadly as a complex cognitive stressor[2] and a non-linear, fluctuating process.[3]

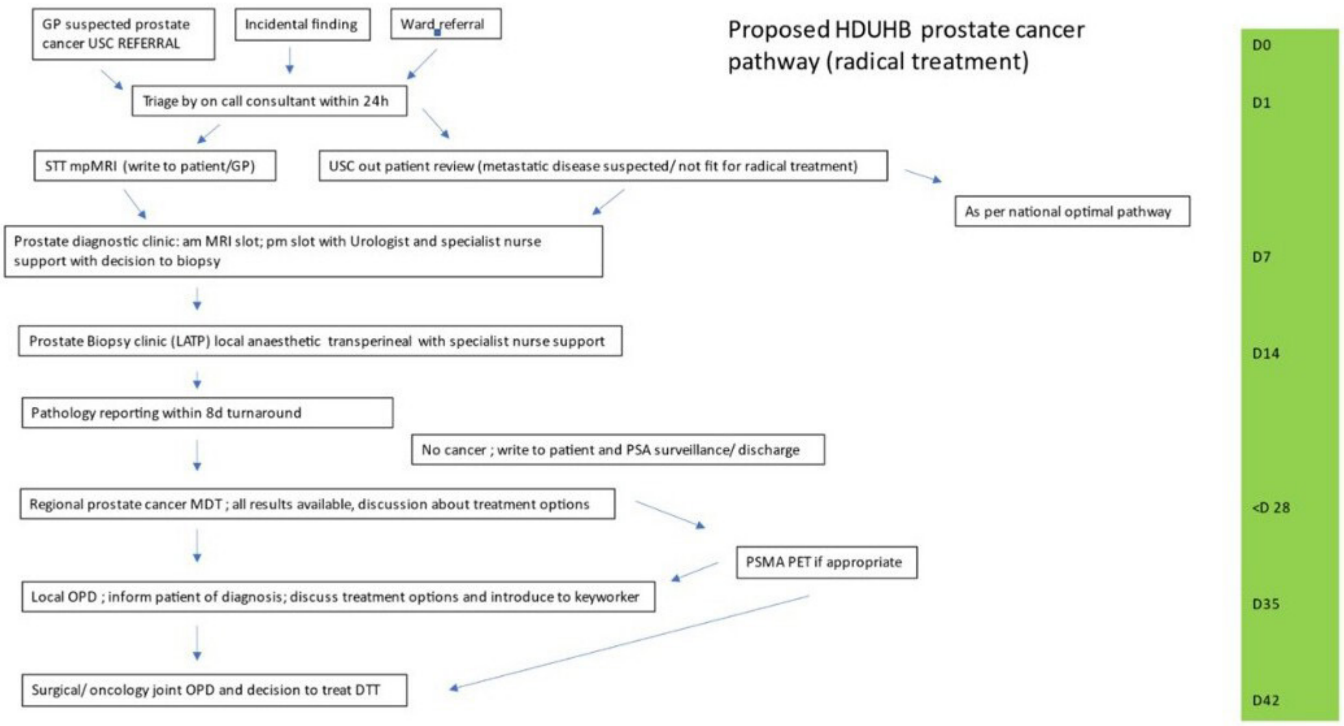

Figure 1 Prostad pathway. This reflects how Prostad is intended to work, its time goals, etc. DTT, decision to treat; GP, general practitioner; HDUHB, Hywel Dda University Health Board; LATP, local anaesthetic transperineal; MDT, multidisciplinary Team; mpMRI, multiparametric Magnetic resonance imaging; OPD, out-patient department; PSA, prostate-specific antigen; PSMA, prostate-specific membrane antigen; STT, straight to test; USC, urgent suspected cancer.

Although illness uncertainty is a normal part of life, it is intensified by prolonged waiting times between recognising symptoms and receiving a referral, test results, treatment delays and inadequate communication.[4] Most patients do not delay visiting the general practitioner (GP) if they experience concerning symptoms,[5] but in cases where individuals have been experiencing vague symptoms, they may have already been managing uncertainty for some time prior to interaction with medical professionals.[6]

Rationale

In the UK, prostate cancer (PCa) is the most common form of cancer affecting men or those assigned male at birth,[7] and patients regularly experience delays to diagnosis, particularly prior to referral (ie, in primary care) and during the diagnostic phase.[5] Rapid diagnosis pathways (RDPs) constitute one approach to reducing the time to diagnosis by reducing the number of steps in the diagnostic pathway and/or initiating new ways of working to provide faster results.[8–11] A systematic review of RDPs found that they reduce time to diagnosis or discharge.[12]

In 2024, a PCa diagnosis RDP was trialled in Wales with a view to implementation, if effective. The pathway is called *Prostad*, Welsh for *prostate*. Figure 1 illustrates Prostad's features and time goals; figure 2 depicts the standard or conventional (non-RDP) pathway for comparison, and the average time spent at each step of the diagnostic process. The aim of Prostad is to reduce time to diagnosis or discharge, with an expectation that this will have clinical and experiential benefits for patients. This paper explores the potential experiential benefits, specifically reduced patient anxiety. The findings reported here are part of a larger evaluation; the protocol was published as a preprint in July 2024.[13] The pathway and its evaluation are part of Cancer Research UK's (CRUK) Test, Evidence, Transition programme. This paper is organised according to the RAMESES framework[14] (see Supplementary Material: Research Checklist).

Normative theories

We use the term normative theories to refer to assumptions regarding how Prostad should work, that is, without consideration of contextual or mechanistic factors that may support or impede its intended outcomes. We based normative theories on documentation describing Prostad's development, conversations with those who designed the service and attendance at monthly project meetings (figure 3). The intervention is described in greater detail under 'Methods' section. The normative theory associated with patient experience is that reducing the time to PCa diagnosis or discharge will improve patient experience by mitigating unnecessary anxiety. This is the focus of this article.

Objectives

We examine patient, caregiver and staff perspectives of Prostad, a model PCa RDP, to develop and refine theories regarding how and under which circumstances Prostad works for patients. The term programme theory refers to an advanced theory developed through direct evaluation of the intervention. Programme theories consider the contextual

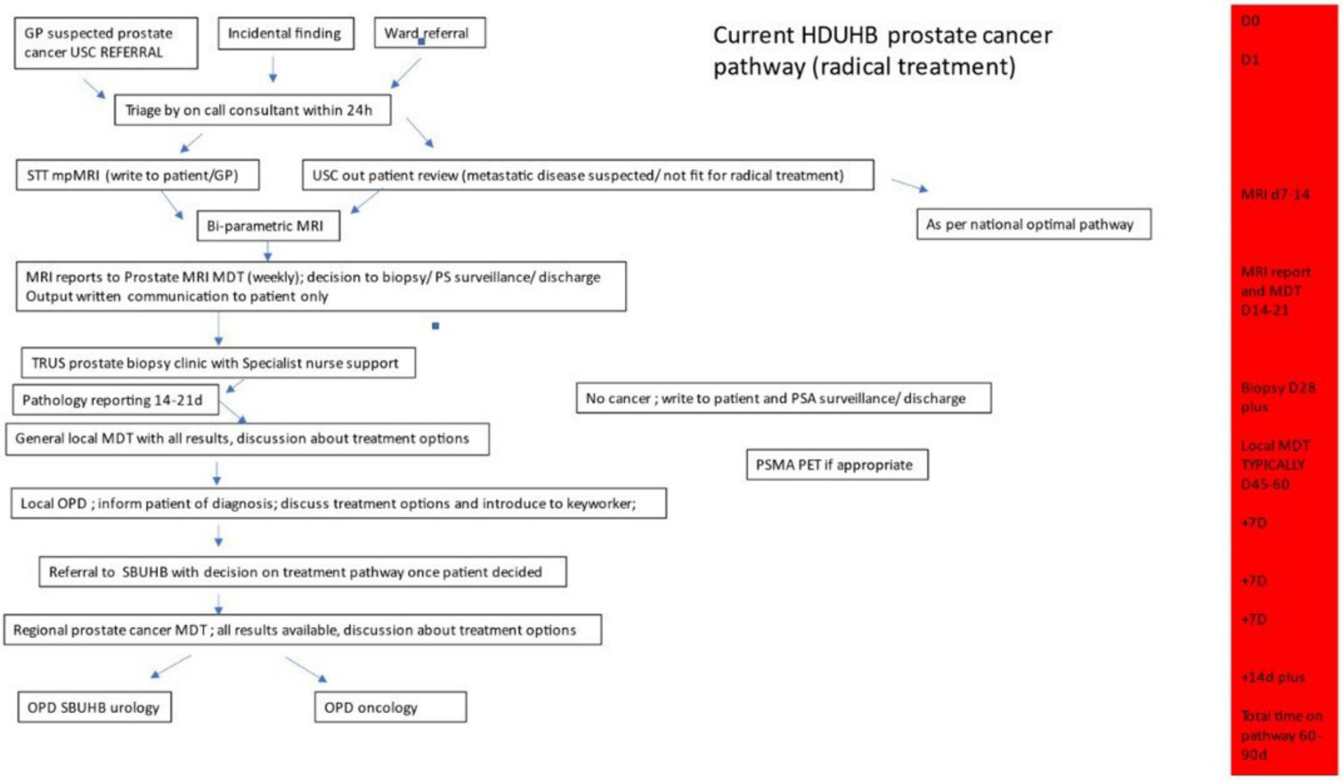

Figure 2 Conventional pathway. This is the standard prostate cancer diagnostic pathway for non-Prostad patients and illustrates the time patients spend on the pathway based on routine data prior to Prostad's development. DTT, decision to treat; GP, general practitioner; HDUHB, Hywel Dda University Health Board; LATP, local anaesthetic transperineal; MDT, multidisciplinary Team; mpMRI, multiparametric Magnetic resonance imaging; OPD, out-patient department; PS, prostate surveillance; PSA - prostate-specific antigen; PSMA, prostate-specific membrane antigen; SBUHB, Swansea Bay University Health Board; STT, straight to test; TRUS, transrectal ultrasound; USC, urgent suspected cancer.

and mechanistic factors specific to the environment to which the intervention is introduced. Specifically, we identify:

- contextual factors influencing patient experience of Prostad;
- mechanisms by which Prostad produces intended and unintended outcomes for patients.

This paper focuses on patient perspectives, as well as caregiver and staff beliefs regarding how Prostad may mitigate patient anxiety.

METHODS

Rationale for realist approach

Realist evaluation[15] is a theory-driven approach to understanding how, for whom and under which circumstances an intervention works or fails to work. This approach holds that interventions by themselves do not produce outcomes; rather, it depends on how individuals respond to them.[16] While we want to know whether Prostad works, we also want to understand how and under which circumstances it produces intended and unintended outcomes. As a multistep intervention introduced into a complex system involving multiple actors with divergent responsibilities, realist evaluation constitutes an appropriate methodology to achieve this granular understanding.

Theory development

We used normative theories to inform search approaches for a rapid realist review, published in 2024.[17] The findings of this review alongside conversations with our patient and public involvement (PPI) group and attendance at monthly project meetings (attended by urologists, cancer nurses and the evaluation team) informed a series of initial theories, which in turn guided the development of realist interview questions. We distinguish between normative, initial and programme theories to indicate the iterative process of theory development. Programme theories are more advanced than both normative and initial theories in that they are produced cumulatively and expressed as causal chains that establish connections between context (C), mechanisms (M) and outcomes (O) (CMO chains).

Patient and public involvement

A PPI group consisting of men who had been diagnosed with PCa shaped this evaluation. Members of the group were compensated for four meetings over the course of the project, focusing on evaluation questions (including scope and interview questions), data analysis (involving interpretation of anonymised participant transcripts) and dissemination.

Context	Inputs	Outputs	Short-term outcomes	Longer-term outcomes
Delays to MRI scans and results, caused by: • Radiology referrals 'bouncing back' to GP due to unfulfilled/unclear referral criteria. • Delays to radiology reporting (due to resources and efficiency issues) Rural and older population. Positive experiences in pathway reform for lung and breast cancer diagnosis	Evidence and guidelines, for example, NICE, evidence relating to efficacy of multiparametric MRI scanning, evidence suggesting reduced risk of infection for LATP biopsies compared to TRUS. Process mapping, including: • Formal & informal conversations between urology, GPs, radiology and service improvement leads; SBUHB & HDdUHB • Working with students writing MSc dissertations on following topics: 1. PCa diagnosis delays (eg, bottlenecks in process); 2. Role of patient navigators; 3. Patient experience of RDPs. LATP training for staff	Redesigned PCa diagnostic pathway, Prostad: • Refined and mutually agreed referral processes; • eight dedicated MRI slots at two locations (Bronglais & Withybush) • Multiparametric MRI scanning; • MRI results within 48 hours of scan; • LATP biopsy same day as MRI results if appropriate Workforce trained in LATP biopsies Routine adoption of gold standard diagnostics of multiparametric MRI and LATP into the diagnostic pathway. Training and pathway documentation to aid role out across Wales and the UK	Improving patient communication, experience and outcomes during and beyond their time on the pathway Reduced patient anxiety Reduced time to PCa diagnosis or discharge for patients referred to Prostad compared with conventional pathway. Improved efficiency. Fewer complications and infections at biopsy stage	Better clinical outcomes for patients receiving a PCa diagnosis, eg, diagnosed at an earlier stage with more treatment options Improved integration between health boards (SBUHB and HDdUHB) Cost benefit of fewer infections/hospital stays at biopsy stage

Figure 3 Logic model. Prostad normative theories. GP, general practitioner; HDdUHB, Hywel Dda University Health Board; LATP, local anaesthetic transperineal; NICE, National Institute for Health and Care Excellence; PCa, prostate cancer; RDP, rapid diagnostic pathway; SBUHB, Swansea Bay University Health Board; TRUS, transrectal ultrasound.

The model PCa RDP

Context

The Prostad pathway received its first referrals in June 2023. The service is provided by Hywel Dda University Health Board (HDdUHB), which serves a rural area in West Wales (UK). The Hywel Dda region's clinical services are dispersed across a rural landscape and provide for a large, widespread ageing population with a higher relative incidence of PCa compared with the rest of Wales and the UK.[18] Diagnostic resources and capacity are distributed across multiple sites across a large rural area; distance between two key sites is around 70 miles (around 2 hours by car) with poor public transport links. Patients referred to HDdUHB's PCa standard diagnostic pathway were likely to experience delays to diagnosis. Figure 2 shows the average waiting times between procedures for the conventional pathway.

The pathway

The Prostad pathway focuses on reducing the time to diagnosis by streamlining and shortening the pathway at key points; the pathway does not directly address the period after diagnosis (ie, diagnosis to first treatment). Prostad requires staff to work differently, dedicating MRI slots one morning a week to Prostad patients and interpreting and reporting on the scans within 24 hours to deliver the results to patients by phone consultation the following day. Prostad also incorporates local anaesthetic transperineal (LATP) biopsy techniques, as opposed to transrectal ultrasound (TRUS) biopsies. The normative theory underpinning these changes are that they will support a reduction in time to diagnosis (or discharge), producing more desirable clinical and experiential outcomes (eg, earlier diagnosis of PCa at an earlier stage, which is associated with improved treatment options and survival). This evaluation focuses on patient experience of the pathway and the theory that reduced waiting time is associated with reduced anxiety. The pathway's normative theories (ie, how Prostad should work) are described in figure 3.

Data collection

The evaluation is a partnership between HDdUHB, Swansea University and the TriTech Institute, which is an NHS Wales research and innovation organisation that supports and conducts research and evaluation.

Pathway documentation

We attended monthly project meetings, where a researcher (KJ) took notes by hand. Project meetings were attended by service-related staff at HDdUHB (urologist, cancer nurse, etc) and the evaluation team (Swansea University and TriTech). Project meetings occurred monthly throughout the trial and the implementation of the pathway's steps was discussed. The accuracy of these notes was verified through conversations with the project lead and against available documentation. We also used literature related to the development of the pathway (eg, documents composed during the development phase, like funding bids) to inform our understanding of how the Prostad pathway is intended to work and to document any changes to the pathway during the implementation process.

Interviews

Swansea University researchers were only granted access to anonymised data; TriTech Institute researchers (AC; JC) collected and anonymised interview data. The TriTech Institute is an NHS Wales organisation; its staff are unaffiliated with provision of the Prostad pathway.

Semi-structured realist interviews using an interview schedule were conducted by phone or conferencing software (depending on preference) and recorded, anonymised and transcribed (JC and AC). As per the realist methodology, interview questions were adapted, supplemented or reformulated at the direction of Swansea University researchers (KJ and JR) as our understanding evolved through data familiarisation and the involvement of the PPI group.

Convenience sampling was used. Patients were contacted and invited to participate based only on the fact of their referral to the pathway. Interviews occurred between February and May 2024 and we interviewed as many patients as possible during that time. Anonymised transcripts were securely shared for analysis with Swansea University researchers (JR and KJ) via OneDrive. Participants' verbal informed consent was obtained and recorded by the interviewer.

Inclusion/Exclusion

All participants are adults (aged 18+ years); we invited patients referred to the Prostad pathway, partners/carers of patients and stakeholders perceived to be involved with Prostad's delivery, these included urologists, service delivery managers, radiologists and GPs.

Recruitment

Patients and partners/carers of patients who have been referred to Prostad were initially contacted by phone by TriTech Institute researchers (JC and AC) and invited to participate in interviews.

We aimed for three to five carer/partner perspectives; we asked patients if they had a partner or carer who might be willing to be contacted and interviewed separately to the patient.

Twelve stakeholders were identified in advance (eg, referring GPs, urologists, radiologists, etc) and invited to participate in phone or Zoom/virtual interviews; all agreed.

Data from other sources

Routine data—including Gleason scores, diagnosis details and sociodemographic data—were collated by another research team to inform separate work packages. We had access to these data via a currently unpublished report submitted to the project funder (CRUK) in September 2024.[19] We use the information they collated regarding timeliness, that is, how long patients spent at each stage of the Prostad pathway.

Analysis

A researcher (KJ) read and thematised the anonymised transcripts in NVivo (V.1.7.1 1999–2022); themes were read and checked for agreement (JR). While thematisation and interpretation were guided by normative and initial theories,[17] we aimed to take an open approach to thematisation in order to remain alert to how the specificities of context may challenge normative and initial theories. After thematisation, we organised the data into an Excel spreadsheet, organising data to produce CMO chains. We also had access to the currently unpublished findings from an economic evaluation,[19] which provided data regarding clinical and cost-effectiveness evaluations, and we used this information to support theory development (table 1).

FINDINGS

From the start of the pilot to the end of data collection (February–May 2024), 117 patients were referred to Prostad. Eighteen realist interviews were conducted with patients (n=15) and patients' partners/carers (n=3). This is the maximum number we were able to recruit for participation within the evaluation's timeframe. Twelve realist interviews were conducted with other participants

Table 1 Theory development

Initial programme theory (rapid realist review)	Data themes	Representative quotes (C)	Representative quotes (M)	Representative quotes (O)	Refined programme theory 1	Refined programme theory 2
If ‘Cancer’ constitutes a frightening word that potentially engenders an existential confrontation with mortality (C), then a pathway with fewer steps (eg, phone call consultations, rather than in-person) and materials that assuage anxiety (M) will lead to relief and reassurance, minimising the amount of time spent in an anxious waiting phase for cancer-free patients (O). Conversely, patients who receive a PCa diagnosis will have undergone diagnostic tests and received a worrisome result in a short period (M), potentially leading to greater shock, poor absorption of information and diminished decision-making capabilities (O).	Communication; rapidity; emotions; anxiety; waiting and delays; errors and confusion	“they’re just seeing and hearing the word cancer, you know” (PS1, urology); “It’s [the MRI scanner] like being in a coffin” (P10)	“It’s just the way the systems are, bureaucracy going from department to department” (P8); “right now, I am alone(…)what is my case? I have no idea. I called in one hospital, urology department. I called last week, the urology department, and nurse only promises call you, they inform you. But they call, open my case in computer and say ‘no result’ and stop” (P1); “I had to ring again because they never came back to me, but they eventually did get through after a week and they sorted it within a few days and I have this appointment which I am attending tomorrow. Clearly, there is a problem with the administration, I think. It doesn’t help the anxiety of the patient, having to make these phone calls and find out that you are no longer on the list” (P6); “I had a phone call from one of your urology nurses—like a clinical one, like, she was like a specialist. And then that opened up a whole avenue of support from them … no, I wouldn’t say counselling. I have had counselling that was provided. There was a support”. (P13)	“I was in within weeks. So, it’s just getting the diagnostics done quickly, if there’s a problem, hopefully I can do something about it” (P9); “It was just the speed at which it was that they were able to give me that information truthfully and it basically pushed me up the process rather than, you know, wait anxiously for a week or fortnight’ (P13); it was really sort of speedy and positive, and I was well looked after”. (P9)	Exacerbated distress: in the context of a busy system in which errors and long waiting periods may occur (C), repeated frustrated attempts to contact health professionals (M) and a lack of recourse should errors occur (M) during long periods without communication and of not knowing what is happening with their care (M) engenders a forced passivity (M), which in turn may lead to exacerbated feelings of distress, disempowerment and a sense of hopelessness (O); “if it’s good news or bad news, it’s nice to know as soon as possible”. (P14)	Mitigating unnecessary distress through agency: illness constitutes a loss of control (C). Patients who experienced the pathway as consistent and the staff as communicative and supportive (M), experienced a greater degree of agency (M) that mitigated against unnecessary forms of distress (O), such as feelings of ‘objectification’ and forced passivity.

Continued

Table 1 Continued

Initial programme theory (rapid realist review)	Data themes	Representative quotes (C)	Representative quotes (M)	Representative quotes (O)	Refined programme theory 1	Refined programme theory 2
If 'Cancer' constitutes a frightening disease and is a word that potentially engenders a confrontation with mortality (C), then patients who receive the all-clear (M) may experience reduced anxiety or a shorter anxious period (O). Conversely, patients may experience the speed as disorientating, related to severity (even in cases where they receive the all-clear) and sudden with less time to digest important information (M), which may lead to longer lasting psychological symptoms (eg, anxiety or depression) in the case of those receiving a PCa diagnosis and/or diminished decision-making abilities (O).	Communication; anxiety; mitigated anxiety; rapidity; patient emotions; perceptions/expectations of the NHS and health services	"they're just seeing and hearing the word cancer, you know" (PS1, urology); "It's [the MRI scanner] like being in a coffin" (P10); "The thing is, you think that you know that deep down there is something wrong, but when you keep being told it's nothing, you take their (the GPs) word—but then still you've got that niggle" (P18, carer)	"I had a concern and I was basically sent to hospital to have a scan within a few well within a week or so, so I was quite impressed by it to be honest" (P3); "they said you'll get a phone call tomorrow from the consultants with the results, which, again, you know, I mean that's something that you think's going to take a couple of months" (P7, carer)	"he was making an urgent referral for the—to(…)the urology department which at that time came as a huge shock to me(…)it was urgently arranged for me to have an MRI scan and that happened within 10 days of that initial referral' (P13)"; "They needed kidney function as well which I haven't done. I literally had just the PSA reading. So… may have been a confusion that this all was happening so quickly—and to get the blood test done before I went into the MRI" (P2); "couldn't fault it—we're just we were in a little bit of the daze because of the speed of it all to be honest" (P7, carer); "if I was a single guy on my own(…) then all this could easily get confusing". (P8)	Rapidity and expectations: Referral to a cancer diagnosis pathway is a distressing life event (C). The patients we interviewed had low expectations of NHS services (M). In cases where there was good communication regarding the pathway (M), patients were impressed or pleased with the speed of the pathway (O). In cases where there was poor communication regarding the pathway's purpose (M), this led to a (false) belief that the speed was proportional to the seriousness of their condition (O).	Continuity and confusion: for many people, the inner workings of health service processes are oblique (C). In a rural area where services are dispersed (C), the multiple centres and departments involved in the patient's care and the receipt of lots of information in a short timeframe (M) contributed to a sense of confusion (M), compromising patients' ability to manage their care (O), retain information (O) and discern who to contact (O).
If a PCa rapid pathway is implemented in a remote area (C), then patients may find virtual consultation more convenient due to the fewer hospital appointments required (M), leading to greater engagement with the service (O).	Communication; virtual communication; speed; emotions; geography and travel; continuity of care	"If I'm brutally honest, I think the treatment (sic. P10 referring to diagnostic pathway) is spread far and wide over West Wales" (P10); "I think if you're an older chap, particularly relying on public or hospital transport, it could be quite a bit of a drag up there". (P12)	"It's a very fluffy time and it's—sometimes it's like trying to make the right time. So, if I knew for a fact that Doctor Jones or whoever is going to phone me at 4:30 on the dot, I can prepare" (P12); "It was just the speed at which it was that they were able to give me that information truthfully and it basically pushed me/that up the process" (P13); "I was fine over the phone because most of the correspondence I've had, other than when I was requested to go in and see the consultant, everything else has been over the phone" (P13)	"over the phone for me personally has been fine" (P13); "I would not be bothered to be told over the phone, now from face to face" (P14); "I had an appointment at [hospital] for the MRI and then within 48 hours, I believe I had a phone call from the specialist to say 'Yes, we need to give you a biopsy'. So, within three weeks I had the biopsy. And within three weeks after that, I had the results. So, I got to say, it was really sort of speedy and positive, and I was well looked after". (P9)	Virtual Consultations: In a post-Covid world where people may be used to virtual communication and a geographically dispersed area (C), patients who had previous experience of phone consultations believed that they sped up the process or pushed their case forward (M), leading to greater acceptability of virtual consultations (O) (with some caveats relating to communication and organisation)	Virtual consultations: in a rural area where virtual consultations are preferred (C), in cases where patients do not receive an exact time for a phone consultation (C), virtual consultations are perceived as unpredictable (M), inhibiting patients' ability to prepare and feel in control (O).

GP, general practitioner; NHS, National Health Service; PCa, prostate cancer.

and staff stakeholders (PS) who were identified as playing key roles within or adjacent to the service. We indicate the role of stakeholder participants, but due to the small pool of potential participants, we do not provide demographic information as this would compromise our efforts to preserve anonymity.

We know from time-stamp data that, during the pilot period, Prostad reduced the average time to diagnosis or discharge by 28 days from a 98-day average to a 70-day average when compared with the conventional PCa diagnostic pathway.[19] Most time was saved at the 'front end' (ie, MRI referral, scan and results) with biopsy and results taking longer than planned.[19] The urology department needed to build capacity to perform LATP biopsies (in terms of training staff and implementing this practice within the health board) concurrently with Prostad's trial, which impacted the time to biopsy during the pilot period for some patients.

We propose five programme theories, organised under five broad themes. Representative quotes from which we developed themes and programme theories are stated below and further supporting data extracts can be viewed in table 1.

Rapidity

A number of factors influenced patients' experiences of rapidity. Many cited low expectations of health services, which led to surprise at the speed of their MRI referral, scan and results. For some, poor communication of the pathway's purpose rendered this speed a shock that was potentially concerning:

> [the GP] was making an urgent referral for the—to […] the urology department which at that time came as a huge shock to me (P13).

Other patients also expressed surprise at the pathway's speed, but did not link it with severity. For these patients, the speed was received positively:

> I had a concern and I was basically sent to hospital to have a scan within a few well within a week or so, so I was quite impressed by it to be honest. (P3)
> they said you'll get a phone call tomorrow from the consultants with the results, which, again, you know, I mean that's something that you think's going to take a couple of months. (P7, carer)

Theory 1, rapidity and expectations

Referral to a cancer diagnosis pathway is a distressing life event (C). The patients we interviewed had low expectations of NHS services (M). In cases where there was clear communication regarding the pathway's purpose and timeliness (M) and/or patient disposition, personality or health history made them less prone to panic (M), patients were impressed and pleased with the speed of the pathway (O). In cases where there was limited, inconsistent or unclear communication regarding the pathway's purpose (M), this led to a (false) belief that the speed was proportional to the seriousness of their condition (M), leading to increased anxiety (O).

Communication and virtual consultations

Patients received their MRI results by phone. Staff interviewed were unanimous regarding the convenience of phone consultations to deliver MRI results; they believe that patients also experience these as more convenient:

> they do seem to like the fact that they've, you know, they can be sitting at home in their own environment. (PS1, urology)

While not explicitly mentioned, we know that virtual consultations became a norm during the COVID-19 pandemic for many people, and patients described feeling accustomed to this method:

> I was fine over the phone because most of the correspondence I've had, other than when I was requested to go in and see the consultant, everything else has been over the phone. (P13)

Others felt that phone consultations sped things up, which they perceived positively:

> It was just the speed at which it was that they were able to give me that information truthfully and it basically pushed me/that up the process. (P13)

Patient participants described caveats to the acceptability of phone consultations—for instance, not having an exact time (as you would with an in-person consultation) is inconvenient for the patient and may impinge on their ability to prepare or coordinate with a loved one to be with them during that call. It may also add to feelings of uncertainty, unpredictability and lack of control as the patient must passively wait:

> It's a very fluffy time and it's—sometimes it's like trying to make the right time. So, if I knew for a fact that Doctor Jones or whoever is going to phone me at 4:30 on the dot, I can prepare. (P12)

Theory 2, virtual consultations

For working or otherwise busy patients (C), in cases where patients do not receive an exact time or narrow timeframe for a phone consultation (C), virtual consultations are perceived as unpredictable (M), inhibiting patients' ability to prepare and feel in control (O).

Theory 2b, virtual consultations

In a post-COVID-19 world (C) where people may be used to virtual communication (M), patients who had previous experience of phone consultations believed that they sped up the process or pushed their case forward (M), leading to greater acceptability of virtual consultations (O) (with some caveats relating to communication and organisation).

Communication and continuity

Staff felt that the earlier parts of the pathway (MRI scan and results) worked best:

> We're certainly getting the MRI scans done, you know, in a timely manner. It's what comes after that. That's still a bit of a sticking point. (PS1, urology)

Patients who experienced the pathway as it should be (ie, meeting or closely meeting the time goals) described a positive experience:

> I had an appointment at [hospital] for the MRI and then within 48 hours, I believe I had a phone call from the specialist to say 'Yes, we need to give you a biopsy'. So, within three weeks I had the biopsy. And within three weeks after that, I had the results. So, I got to say, it was really sort of speedy and positive, and I was well looked after. (P9)

All patients interviewed described a positive experience of MRI scanning and results. Some patients requiring further investigation described delays and admin errors—though it is worth noting that, while we did not interview patients on the conventional pathway, the waiting times are longer than on the Prostad pathway. That said, when delays and miscommunications occurred, a sense of insecurity or 'feeling lost' emerged:

> the fact that you deal with multiple departments, never quite sure who you are dealing with. Is it Glangwili? Is it Llanelli? Is it the waiting list people? Is it the preadmissions people? Is it the Urologists themselves? Or is it their PA? or is it just the nurse? You get a little bit lost in where you are along the way. (P2)

The above extract implies the work a patient may have to do to gather information about their care. Miscommunications or stilted communication added to confusion and patient labour—for instance, having to make repeat trips for tests that could have been performed at the same time:

> They needed kidney function as well which I haven't done. I literally had just the PSA reading. So… may have been a confusion that this all was happening so quickly. (P2)

Overall, patients experienced the speed of the pathway positively, and emphasised the importance of having support to process information that could feel overwhelming:

> if I was a single guy on my own […] then all this could easily get confusing. (P8)
> couldn't fault it—we're just we were in a little bit of the daze because of the speed of it all to be honest. (P7, carer)

Theory 3, continuity and confusion

For many people, the inner workings of health service processes are oblique (C). In a rural area where services are dispersed (C), the multiple centres and departments involved in the patient's care and the receipt of lots of information in a short timeframe (M) contributed to a sense of confusion (M), compromising patients' ability to manage their care (O), retain information (O) and discern who to contact (O).

Disempowerment and distress

Related to the above themes of mix-ups, patient labour and confusion, patients who experienced longer waiting times and/or were impacted by administrative errors or lack of communication expressed distress, loneliness and feelings of enforced passivity and disempowerment. It is important to note that these experiences are likely shared among patients referred to the conventional (non-RDP) pathway. They described their experience in language suggestive of a form of objectification, as they are passed from department to department and trapped within bureaucratic processes:

> right now, I am alone […] what is my case? I have no idea. I called in one hospital, urology department. I called last week, the urology department, and nurse only promises call you, they inform you. but they call, open my case in computer and say 'no result' and stop. (P1)
> I had to ring again because they never came back to me, but they eventually did get through after a week and they sorted it […] Clearly there is a problem with the administration, I think. It doesn't help the anxiety of the patient, having to make these phone calls and find out that you are no longer on the list. (P6)
> It's just the way the systems are, bureaucracy going from department to department. (P8)

As mentioned, the above experiences of several participants are likely shared by patients referred to the conventional pathway. Unfortunately, we did not interview patients referred to the conventional pathway for comparison. However, as the distress is primarily related to errors and long waiting periods, we can say that Prostad significantly reduced waiting periods for most patients, and therefore we propose the theory below.

Theory 4, distress

In the context of a busy system in which errors and long waiting periods may occur (C), Prostad has fewer steps (M) and patients move through the first part of the pathway quickly (M), resulting in a large proportion discharged from the pathway within 48 hours of their MRI (M), leaving less time for many patients to experience errors and long waiting periods (M), which in turn may lead to reduced time-related distress among most patients compared with the conventional pathway (O).

Agency mitigating anxiety

A referral to a cancer diagnostic pathway is a distressing life event; some staff acknowledged the impact on patients:

> they're just seeing and hearing the word cancer. (PS1, urology)

However, supporting patients to process the information and the emotional response to this information was not a particularly prevalent theme for staff interviewed. This may be unsurprising as the staff stakeholders are predominantly clinical and their priorities tended towards medical outcomes. Some staff queried the benefit of earlier diagnosis if patients chose to 'watch and wait', as opposed to 'curative' options or treatment, implying a focus on clinical outcomes, at the expense of informed decision-making:

> [if] the patient, doesn't want any radical treatment for a complete prostatectomy or any other, you know, radiotherapy or any other things, then why we are investigating so quickly. (PS9, radiology)

The prevalence of this view is unclear (with just 12 staff interviewees), and it is important to note that it emerges in the context of a service struggling to meet the needs of multiple specialisms, including but not limited to PCa diagnostic services. Nonetheless, patients highlighted the emotional benefit of knowing concretely if something is wrong, minimising the period of uncertainty—regardless of the decision they come to. In this way, consistent communication and a sense of 'knowing' was described as mitigating certain types of distress and supporting feelings of control and agency:

> Rather than hanging around and dwelling on it, what—could it be this? Could it be that. (P9)
> because the big the biggest thing and not just for me, but for my wife as well was the waiting. The waiting to find out things (P11). if it's good news or bad news, it's nice to know as soon as possible. (P14)
> It was just the speed at which it was that they were able to give me that information truthfully and it basically pushed me up the process rather than, you know, wait anxiously for a week or fortnight. (P13)

Patients who described consistent communication reported a sense of feeling cared for, which was related to their experience of regular, accurate communication and timely interventions:

> I had an appointment at [hospital] for the MRI and then within 48 hours, I believe I had a phone call from the specialist to say 'Yes, we need to give you a biopsy'. So, within three weeks I had the biopsy. And within three weeks after that, I had the results. So, I got to say, it was really sort of speedy and positive, and I was well looked after. (P9)

They also valued empathic interactions initiated by staff, which they differentiated from formal support processes, emphasising the importance of developing relationships with the people involved with their care:

> the urology team has been fantastic because within a week I had a phone call from one of your urology nurses—like a clinical one, like, she was like a specialist. And then that opened up a whole avenue of support from them. (P13)

Theory 5—mitigating unnecessary distress through agency

Illness constitutes a loss of control (C). Patients who received communication at regular intervals as expected (M) felt they understood the pathway and their position on it (M), thereby experiencing a greater degree of agency (M) that mitigated against unnecessary forms of distress (O).

Futures

While a sense of 'knowing' was perceived as mitigating distress, decision-making is also fraught with its own anguish. Treatment options force patients to weigh up risk and 'chances' (P12), and choosing to delay the medical route might be attractive for some patients given the potential side effects of treatment:

> it's some quite big decisions to make, you know, I'm, my gut is currently telling me to sit on a careful watch and wait, so repeat MRI and repeat biopsy before I jump down the radiotherapy or proctectomy pathway […] I've got to live with the consequences of any treatment. (P12)

We include this patient reflection on the future to highlight the importance of viewing an RDP within the context of a broader system. In other words, the ability of any RDP to minimise anxieties related to waiting also depends on the style of care each person receives post-diagnosis, in terms of timeliness, communication and support.

DISCUSSION

Summary of findings

Above, we present theories generated in relation to patient experience of a PCa RDP, which significantly reduced waiting periods for most patients compared with the standard PCa diagnostic pathway. In cases where the pathway worked as intended, patients appreciated and praised the speed of the RDP. When the pathway did not work as intended, patient anxieties related to waiting, lack of communication and experiences of instability or inconsistency—though we stress that these shortfalls can occur on any diagnostic pathway.

Our evaluation implies that opportunities for patients to experience predictability and exert agency during this process may mitigate unnecessary feelings of illness uncertainty and distress—that is, feelings of distress engendered by poor communication, oblique or mysterious bureaucratic processes and enforced passivity during extended waiting periods. The patients interviewed view agency within the context of a communicative relationship that allows them to be vulnerable (or 'cared for') while also empowering them with regular and clear communication regarding their care, which in turn supports decision-making. When Prostad worked well for the patient, the pathway provided patients with consistency within an acceptable timeframe.

Strengths and limitations

To our knowledge, this is the first realist evaluation of patient experiences of an RDP. Patient involvement constitutes a strength of this paper, as does its focus on and applicability to real-world interventions. There are limitations regarding its transferability beyond PCa RDPs. Our data collection approach also posed methodological challenges—such as a limited opportunity to adapt interview questions iteratively.

Comparison with existing literature

Our findings can be situated within the body of research that emphasises the vulnerability of unwell people to experiences of loss of agency.[20] While experiences of ill-health are inevitable, health uncertainty is exacerbated by long waiting periods, enforced passivity and bureaucratic barriers to timely informed decision-making.[4 21] Research exploring patient experiences of standardised cancer pathways emphasises the passivity engendered by the standardisation of these processes.[22] This passivity emerges as a theme in our evaluation, with possibilities for two-way communication providing a mitigating factor and, conversely, lack of opportunity to communicate exacerbating distress and frustration. Our evaluation chimes with research underlining patients' need to exert agency alongside a desire for expert support in decision-making processes and in the navigation of (usually) unknown systems and processes.[21–23]

Long waiting periods are associated with diminished patient satisfaction and trust.[24] However, there are opportunities to reduce anguish or uncertainty through consistent communication, which may offer greater predictability.[25 26] Predictable experiences might be particularly important for people with a PCa diagnosis, which can be experienced as a loss of control and an assault on 'normative' markers of masculinity.[26] Explorations of this topic suggest that retaining or experiencing forms of control—whether through knowledge or other assertions of agency—constitutes mitigating factors or coping strategies for people with PCa [[27]]. In addition to consistent and accurate communication from healthcare professionals or their representatives, interviewees highlighted the requirement for a single point of contact, empowering them to initiate communication to ask questions.

Conclusion and recommendations

Patient experiences of a PCa RDP emphasise the importance of consistent communication to facilitate a predictable experience of the diagnostic process. For the patients we interviewed, regular communication offered opportunities to exert agency that may mitigate unnecessary distress and illness uncertainty.

Recommendation 1: ensure patients are made aware of a single point of contact/care navigator to access information regarding their case throughout the pathway or that this information is easy to access (eg, online or in a leaflet).

Recommendation 2: the pathway's purpose and its time stamps should be discussed with patients, providing them with predictability.

Recommendation 3: in cases where errors occur, patients should be informed of how this will impact their journey through the pathway and given an opportunity to ask questions or discuss these changes.

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Contributors JR acted as guarantor. JR is the Principal Investigator, responsible for the conception and design of the realist evaluation (work packages 1 and 2). JR developed the initial interview schedules; KJ, JR, AC, JC and the West Wales Prostate Cancer Support Group developed further iterations of the interview schedules over the course of the project in line with the realist evaluation approach. JC, AC, SS and SF recruited participants, obtained informed consent, conducted interviews and transcribed the interview data. KJ, JR and the West Wales Prostate Cancer Support Group analysed and interpreted the data. KJ composed the first substantive draft of the article and prepared figure 3 and Table 1. KJ, JR, AC and SF organised and presented materials to the PPI group to facilitate contribution and involvement. RG, SS, YN, CH, SF and JM were responsible for funding acquisition and the conception of the overall evaluation project (comprising five work packages, each with its own Principal Investigator); RG, SS, YN, CH, SF and JM prepared figures 1 and 2. All authors reviewed and provided feedback prior to submission.

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REFERENCES

1 Haste A, Lambert M, Sharp L, *et al*. Patient experiences of the urgent cancer referral pathway-Can the NHS do better? Semi-structured interviews with patients with upper gastrointestinal cancer. *Health Expect* 2020;23:1512–22.
2 Mast ME. Adult uncertainty in illness: a critical review of research. *Sch Inq Nurs Pract* 1995;9:3–24; .
3 Wright LJ, Afari N, Zautra A. The illness uncertainty concept: A review. *Current Science Inc* 2009;13:133–8.
4 Lange M, Mertz BG, Vedsted P, *et al*. Factors associated with time to diagnostic imaging after symptoms in cancer patients: A systematic review. *Cancer Epidemiol* 2024;89:102545.
5 Swann R, Lyratzopoulos G, Rubin G, *et al*. The frequency, nature and impact of GP-assessed avoidable delays in a population-based cohort of cancer patients. *Cancer Epidemiol* 2020;64:101617.
6 Hoppe S. Shifting uncertainties in the pre-diagnostic trajectory of early-onset dementia. *Dementia (London)* 2019;18:613–29.
7 Cancer Research UK (CRUK). About Prostate Cancer. London: CRUK, 2022.
8 Tafuri A, Ashrafi AN, Palmer S, *et al*. One-Stop MRI and MRI/transrectal ultrasound fusion-guided biopsy: an expedited pathway for prostate cancer diagnosis. *World J Urol* 2020;38:949–56.
9 Hawks C, Moe A, McCombie S, *et al*. "One Stop Prostate Clinic": prospective analysis of 1000 men attending a public same-day prostate cancer assessment and/or diagnostic clinic. *ANZ J Surg* 2021;91:558–64.
10 Eldred-Evans D, Connor MJ, Bertoncelli Tanaka M, *et al*. The rapid assessment for prostate imaging and diagnosis (RAPID) prostate cancer diagnostic pathway. *BJU Int* 2023;131:461–70.
11 Shah J. Assessment of activity and outcome from a one-stop clinic for men with suspected prostate cancer: Five years' experience. *J Clin Urol* 2016;9:5–10.
12 Friedemann Smith C, Tompson A, Holtman GA, *et al*. General practitioner referrals to one-stop clinics for symptoms that could

be indicative of cancer: a systematic review of use and clinical outcomes. *Fam Pract* 2019;36:255–61.
13 Jones K, Rees S, Farrington S. Prostad: the development and evaluation of a prostate cancer rapid diagnostic pathway, a protocol. *Oncology* [Preprint].
14 Wong G, Westhorp G, Manzano A, *et al*. RAMESES II reporting standards for realist evaluations. *BMC Med* 2016;14:96.
15 Pawson R, Tilley N. Realist Evaluation. London: Sage, 1997.
16 Jagosh J, Tilley N, Stern E. Realist evaluation at 25: Cumulating knowledge, advancing debates and innovating methods. *Evaluation (Lond)* 2016;22:267–9.
17 Jones K, Chandran A, Rance J. Rapid diagnostic pathways for prostate cancer: A realist synthesis. *J Cancer Policy* 2024;42:100514.
18 NHS Wales. Cancer incidence in wales 2002–2020. Cancer Intelligence Unit; 2023. Available: https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/cancer-reporting-tool-official-statistics/cancer-incidence/
19 Sewell B, Jones M, Erdem E, *et al*. Work package 4: health economic evaluation. prostad: the development of a model prostate cancer diagnostic pathway. TriTech, CRUK Report; 2024.
20 Carel H. Phenomenology of Illness. Oxford: Oxford University Press, 2016.
21 Andersen-Hollekim T, Melby L, Sand K, *et al*. Shared decision-making in standardized cancer patient pathways in Norway-Narratives of patient experiences. *Health Expect* 2021;24:1780–9.
22 Solberg M, Berg GV, Andreassen HK. Lost in the loop - a qualitative study on patient experiences of care in standardized cancer patient pathways. *BMC Health Serv Res* 2023;23:1371.
23 Chen M, Wu VS, Falk D, *et al*. Patient Navigation in Cancer Treatment: A Systematic Review. *Curr Oncol Rep* 2024;26:504–37.
24 Bleustein C, Rothschild DB, Valen A, *et al*. Wait times, patient satisfaction scores, and the perception of care. *Am J Manag Care* 2014;20:393–400.
25 Solbjør M, Sand K, Ervik B, *et al*. Patient experiences of waiting times in standardised cancer patient pathways in Norway - a qualitative interview study. *BMC Health Serv Res* 2021;21:651.
26 Salifu Y, Almack K, Caswell G. “Out of the frying pan into the fire”: a qualitative study of the impact on masculinity for men living with advanced prostate cancer. *Palliat Care Soc Pract* 2023;17.
27 Langelier DM, Jackson C, Bridel W, *et al*. Coping strategies in active and inactive men with prostate cancer: a qualitative study. *J Cancer Surviv* 2022;16:421–31.