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Exploring the experiences of patients, general practitioners and oncologists of prostate cancer follow-up: A qualitative interview study

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ABSTRACT

Purpose: To examine the experiences of patients and healthcare professionals of prostate cancer follow-up in primary care and to identify areas where current policy and practice could be improved.
Methods: Semi-structured interviews with patients, GPs and oncologists explored experiences of prostate cancer follow-up. Interviews were audio recorded and transcribed verbatim. Data were analysed using thematic analysis. The three participant groups were analysed as individual datasets but the same key themes were evident across the groups.
Results: 14 patients, 6 GPs and 5 oncologists were interviewed. Four main themes were identified: Experience of current practice; Knowledge and understanding of prostate cancer follow up; Disparity of processes and pathways; Unclear roles and responsibilities.
Conclusions: Findings from this study highlight the variation in the approach to prostate specific antigen monitoring and emphasise the lack of clear policies and practices. The lack of clarity around existing follow up and monitoring processes could cause delays in the diagnosis of recurrence. There is a need for a new and improved pathway for prostate cancer follow up. The pathway should include clear and concise guidance for patients, primary care and secondary care and all relevant parties need to understand what their role is within the pathway.

1. Introduction

Prostate cancer is the most common cancer in men in the UK (Cancer Research UK) and the number of prostate cancer diagnoses is set to increase in the future largely due to improvements in detection (Maddams et al., 2012). Over the last ten years the treatment of prostate cancer has changed dramatically and there has been a considerable increase in the treatment options available to those with relapsed, metastatic or progressive disease. As a result, patients can live for many years and the pressure to manage hospital based follow-up (either in urology or oncology) in this patient group is considerable (Yip et al., 2015). As a result, alternative methods of follow-up have begun to be explored. These methods include the use of digital technology (Frankland et al., 2019; Nanton et al., 2017), nurse-led follow-up (Frankland et al., 2017) primary care based follow-up (Heins et al., 2018) and shared care approaches (Emery et al., 2014; Lund et al., 2016). Many of these approaches involve an element of shared care between several care providers which means the pathway is complex and information needs to be communicated to a number of different people (Heins et al., 2018). If the pathway is not robust then there is a potential for patients to become lost to follow up and possible recurrence may be missed.

The most common follow up approach for prostate cancer in the UK is to discharge patients to primary care after initial follow up in hospital based setting. National Institute of Clinical Excellence (NICE) guidelines recommend that remote follow up should be considered for prostate cancer patients after at least 6 months of regular follow up (NICE, 2019); but they do not specify exactly what this should include and what is expected of primary care.

A key element of prostate cancer follow up is regular monitoring of Prostate Specific Antigen (PSA) levels. The PSA test is a simple blood test which can be used to identify potential prostate cancer recurrence (Watson et al., 2011). It is important to monitor PSA levels after treatment because a rise in PSA is usually the first indicator of disease recurrence (Hennessey et al., 2013; Lattouf and Saad, 2003). The

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importance of PSA testing and monitoring is well recognised but guidance specifying exactly when monitoring should take place and at what point a re-referral should happen is limited (McIntosh et al., 2009). NICE recommend that prostate cancer patients should have their PSA checked at least every 6 months for the first 2 years, and then at least once a year after that (NICE, 2019) but do not specify exactly when re-referral to their specialist teams should be take place. There is a distinct lack of evidence to inform optimum PSA testing schedules and surveillance guidelines as no randomized controlled trials have been conducted in this area. As a result there is huge variability between the guidelines presented in different countries and by different NHS organisations (Loblaw et al., 2017).

As well as variations surrounding the ideal timing and frequency of PSA testing, there is also inconsistency with regards to the procedures and notification of PSA testing in the UK and feedback of results to patients is often lacking (Khan et al., 2011). In primary care, patients were often only informed of PSA results if there was a problem which left them with feelings of uncertainty, whereas in the oncology setting, they reported feeling reassured when results were discussed with them (O'Brien et al., 2010). Prostate cancer patients expressed a desire for more information about PSA test results and at what point further treatment would be offered (Khan et al., 2011). There is evidence to suggest that PSA testing is not always conducted as part of routine follow-up and the onus often falls on patients to arrange it (Watson et al., 2011). There is a concern that patients may be lost to follow-up if the responsibility for routine appointments and monitoring lies solely with them (Watson et al., 2011). There may be a group of patients who are elderly or have other comorbidities which could limit their ability to self-manage in this way (Lund et al., 2016).

The aim of this study is to explore the experiences of patients, oncologists and GPs of prostate cancer follow-up and identify any problems in the existing system and to determine how current pathways may be improved.

2. Methods

Patient participants were recruited from a pool of patients who had participated in a previous research study (unpublished data). The medical records of 300 patients who had been discharged to primary care in two geographical locations from a specialist cancer hospital were extracted to explore patterns of prostate cancer follow up. The geographical locations were purposively selected to reflect two areas with differing socioeconomic characteristics based on the Indices of Deprivation (Ministry of Housing Community and Local Government, 2019), a more deprived area with a deprivation score of 18 and a less deprived area with a score of 191. The majority of these men had been treated with radiotherapy and the majority were being followed up on a six monthly basis. Questionnaires were sent to the patient group to explore their experiences. Questionnaires were returned by 222 patients and 110 of these patients said they would be willing to take part in an interview. Patients were purposively selected for interview based on their questionnaire responses in order to select participants with varying levels of engagement with prostate cancer follow up. A random sample may have meant that we selected all patients who had good or poor levels of engagement whereas a purposive sample ensured each group was represented. Purposive sampling is a robust method frequently used in this type of qualitative research. Fourteen patients were contacted by telephone and all agreed to be interviewed. Interviews were conducted over the telephone. An email was sent by the local Macmillan GP and cancer lead to 20 GPs in the area asking if they would participate in an interview. Six GPs responded and were interviewed by telephone. Five oncologists from a specialist cancer centre were contacted by HJ and all participated in face to face interviews.

Interviews were conducted by two female interviewers HJ (a specialist nurse) or SP (research assistant); both had limited previous research experience or qualifications but received interview skills training from an experienced qualitative researcher. Interview recruitment was stopped when no new themes were emerging and we felt data saturation had been reached. HJ was motivated to conduct research in this area following experiences in her professional role; therefore she may have had some ideas and preconceptions about current service provision and areas for improvement. SP had not previously worked in this area and therefore is unlikely to have had any preconceived ideas about how interviewees would respond. Interviewers did not have any contact with patient participants prior to the interview. Topic guides were used to structure the interviews; they were developed to address the aims of the study and were informed by the literature. Participants provided written informed consent prior to commencing the interview. All interviews were audio recorded and transcribed verbatim. The interviewer reflected on each interview after it was completed. Interview transcripts were not returned to participants unless specifically requested. Interviews with patients and health professionals lasted approximately 25 and 27 min respectively.

Interviews were analysed using an inductive approach to thematic analysis (Braun and Clarke, 2006). The patient, oncologist and GP interviews were analysed as distinct groups by ST, HJ, JB and SP. Each patient transcript was coded individually by two researchers. The codes were then discussed and consensus reached in order to develop the coding scheme. The same process was followed for the oncologist transcripts and then the GPs. Nvivo software was used to manage the coding process. Once coding schemes had been developed for each participant group, themes were then identified. Although the coding schemes were distinct for each of the three groups, the same four main themes were evident across the groups. The term 'participants' is used throughout the results to illustrate themes that are reflective of the experiences of participants in all three participant groups (patients, GPs and oncologists). Any ambiguities when developing the themes were discussed and a consensus reached. Due to time restrictions, participants were not contacted to provide feedback on the results. Ethical approval for the study was granted by *Yorkshire & The Humber - Bradford Leeds Research Ethics Committee (18/YH/0266, July 10, 2018)*.

3. Results

Four themes were derived from the data: i) Experience of current practice; ii) knowledge and understanding of prostate cancer follow up; iii) disparity of processes and pathways; and iv) unclear roles and responsibilities (Fig. 1). Experience of current practice was a central theme and patients, oncologists and GPs experiences in current practice influenced their thoughts on the other themes which were all interlinked. Unclear roles and responsibilities and lack of understanding and knowledge meant it was difficult to implement effective processes and pathways. Similarly, disparity in processes and pathways meant there was a lack of understanding regarding prostate cancer follow up and no one was clear what their role in the process should be and what was expected of them.

3.1. Experience of current practice

Participants discussed their experiences of the current system. They described what they felt worked well in the current system and some of the potential problems. They also highlighted how the roles that people played had a big impact on the effectiveness of the current system. The majority of patients were satisfied with the care they had received and felt comfortable with the discharge and follow up procedure. Patients had mixed feelings about being discharged from specialist oncology care, for some it was a relief because their GPs was much easier to get to. Others felt it meant everything was 'hunky dory' and they didn't have to worry about prostate cancer anymore which had implications for their engagement with follow up. Others were a little concerned as they were not as confident in follow up with their GP as they were with follow up in specialist care. Oncologists also expressed concerns that patients may

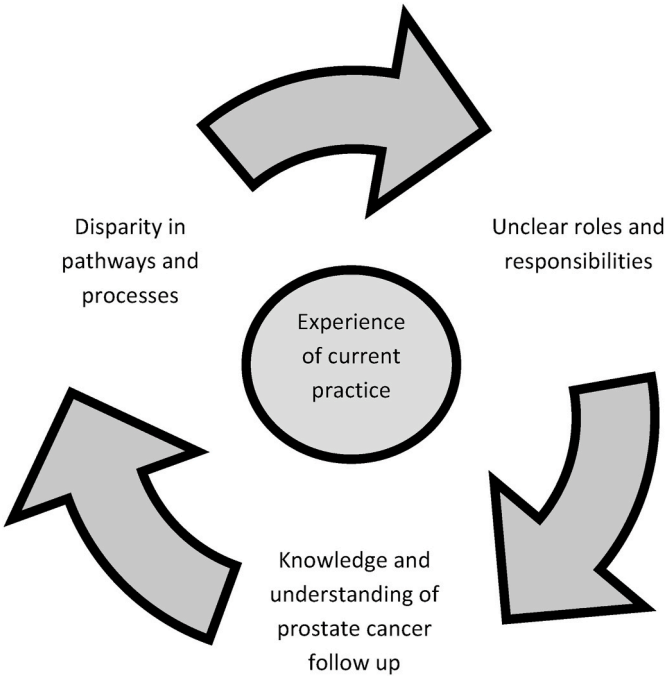

Fig. 1. Themes from analysis of data.

not be happy to be discharged.

> 'Yeah, I was a little concerned, I don't know why, but it's like something that's always hanging over your head and I just felt I was confident in what [specialist oncology hospital] had done for me' Patient 13.

> 'I think the tricky thing is, lots of patients don't want to be discharged to primary care and would also like to be under the care of specialist oncology' Oncologist 5.

Under the current system participants spoke about feelings of trust or confidence in others to perform their roles. Some GPs felt quite confident that patients were motivated enough to attend for monitoring when required. Others had concerns, particularly as patients got older or perhaps as patients get further away from their discharge, they may be less engaged with routine follow up and monitoring. GPs expressed their confidence in the role of secondary care in various aspects of prostate cancer management. They were confident that patients would not be discharged from secondary care until urology and/or oncology were happy with the patient's progress, they were assured of a quick referral route, and satisfied with the treatment and advice they provided. Some GPs felt self-assured in their role in follow up but others had concerns. Workload and resource constraints often meant health professionals did not always feel capable of fulfilling their role. Improvements to the pathway or the information provided would improve the GPs confidence in management.

> 'So, yeah, a better pathway would certainly give me much more confidence in primary care managing them. I suppose the only other bit that fills me with a little bit of trepidation is the recall.' GP 4.

> 'It feels quite loose and it doesn't feel that safe' GP 2.

Generally, oncologists did not seem that confident in discharging patients to primary care. There was a lot of uncertainty around whether patients were actually being followed up. Oncologists talked about putting their trust in GPs to do the follow up but there seemed to be a sense of unease about the process. In some cases, if the oncologist was particularly concerned about follow-up in primary care then they kept the patient under hospital care longer than they may have done otherwise.

> 'So I think that is a … that's almost not a negotiation but an agreement that you and the patient reach at the time of discharge. If you think they're going to be an unreliable discharge then you don't discharge those patients.' Oncologist 3.

> 'in certain geographical areas I will keep on to them because my worry is that if I discharge them back to the care of the GP or to their urologist, they won't get access to further treatments in a timely fashion, there may well be a delay to coming back.' Oncologist 1.

3.2. Disparity in processes and pathways

Participants highlighted the disparity in the processes and pathways with regards to discharge, monitoring, re-referral and treatment. Patients discussed the processes and the pathways throughout all stages of their illness trajectory from diagnosis through to follow-up. Processes were often complex, involving a wide array of health professionals and as a result some patients did not necessarily have access to the right support or services.

> 'Yeah, I think there's a possibility. I guess the other difficulty is that there's lots of different hospitals, and sometimes different consultants have different ways of managing things, or they might have a different policy depending on where the patient goes to, and that might be confusing. If there was a standardized, kind of, like a GM policy for the whole of the area that we all work to because that might work well. And then all nurses could, kind of, feed in to that, so, that could work well.' GP 3.

> 'I think everybody needs some support. The thing with me is that I found is that you didn't really get, there was nowhere to go to ask questions to anybody.' Patient 10.

There were no definitive guidelines in place to facilitate monitoring of prostate patients in the long term therefore discharge guidelines were often unclear. The majority of GP surgeries did not routinely communicate PSA results to patients making it difficult for patients to keep track of them. It was assumed by patients that their GP would contact them if there was a concern.

> 'No. I take it if there's anything untoward they'd act on it. They act on other things when I have blood tests, so I suspect if they found something which was out of the ordinary it would be brought to the attention and we'd discuss it.' Patient 9.

An electronic reminder system was mentioned by a number of participants as a way of prompting patients about blood tests and ensuring they do not get missed. Some GP surgeries had these in place; others mentioned it as something that would be beneficial in the future. There were a lot of uncertainties around the process of managing of PSA monitoring, in particular the frequency of testing and the interpretation of results. As there were no clear guidelines indicating when a re referral should be triggered, the processes followed by GPs varied, some would refer back to the patents discharge letters but others would use an arbitrary cut off. Oncologists could not give any definitive guidelines for red flags (i.e. when patients should be re-referred) as the guidelines would vary depending on the patient and the treatment they had. The nuances in the follow up made it very difficult for guidelines to be established.

> 'I suppose the issues comes in is blood tests … the results get distributed out to lots of different doctors and so I think it would be classed as normal if it's below a certain level according to the lab and we would just click no action required' GP 5.

> 'So, you might, if you wanted to be more elaborate, you might have a risk based follow up approach rather than a one size fits all. That then

becomes complicated for GPs, it becomes complicated for staff and patients and things change.' Oncologist 3.

3.3. Knowledge and understanding of prostate cancer follow up

All participants spoke about the lack of knowledge around prostate cancer follow-up and the need for reliable information to improve the current system. There was a concern amongst oncologists and GPs that some patients did not fully understand the purpose of PSA monitoring and the importance of having regular tests. Patients often did not have a clear idea of how often they should be having their PSA monitored, what their PSA should be to trigger a re referral or who to contact if they felt a referral was necessary. There were a lot of assumptions and hopes discussed when talking about their knowledge of the referral pathway.

'I would just go through my GP and then hope that they would get me in touch with someone else. Go through the doctor to pass it up the line.' Patient 7.

There was a clear need for education for the whole community team, not just primary care as it was not just the GPs who would deal with PSA results. Primary care staff often did not know how to interpret the results of PSA and were not always aware of the need to have the tests done regularly.

'I think the whole PSA thing is very, very unclear for us, and PSA then obviously comes through diagnosis, monitoring' GP 2.

'Because it's only like the nurses and the receptionist. I mean, if it went to up 3, they'd say, oh, it's normal. But it's not normal, because it shouldn't go up, and we have to explain this to them. They don't seem to understand that there shouldn't be any increase my PSA.' Patient 1.

'And I had a little resistance from the nurse to have the test, who said that, if I didn't have any symptoms, I shouldn't be having this test.' Patient 11.

3.4. Unclear roles and responsibilities

It was evident from the participant interviews that there were no clear definitions of individuals' roles and responsibilities which was seen as a possible 'point of contention' amongst health professionals. Participants had expectations of other peoples' roles in the follow up process but this did not always happen in reality. Generally, GPs felt that follow-up of prostate cancer patients did fall within their role but there were concerns about how this would work in reality due to resource and workload constraints. From the patients' perspective, the GP seemed to take a 'hands off' approach in the follow-up process. Patients did not feel they saw their GP any more frequently after discharge and they rarely discussed their prostate cancer. If PSA testing was conducted, it was often carried out by the practice nurse and the patient may not see the GP at all.

'No, I haven't seen my GP for PSA monitoring, and the reason being that neither of us knew that it needed to be done, as far as I'm aware.' Patient 7.

'and, as I've kind of alluded before, GPs not really realising they are still on follow-up, that this is a follow-up process; it's a … while they've been discharged from oncology they must be … ' Oncologist 1.

The majority of patients took a leading role in the management of their PSA monitoring; they would arrange their own appointments and keep a record of their results. Some patients however left the responsibility with the GP. Patients often made assumptions that they hadn't been contacted then everything was ok. One patient had waited for the GP to contact him and as a result had not had a PSA test done for five years. Patients were not routinely told the results of their PSA test; patients had to actively contact their GP to get this information.

'I don't think, if I didn't monitor it, I'm pretty certain that nobody else would monitor it, unless it went high. Because when my blood result goes back, and they look at it, they're just going to look at my result, compared to the result before.' Patient 10.

GPs and oncologists stressed the importance of patients taking ownership for their own monitoring. It was evident though that patients may not always be aware that responsibility is in their hands or there may be issues that mean patients are unable to take this responsibility as a result, patients may miss monitoring and at present there is no 'safety net' to pick these patients up again.

'No, I tell the patients. I say, don't expect your GP to call for you; you'll need to remember that, you know, around Christmas time you need to have a blood test with your GP.' Oncologist 2.

'So, it's almost like it's handed over to the patient but without a formal conversation, so I think it is a problem area.' GP 6.

A number of participants mentioned the possibility of a shared care pathway but the definition of what they meant by shared care often differed. Some felt care should be shared by the patient and primary care, others mentioned the role of oncology, urology and specialists nurses.

'I think so they have an equal partnership and then obviously the GP is legally liable to respond to it. So, they probably have to take more emphasis on it so if the patient doesn't respond to it, you know, that's the patient's problem.' Oncologist 4.

'I think the responsibility of the GP should be, I guess, in a sort of shared care model, to take responsibility for routine monitoring. And I guess it doesn't have to be a GP, it could be a nurse within the GP practice, so we'll call it the community team, shall we?' Oncologist 5.

4. Discussion

This qualitative study conducted with patients, GPs and oncologists has highlighted problems within the current prostate cancer follow up system that suggests that some men are not being monitored safely. Ineffective follow up systems mean that men will be at risk of receiving a late diagnosis of recurrence which has implications for future treatment and patient outcomes. The problems with the current system stemmed from the fact that there are no clear roles or responsibilities to define what is expected of patients and health professionals and there are no clear guidelines and processes in place for prostate cancer follow up. As a result there is a lack of knowledge particularly amongst patients and primary care about how prostate cancer follow up should be managed.

Overall participants were satisfied with their current follow-up but there were some concerns, particularly in the confidence in others to perform their roles and their ability in reality to fulfil what was expected of them as part of their role. Evidence from others studies (O'Brien et al., 2010) and in the interviews suggest that some patients may feel more comfortable being followed up in secondary care. The reason for this preference was often because patients did not see GPs as having the specialist skills required to deliver prostate cancer follow up (Hudson et al., 2012). Providing primary care with access to the right information and education may help to alleviate this problem. One study developed a new protocol for follow up and found that the majority of patients were happy with primary care follow up (Heins et al., 2018). The key components of the system seemed to be clarification of the pathways for all aspects of follow up care including monitoring and re referral and giving clear and concise information about these processes to GPs. GPs also had an easy access route back to oncology for queries if required (Heins

et al., 2018).

From the interviews it was clear that there was a huge disparity in processes and pathways for prostate cancer follow up and no definitive guidelines in place for discharge, monitoring, re-referral and treatment. Patients viewed discharge as a sign that they were clear of cancer as other research has also found (Hudson et al., 2012) and may suggest why men are less proactive in engaging with follow up. These men may be lost to follow up if the onus is on them to arrange appointments. Evans et al. (2019) explored patient and GP opinions on the handover of responsibility of care to patients. Patients were open to accepting this responsibility but they needed clear guidance from their GPs detailing what they needed to do. GPs concluded that patients needed to be aware of the seriousness of the situation and know that they could be put at risk if they did not comply with the procedures (Evans et al., 2019). Research has found cases where patients have been lost to follow up because they were not contacted by their GP and in some cases this meant that a recurrence was not identified as quickly as it should have been (O'Brien et al., 2010). There will always be losses to follow up in every system but this number will be far greater if all parties involved are not clear what their role is within the process.

It is also important to recognise that PSA monitoring is not the only aspect of prostate cancer follow up, many other aspects of the patients health also need to be taken into consideration (Hudson et al., 2012) including ongoing treatment consequences which could be wide ranging but could include urinary and bowel toxicity, sexual dysfunction and emotional and psychosocial concerns (Adsul et al., 2016; Noonan and Farrell, 2016). Whoever is responsible for the care of these men need to have the knowledge and expertise to support individuals with these issues and patients need to have the confidence and skills to be able to manage the potential consequences of their treatment and know where to go to get further help.

This study and similar research has highlighted the need to improve the knowledge of the follow up process amongst primary care and build strong communication systems (Arora et al., 2011). The lack of robust clinically proven guidelines and protocols for prostate cancer follow up means there is a lack of knowledge amongst all parties. There is a need for increased education about the appropriate management of prostate cancer follow up. Research has shown that men's knowledge and beliefs about prostate cancer were strongly associated with their engagement in the follow up system (Avery et al., 2012). Participants spoke about hopes and assumptions and almost a 'blind faith' that the monitoring would happen without really knowing that it would. There was a need for education, particularly for patients and the wider primary care team about the importance of PSA monitoring and what their role in this process should be. Patients did not always seem to understand what follow up in primary care should consist of, a finding echoed in another study where a patient said primary care did not provide any follow up cancer care but then later said they had their PSA checked in primary care (Hudson et al., 2012).

Roles and responsibilities within the follow up pathway were unclear. There was often contention amongst health professionals about who was accountable for monitoring. The majority of GPs did see follow up as their responsibility, however had many demands on their time and resources (Meiklejohn et al., 2016) which often meant that in reality they were unable to provide the level of commitment they felt they should. It seems as though the current system is designed for patients to take ownership but this was not communicated to the patients, so in many cases they would wait for others to act. GPs however often took 'a back seat' as well and therefore patients were not being followed up as often as they should be. As echoed in other research, it is clear that some patients are unsure whose responsibility it is to initiate follow up appointments and organise PSA tests (O'Brien et al., 2010). GPs often felt patients were well motivated and capable of taking the initiative to organise appointments (Watson et al., 2011) but in reality patients did not always fulfil this leading role.

If prostate cancer follow up care is to continue to be delegated to primary care in the future, in order to create a safe and effective service, a more cohesive approach and follow up structure needs to be introduced. As a result of the COVID-19 pandemic, there has been a rapid increase in the use of remote rather than face to face care, many of the new systems however have not been developed following the principals of evidence based practice to determine how these systems may be most effective. A new pathway should clarify the role of patients and caregivers and make sure they understand they have to take ownership of their follow up care and PSA monitoring. The pathway should ensure that discharge letters to GPs follow a pre-defined template that includes all key information and is easy to understand, with a system to ensures that results are communicated with patients.

The main limitation to this study is the sample. The sample was taken from a small number of patients and health professionals from two areas within Greater Manchester; therefore, the results may not be generalisable given the limited diversity within the sample. Demographic data was not collected as part of the interview process therefore we cannot provide these details within the manuscript. Unfortunately, given the time and funding constraints of the study, we were also unable to interview urologists or clinical nurse specialists. The role of both of these parties was mentioned during the interviews and warrants further exploration.

Findings from this study support the need for a new and improved pathway for prostate cancer after care in our local area and funding has been secured to pilot the pathway in Greater Manchester with the hope that this may be rolled out more widely in the future. The pilot will be based on the work done by prostate cancer UK as part of theTrueNth project. Patients will continue to be cared for by their hospital based team but on a 'remote basis' where they are reminded about PSA testing, have access to an on-line service allowing them to check PSA results and access their clinical team with the support of a 'key worker'. Each patient's monitoring pathway will be individually tailored to them to enable us to deliver a true supported self-management program of care. The key components of this follow up package are reflected in the needs of patients and health professionals identified in this research project.

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CRediT authorship contribution statement

Sally Taylor: Conceptualization, Methodology, Formal analysis, Data curation, Writing - original draft, Writing - review & editing, and reviewing and editing, Visualization, Project administration, Funding acquisition. **Helen Johnson:** Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - review & editing, Project administration, Funding acquisition. **Sara Peat:** Investigation, Project administration. **Jane Booker:** Formal analysis, Writing - review & editing. **Janelle Yorke:** Conceptualization, Methodology, Supervision, Writing - review & editing, Funding acquisition.

Declaration of competing interest

The authors declare that they have no conflict of interest.

References

Adsul, P., Darwish, O.M., Siddiqui, S., 2016. Prostate cancer survivors: physical, emotional and practical concerns from the LIVESTRONG survey. AIMS Public Health 3, 216–227. https://doi.org/10.3934/publichealth.2016.2.216.

Arora, N.K., Reeve, B.B., Hays, R.D., Clauser, S.B., Oakley-Girvan, I., 2011. Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. J. Clin. Oncol. 29, 1280–1289. https://doi.org/10.1200/JCO.2010.32.1554.

Avery, K.N.L., Metcalfe, C., Vedhara, K., Lane, J.A., Davis, M., Neal, D.E., Hamdy, F.C., Donovan, J.L., Blazeby, J.M., 2012. Predictors of attendance for prostate-specific

antigen screening tests and prostate biopsy. Eur. Urol. 62, 649–655. https://doi.org/10.1016/j.eururo.2011.12.059.
Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3, 77–101. https://doi.org/10.1191/1478088706qp063oa.
Emery, J., Doorey, J., Jefford, M., King, M., Pirotta, M., Hayne, D., Martin, A., Trevena, L., Lim, T., Constable, R., Hawks, C., Hyatt, A., Hamid, A., Violet, J., Gill, S., Frydenberg, M., Schofield, P., 2014. Protocol for the ProCare Trial: a phase II randomised controlled trial of shared care for follow-up of men with prostate cancer. BMJ Open 4, e004972. https://doi.org/10.1136/bmjopen-2014-004972.
Evans, J., Macartney, J.I., Bankhead, C., Albury, C., Jones, D., Ziebland, S., Nicholson, B. D., 2019. How do GPs and patients share the responsibility for cancer safety netting follow-up actions? A qualitative interview study of GPs and patients in Oxfordshire, UK. BMJ Open 9, e029316. https://doi.org/10.1136/bmjopen-2019-029316.
Frankland, J., Brodie, H., Cooke, D., Foster, C., Foster, R., Gage, H., Jordan, J., Mesa-Eguiagaray, I., Pickering, R., Richardson, A., 2019. Follow-up care after treatment for prostate cancer: evaluation of a supported self-management and remote surveillance programme. BMC Canc. 19, 368. https://doi.org/10.1186/s12885-019-5561-0.
Frankland, J., Brodie, H., Cooke, D., Foster, C., Foster, R., Gage, H., Jordan, J., Mesa-Eguiagaray, I., Pickering, R., Richardson, A., 2017. Follow-up care after treatment for prostate cancer: protocol for an evaluation of a nurse-led supported self-management and remote surveillance programme. BMC Canc. 17, 656. https://doi.org/10.1186/s12885-017-3643-4.
Heins, M., Schellevis, F., Schotman, M., van Bezooijen, B., Tchaoussoglou, I., van der Waart, M., Veldhuis, L., van Dulmen, S., Donker, G., Korevaar, J., 2018. Feasibility and acceptability of follow-up for prostate cancer in primary care: a pilot study. BJGP open 2. https://doi.org/10.3399/bjgpopen18X101616 bjgpopen18X101616.
Hennessey, D.B., Lynn, C., Templeton, H., Chambers, K., Mulholland, C., 2013. The PSA tracker: a computerised health care system initiative in Northern Ireland. Ulster Med. J. 82, 146–149.
Hudson, S.V., Miller, S.M., Hemler, J., Ferrante, J.M., Lyle, J., Oeffinger, K.C., Dipaola, R. S., 2012. Adult cancer survivors discuss follow-up in primary care: "Not what i want, but maybe what i need''. Ann. Fam. Med. 10, 418–427. https://doi.org/10.1370/afm.1379.
Khan, N.F., Evans, J., Rose, P.W., 2011. A qualitative study of unmet needs and interactions with primary care among cancer survivors. Br. J. Canc. 105, S46–S51. https://doi.org/10.1038/bjc.2011.422.
Lattouf, J., Saad, F., 2003. Digital rectal exam following prostatectomy: is it still necessary with the use of PSA? Eur. Urol. 43, 333–336. https://doi.org/10.1016/S0302-2838(03)00046-0.
Loblaw, A., Souter, L.H., Canil, C., Breau, R.H., Haider, M., Jamnicky, L., Morash, R., Surchin, M., Matthew, A., 2017. Follow-up care for survivors of prostate cancer - clinical management: a program in evidence-based care systematic review and clinical practice guideline. Clin. Oncol. 29 (11), 711–717. https://doi.org/10.1016/j.clon.2017.08.004, 0.
Lund, A.S., Lund, L., Jønler, M., Graversen, P., Bro, F., Borre, M., 2016. Shared care in prostate cancer: a three-year follow-up. Scand. J. Urol. 50, 346–351. https://doi.org/10.1080/21681805.2016.1206618.
Maddams, J., Utley, M., Møller, H., 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. Br. J. Canc. 107, 1195–1202. https://doi.org/10.1038/bjc.2012.366.
McIntosh, H.M., Neal, R.D., Rose, P., Watson, E., Wilkinson, C., Weller, D., Campbell, C., 2009. Follow-up care for men with prostate cancer and the role of primary care: a systematic review of international guidelines. Br. J. Canc. 100, 1852–1860. https://doi.org/10.1038/sj.bjc.6605080.
Meiklejohn, J.A., Mimery, A., Martin, J.H., Bailie, R., Garvey, G., Walpole, E.T., Adams, J., Williamson, D., Valery, P.C., 2016. The role of the GP in follow-up cancer care: a systematic literature review. J. Cancer Surviv. 10, 990–1011. https://doi.org/10.1007/s11764-016-0545-4.
Ministry of Housing Community and Local Government, 2019. The English Indices of Deprivation 2019.
Nanton, V., Appleton, R., Dale, J., Roscoe, J., Hamborg, T., Ahmedzai, S.H., Arvanitis, T. N., Badger, D., James, N., Mendelsohn, R., Khan, O., Parashar, D., Patel, P., 2017. Integrated care in prostate cancer (ICARE-P): nonrandomized controlled feasibility study of online holistic needs assessment, linking the patient and the health care team. JMIR Res. Protoc. 6, e147. https://doi.org/10.2196/resprot.7667.
NICE, 2019. Recommendations | Prostate Cancer: Diagnosis and Management | Guidance. NICE.
Noonan, E.M., Farrell, T.W., 2016. Primary care of the prostate cancer survivor. Am. Fam. Physician 93, 764–770.
O'Brien, R., Rose, P.W., Campbell, C., Weller, D., Neal, R.D., Wilkinson, C., Watson, E.K., 2010. Experiences of follow-up after treatment in patients with prostate cancer: a qualitative study. BJU Int. 106, 998–1003. https://doi.org/10.1111/j.1464-410X.2010.09292.x.
Watson, E.K., O'brien, R., Campbell, C., Weller, D., Neal, R.D., Wilkinson, C., Rose, P.W., 2011. Views of health professionals on the role of primary care in the follow-up of men with prostate cancer. Fam. Pract. 28, 647–654. https://doi.org/10.1093/fampra/cmr034.
Yip, K., McConnell, H., Alonzi, R., Maher, J., 2015. Using routinely collected data to stratify prostate cancer patients into phases of care in the United Kingdom: implications for resource allocation and the cancer survivorship programme. Br. J. Canc. 112, 1594–1602. https://doi.org/10.1038/bjc.2014.650.