



**GP experience and understandings of providing follow-up care in prostate cancer survivors in England**

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5 **Title:** GP experience and understandings of providing follow-up care in prostate cancer  
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7 survivors in England  
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12 **Abstract**  
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15 Survival times for prostate cancer have increased substantially, meaning more survivors will be  
16 discharged to General Practitioners' (GP) services. The detection of recurrence and monitoring  
17 of symptoms and long-term side-effects in prostate cancer survivors requires the active  
18 involvement of GPs in their follow-up care. In order to address this, the transition and  
19 discharge from hospital to primary care must be managed effectively. The objective of this  
20 study was to examine the preparedness, concerns and experiences of GPs in relation to their  
21 role in providing follow-up care to prostate cancer survivors. Purposive sampling was used to  
22 recruit GPs with experience in providing care to prostate cancer survivors. Twenty semi-  
23 structured telephone interviews were conducted with GPs across England. The interviews  
24 were audio-recorded, transcribed verbatim and analysed using thematic analysis. Participants  
25 described their current role in the follow-up pathway, a number of challenges and barriers in  
26 assuming this role, and potential ways to resolve these and improve their involvement. They  
27 expressed a range of views about their preparedness and willingness to take over follow-up  
28 care after discharge for this group of patients. GPs had reservations about workload, lack of  
29 resources, expertise and deficiencies in communication with hospitals. Findings from this study  
30 suggest that GPs will be ready to take over the follow-up care of prostate cancer survivors if  
31 better information, additional training and adequate resources are provided and  
32 communication lines with hospital specialists are clear. Understanding the issues faced by GPs  
33 and overcoming identified barriers to providing follow-up care to prostate cancer survivors will  
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4 provide the insight necessary to make the process of transferring care from secondary to  
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6 primary teams a more straightforward task for all stakeholders.  
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9 **Keywords:** patient discharge; aftercare; prostate cancer; prostate cancer survivors; cancer  
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11 survivors; primary health care; follow-up care; General Practitioners; GP; qualitative;  
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13 interviews  
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### 20 ***What is known about this topic?***

- 21  
22 • NICE (2014) suggested an earlier discharge of prostate cancer patients from specialists  
23  
24 to GPs for their follow-up after treatment.  
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26
- 27 • Little is known about whether GPs feel well-prepared to deal with these patients'  
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29 survivorship needs and that they have the appropriate services and resources to do so.  
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### 32 ***What this paper adds***

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36 • Follow-up care for prostate cancer survivors was focused mostly on the provision of  
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38 PSA testing, overlooking the physical and psychological side-effects.  
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- 41 • GPs reported that the lack of expertise, knowledge of side-effects and resources may  
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43 prevent them from providing high-quality follow-up care to prostate cancer survivors.  
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- 46 • GPs suggested that timely access to secondary care through detailed treatment  
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48 summaries along with extra training could increase their confidence.  
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## Main text

### Introduction

The UK National Cancer Survivorship Initiative (NCSI) (Richards, Corner, & Maher, 2011) heralded a significant shift towards recovery, health and well-being in people diagnosed with and treated for cancer. Key features include personalised care planning and clinical support for self-management and treatment side-effects. Ten-year survival for localised prostate cancer is 83.8% and more than 47,000 new cases are diagnosed in the UK each year (Cancer Research UK, 2015). Studies show an increased number of consultations among cancer survivors compared with controls (Nord, Mykletun, Thorsen, Bjøro, & Fosså, 2005) so the implications of the NCSI for the workloads of General Practitioners (GPs) dealing with prostate cancer survivors are likely to be considerable.

Cancer patients want GPs and Primary Care Physicians (PCPs) to be involved in their care (Anvik, Holtedahl, & Mikalsen, 2006). A recent survey found that most patients were satisfied with the cancer care provided by their GP (Lang et al., 2017) and research indicates improved physical and psychosocial wellbeing of patients (Ngune, Jiwa, McManus, & Hughes, 2015) and higher Quality of Life (QoL) scores (Kendall et al., 2006) when this occurs. A desire among cancer patients for psychosocial support from GPs and PCPs in connection with fear of recurrence and changes in body-image and self-identity has been noted (Anvik et al., 2006; Kendall et al., 2006; Sisler, Brown, & Stewart, 2004). However, Adams et al. (2011) found that patients did not feel that their GPs were closely involved in their cancer care and Mao et al. (2007) reported that breast cancer patients in the USA considered PCPs not “appropriate” for a cancer-specific follow-up because of the limited communication with the hospital and their inability to manage effects of treatments. Khan, Evans and Rose (2011) found that cancer

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4 survivors viewed GPs as lacking expertise in cancer and as too busy to discuss long-term  
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6 issues, a situation exacerbated by a lack of continuity of care.  
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9 A number of studies have reported survivor concerns regarding a lack of communication  
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11 between specialists and GPs (Adams et al., 2011; Lewis et al., 2009; Mao et al., 2009),  
12  
13 particularly in relation to unmet needs concerning information about the disease and  
14  
15 treatment consequences and coordination between primary and secondary care. Lundstrøm et  
16  
17 al. (2011) carried out a study of cancer patient experiences in three counties in Denmark and  
18  
19 reported that one-third of the sample of 1490 patients reported problems with respect to  
20  
21 coordination of care between the hospital and GP. Sondergaard et al. (2013) found that  
22  
23 discharge from hospital to GP care was associated with the highest level of unmet information  
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25 needs and also with high levels of unmet coordination needs.  
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30 Prostate cancer survivors can experience significant and long-lasting treatment side-  
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32 effects, such as urinary, sexual and bowel dysfunction. They report challenges in talking openly  
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34 to their GPs about these problems and describe how they and their partners deal with them in  
35  
36 the absence of formal support or counselling (O'Brien et al., 2011). Fear of recurrence,  
37  
38 concerns about masculinity and stigmatisation has also been acknowledged as problematic  
39  
40 (Rubin, Vedsted, & Emery, 2011). Patients expressed a desire for their GPs to provide them  
41  
42 with information about their treatment and its side-effects and to deliver prompt advice about  
43  
44 any signs or symptoms of disease re-emergence (Adams et al., 2011). The relationship that  
45  
46 men have with GPs post-discharge needs to be understood in relation to their pre-treatment  
47  
48 engagement with healthcare services.  
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53 **Men are known to use GP services less than women (Wang, Hunt, Nazareth et al., 2013)**  
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55 **and this reluctance to consult GPs can be particularly marked in the case of prostate-related**  
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57 **concerns. For example, a Danish study found that the majority of men with Lower Urinary**  
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4 Tract Symptoms (LUTS) did not report them to their GP (Solvang, Elnegaard & Jarbøl, 2018). A  
5  
6 more recent Danish study found that urinary incontinence was associated with higher odds of  
7  
8 feeling too embarrassed to consult with a GP (Rubach et al, 2019). Men that endorse  
9  
10 traditional views of masculinity are less likely to seek medical care (Himmelstein and Sanchez,  
11  
12 2016) and being ill and seeking help are often perceived as a threat to masculinity, particularly  
13  
14 by older men (Tannenbaum and Frank, 2011). Furthermore, GP consultations with men may  
15  
16 take on a form that constrains men's ability to express emotional responses and concerns  
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19  
20 (Oliffe and Thorne, 2007).  
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22  
23 GPs' ability to detect early signs of recurrence and treat late side-effects is a matter of  
24  
25 concern for themselves and hospital specialists, despite both groups being positive about GP  
26  
27 involvement (Watson et al., 2011). Nevertheless, a British randomised controlled trial found no  
28  
29 significant differences in reoccurrence and death rates, QoL, psychological well-being and  
30  
31 satisfaction with care between GP-led and surgeon-led follow-up for colorectal cancer  
32  
33 survivors (Wattchow et al., 2006).  
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36  
37 For some GPs, financial issues and the lack of a recall system in primary care were  
38  
39 additional sources of worry (Neal, 2008). A study in the UK (Mitchell, Burridge, Colquist, &  
40  
41 Love, 2012) noted that systemic constraints, such as access to relevant clinical information,  
42  
43 and workloads can act to limit GP involvement in cancer care. Research in the USA found that  
44  
45 few PCPs believed that they possessed the time or the specific knowledge of side-effects to  
46  
47 care for prostate cancer survivors and consequently were reluctant to take responsibility for  
48  
49 them (Del Giudice, Grunfeld, Harvey, Piliotis, & Verma, 2009; Skolarus et al., 2014).  
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52 Survivorship and follow-up care are important stages in a patient's cancer journey. The process  
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4 of discharge<sup>1</sup> and transition from secondary care to primary care may be a stressful experience  
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6 for prostate cancer patients and have an impact on their QoL, well-being and survivorship.  
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10 Much of the research into the role of the GP in providing cancer care has been  
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12 conducted outside the UK (e.g. Lundstrøm et al., 2011; Skolarus et al., 2014). The UK based  
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14 research has focused on cancer as a whole and not on specific types of cancer (e.g. Kendall et  
15  
16 al., 2006) and research, in general, has been concerned with cancer care across the disease  
17  
18 trajectory from diagnosis to survivorship. Therefore, the aim of this study was to investigate  
19  
20 the experiences and preparedness of GPs in the UK concerning the more precise needs of  
21  
22 prostate cancer survivors and the challenges that GPs encounter or anticipate in providing  
23  
24 follow-up care following discharge from secondary care. Three research questions were  
25  
26 addressed:  
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- 31 • What are the concerns of GPs caring for prostate cancer survivors after their discharge  
32 from secondary care to primary care?  
33
  - 34 • How well prepared do GPs feel to provide advice concerning, and treatment for, side-  
35 effects?  
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  - 37 • What resources do GPs want in order to improve their services to prostate cancer  
38 survivors?  
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## 44 45 **Methods**

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48 A qualitative approach employing semi-structured interviews was adopted (Sullivan et  
49  
50 al., 2012). The interview topic guide was developed following a review of the literature and  
51  
52 discussions with clinicians (see Table 1). Topics included current experience with prostate  
53  
54 cancer survivors, preparedness and willingness to take over their follow-up care and  
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57 <sup>1</sup> In this paper we refer to discharge as the transition of follow-up care of cancer patients from hospital-  
58 based specialist care to primary based care following successful treatment.  
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4 challenges encountered. The interview questions served as a guide and participants were free  
5  
6 to refer to any experiences or issues they considered relevant. The interview schedule was  
7  
8 piloted with two GPs and minor amendments subsequently made.  
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10 Ethical approval was obtained from the University of East London Research Ethics  
11  
12 Committee.  
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### 15 16 17 18 *Participants and recruitment* 19

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21 The inclusion criteria stipulated that participants be GPs in the UK. GP surgeries were  
22  
23 identified using the website [www.nhs.uk](http://www.nhs.uk) and invitation emails were sent to 50 GPs at their  
24  
25 surgery's email addresses. The researchers did not receive any response via this recruitment  
26  
27 strategy.  
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30 The recruitment process was slower and more difficult than was expected due to GPs'  
31  
32 workload, so potential participants were identified by doctors, clinicians and hospital staff that  
33  
34 had connections with GPs and contact details for the latter were duly provided to the  
35  
36 researchers.  
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39 An invitation email with an information sheet and consent form was then sent. All GPs  
40  
41 interested in participating in the study were asked to contact the researcher to arrange an  
42  
43 interview. The researcher informed participants about the purpose of the research and the  
44  
45 details of the procedure by means of the consent forms, which addressed specific issues such  
46  
47 as the audio-recording of the interview, verbatim transcription and dissemination of findings.  
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49 Informed consent was obtained orally or in writing at the beginning of the interview, ensuring  
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51 anonymity and confidentiality to participants. The written signed consent forms were obtained  
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53 via fax or via email.  
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4 Twenty-eight GPs were invited to take part and 20 agreed to do so. The sample comprised 10  
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6 male and 10 female GPs, with between 4 and 40 years of experience (mean = 19.1 years) from  
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8 surgeries across London, South East and South West England. All had experience of providing  
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10 follow-up care to prostate cancer patients following discharge from hospital-based follow-up  
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12 care (see Table 2).  
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### 19 Data collection

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22 Due to time pressures on GPs, telephone interviews were offered as an alternative to  
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24 face-to-face interviews. Consequently, all but two interviews were conducted via telephone.  
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26 The interviews were conducted between May and September 2015. The average length of  
27  
28 interviews was 14 minutes, with a range of 8 to 23 minutes. Interviews were digitally audio-  
29  
30 recorded and transcribed verbatim to support the analysis process by the first author.  
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33 Transcripts were checked for accuracy and anonymised.  
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### 38 Data analysis

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41 The data were analysed using thematic analysis (Braun & Clarke, 2006). The stages of  
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43 analysis outlined by Braun and Clarke (2006) were followed, including familiarisation with the  
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45 data by repeated reading of each transcript, the generation of initial codes and the  
46  
47 combination of related codes into themes based on shared features.  
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51 The inductive analysis began with the coding of each interview followed by the linking of  
52  
53 codes across interviews to build themes. The inductive approach allows the development of  
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55 broad themes and categories developed from the raw data, which leads to a deeper  
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57 understanding of the content of interviews (Braun & Clarke, 2006). Data saturation was  
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4 considered to have been achieved when no new codes were identified, which occurred by the  
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6 final transcript.  
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9 Previous evidence has shown that after twelve interviews the number of new emerging  
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11 themes was minimal, suggesting that a sample of ten to twelve interviews may be sufficient to  
12  
13 enable the development of high-level meaningful themes and useful interpretations (Guest,  
14  
15 Bunce, & Johnson 2006). Software for the analysis of qualitative data (NVivo 11) was  
16  
17 employed.  
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20 The first author analysed the raw data and all the authors discussed the interpretation  
21  
22 and clustering of the codes and themes to develop the final thematic map. The data resulting  
23  
24 from the analysis and the electronic versions of the transcripts were stored on a password-  
25  
26 protected computer at the University of East London.  
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## 32 **Results**

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35 Three main themes were identified by the analysis. These are shown in Table 3 below.  
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### 41 Care provision and follow-up

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44 There was a shared view that GPs should provide holistic care and not focus solely on  
45  
46 cancer history and recurrence monitoring.  
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49 *“So, we do a holistic, sort of interview with them, about what their*  
50  
51 *concerns are, you know, physical, psychological, financial, work.” (P1)*  
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56 This role encompassed being an advocate and navigator, providing support and listening  
57  
58 to the patients' concerns.  
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4 *“Some patients we have are really good and a long-standing*  
5 *relationship and a lot of trust and things within that. So, they may*  
6 *come to us and they often do come and say “I don’t understand a*  
7 *word when I was in the hospital, can you explain?” (P4)*

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13 *“The GPs here are mainly patients’ advocate or navigator role rather*  
14 *than actually actively doing the investigation”. (P11)*

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21 Fear of recurrence was considered one of the main concerns of patients, making them  
22 particularly vigilant concerning changes in their body and its functioning.

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25 *“Any symptom that they develop almost anywhere around their body,*  
26 *their first understandable worry is that could be related to their*  
27 *previous cancer. So, their expectations can be very focused on the*  
28 *possibility of reoccurrence.” (P7)*

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37 Even though most participants believed GPs should provide holistic care, many viewed  
38 their main role as monitoring PSA levels.

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42 *“We just do the PSA surveillance, and then we refer back to the*  
43 *hospital when the PSA has reached a certain level.” (P19)*

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49 Some believed that because patients did not see them as specialists or particularly trust  
50 them to provide follow-up care they had low-expectations in any case and there was a  
51 recognition that although issues other than PSA testing were important they were not always  
52 addressed.  
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4 *“There is quite a lot of reservation about going back to the GPs and*  
5 *patients feel scared about leaving the specialist setting and they feel*  
6 *that the experts know them really well {...} some patients may think*  
7 *that we may not have a clue and we are not specialists and they do*  
8 *not bother coming.” (P2)*

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18 Preparedness for assuming responsibility

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21 Nine participants considered themselves well-prepared for providing follow-up care.  
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23 This was grounded in their wide experience of managing different cancers and chronic  
24 conditions other than cancer.  
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30 *“Yes, I think the general practices have a place for it, and I think for*  
31 *most cancers there is a sort of central coordinator of all... of care. I*  
32 *think yes I am well-prepared.” (P13)*

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39 *“We are looking after diabetics, COPD, asthma, arthritis, every kind of*  
40 *patients are being monitored in primary care so stable prostate*  
41 *cancer, there is no reason why we cannot monitor them in primary*  
42 *care.” (P19)*

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50 This confidence was, to a degree, dependent on the accessibility of referral back to  
51 specialist care if necessary.  
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57 *“As long as there is an easy pathway back into urology, I would*  
58 *imagine that patients may well be happy because they have*  
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4 *completed their treatment. So, for them, to go back to the hospital,*  
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6 *you know, every six months or once a year, just to get the PSA done, I*  
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8 *can see that this is not necessary” (P17)*  
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13 However, this, in turn, depended on the hospital discharging the prostate cancer  
14 survivors in a stable condition and with a treatment plan. This was considered crucial in  
15 enabling GPs to successfully carry out their duties.  
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22 *“Stable prostate cancer patients can easily be managed in the*  
23 *community with the appropriate clinical protocols. If they are stable*  
24 *and controlled and have a treatment plan, I don’t have a problem*  
25 *with it.” (P12)*  
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33 Participants expressed their concerns involving follow-up and recall and test  
34 interpretation. They worried about the possibility of “losing” some patients between their  
35 follow-up appointments as they would not be able to provide them with reminders. In  
36 addition, they felt that their limited knowledge concerning the interpretation of PSA results  
37 could have a negative impact on the patients.  
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47 *“I would be worried about the monitoring; the responsibility of the*  
48 *monitoring being done totally in primary care. I think of the risk*  
49 *people getting lost to follow up, because people, you know people*  
50 *move around, they could get lost. My other reservation would be that*  
51 *GPs don’t know how to interpret the test results.” (P9)*  
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4 *"We don't have a recall system for PSA. You know, we have a recall*  
5 *system for the Smear. A recall system works really well if we have*  
6 *someone with hypertension, we've got a recall system to make sure*  
7 *we will see him as a minimum once a year."* (12)  
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15 Several expressed a desire for training and updating in order to improve their and their  
16 nurses' skills and knowledge in providing services to prostate cancer patients.  
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23 *"All the cancer treatments are developing all of the time and so if*  
24 *patients are coming out of the hospital and had treatments that you*  
25 *never heard of, obviously, it is really difficult and so I think being kept*  
26 *up to date or keeping yourself up to date is really important."* (P1)  
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34 *"Nurses within the general practice is another focus who often need*  
35 *some assistance and training because some of these problems will*  
36 *present first to nurses."* (P16)  
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#### 43 Challenges for primary care

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46 In spite of a general willingness to take over the routine care of prostate cancer patients,  
47 there were concerns about the implications for resources that were already stretched and  
48 about the information provided to GPs at the point of discharge from secondary follow-up  
49 care.  
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4                   *“This transfer of activity has to be appropriately resourced. Without*  
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6                   *these resources in primary care, GPs will not do this, no matter what*  
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8                   *consultants are going to transfer this activity.” (P7)*  
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13                   There was a general view that this lack of resources and time could have a negative  
14  
15 impact on the patient experience.  
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18                   *“One of the major problems in primary care is to get an*  
19  
20                   *appointment.” (P20)*  
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25                   Managing communication and information exchange with the hospital was also  
26  
27 discussed, with some participants reporting a broadly positive experience.  
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32                   *“So usually, usually the case is the patient's coming from (hospital),*  
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34                   *and letters are comprehensive and more informative.” (P5)*  
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39                   However, a majority expressed concerns regarding communication and collaboration  
40  
41 with hospitals with respect to three issues: difficulties in communicating, concerns about lack  
42  
43 of information in the discharge letter and lack of information about a follow-up plan and  
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45 guidelines.  
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50                   *“One particular problem that both sides of the system have now is the*  
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52                   *delay in receiving information.” (P15)*  
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4 *"We don't get that information, maybe a few weeks later, sometimes*  
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6 *you see the patient before the letter. This makes it a little bit sort of*  
7  
8 *awkward when we see them!" (P6)*  
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13 The discharge letter was identified as a particular issue, in relation to information  
14  
15 provision and timeliness as well as when and for what reasons they should refer patients back  
16  
17 to the hospital. Participants considered the hospital discharge summary to be a key document  
18  
19 and wanted it to be revised in order to focus on specific recommendations about PSA  
20  
21 monitoring frequency and concerning PSA levels as well as providing better guidance for  
22  
23 managing post-treatment side-effects.  
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29 *"The hospital's discharge summaries are pretty inadequate cause all*  
30  
31 *they give is the diagnosis, and then they give a recommendation*  
32  
33 *about PSA and follow-up. They don't give any other recommendation*  
34  
35 *about managing other aspects of these men." (P13)*  
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40 *"There is an uncertainty of where to refer people back for advice."*  
41  
42 (P10)  
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47 Explicit and detailed guidelines about monitoring PSA, which was widely considered the  
48  
49 most important task in primary care, were requested.  
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53 *"It needs to be tailored to the individual patient and it needs to be*  
54  
55 *very, very clear on the information about how frequently PSA testing*  
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4 *is happening, and should the PSA rise above whatever limit has set in*  
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6 *the letter, in particular for this patient.” (P1)*  
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11 Some advocated the provision of an appropriate and tailored follow-up care plan for  
12  
13 each prostate cancer survivor including information such as guidelines about managing long-  
14  
15 term side-effects, monitoring recurrence symptoms and the frequency of PSA tests.  
16  
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19

20 *“More a plan so actually you’ve got a plan and you know what to do*  
21  
22 *if the symptoms get worse or the PSA rises.” (P20)*  
23  
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25

26 *“And maybe more about what the long-term plan is so you know*  
27  
28 *what to look after like if there is a PSA level that they had been*  
29  
30 *concerned about or for how long they are going to follow them up or*  
31  
32 *for how long they are going to see them.” (P18)*  
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38 Easier and more personalised contact and communication with hospital-based  
39  
40 specialists were seen as potentially helpful.  
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43 *“You know there is a big variation in gaining access to secondary care*  
44  
45 *advice. You know some hospital, some specialities, who you can*  
46  
47 *contact, you know whether you can call them or leave a message and*  
48  
49 *they will call you back and help you.” (P1)*  
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54 *“I think we are very lucky to work with (hospital) who has a fantastic*  
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56 *urology department, and we are very lucky that there is a very good*  
57  
58 *nurse and can ask her if we have concerns.” (P19)*  
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Access to support from a specialist cancer nurse was also suggested.

Participants believed that a nurse who specialises in prostate cancer and has the knowledge about its treatments and side-effects would be an important source of support in primary care.

*“More involvement of the clinical nurse specialist will be ideal for the community not just based only on secondary care.” (P8)*

The importance of adequately preparing prostate cancer patients for discharge by informing them about what they should expect from GPs was emphasised.

*“The patients must be appropriately debriefed from the consultants, about why they are discharging to the community and they should convince the patient “Look here, we got a clinical protocol, go and see your GP if there is any problem.” (P19)*

*“So really is whether the patients have been told enough from the hospital, whether they are aware of what the symptoms are and how often they should be seeing us.” (P3)*

## Discussion

There was a consensus among participants that GPs should provide holistic care and support to prostate cancer patients, which is consistent with what these patients and their

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4 carers desire (Kendall et al, 2006). However, in spite of this commitment, in practice, the  
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6 priorities of participants centred around PSA testing and interpretation of results. The  
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8 concerns of secondary care clinicians in relation to GPs' knowledge, especially in interpreting  
9  
10 PSA results and detecting late side-effects of treatment, have been noted in previous studies  
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12 and our participants shared these concerns (Anvik, Holtedahl, & Mikalsen; 2006; Greenfield et  
13  
14 al., 2009; Kantsiper et al., 2009; Watson et al., 2011).

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There were mixed views about preparedness and willingness to be involved in the detail of follow-up care. Some, but not all, participants felt confident in their ability and skills and well-prepared for assuming this role. The concerns expressed by those lacking confidence were influenced by their evaluation of their skills and training, their ability to cope with the extra workload, their previous experience of providing care to these men and their collaboration with secondary care. Some felt confident about managing side-effects of treatments, though many did not see this as part of their role, which stands in contrast to a broad commitment to providing holistic care. Lack of confidence and knowledge among GPs in relation to following-up patients with other types of cancer (i.e. breast cancer, colorectal cancer and lymphoma) has previously been reported (Del Giudice et al., 2009). Indeed, it has been argued that cancer patient needs are unlikely to be generic and instead depend on a complex mix of factors, including gender, type of cancer and demographic factors (Wessels et al., 2010). Watson et al. (2011) found that GPs described different degrees of involvement in managing erectile and urinary dysfunction, which is consistent with our findings. Detection of recurrence has been identified as the most important reason for follow-ups and fear of recurrence has been reported as the main reason for anxiety and need for reassurance and support in cancer patients (Lewis et al., 2009; Mao et al., 2009). In our study, participants stated that patients may not feel safe when being followed-up by them instead of hospital doctors, and studies of breast cancer patients have identified concerns about GPs' ability to address cancer-specific

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4 issues and to provide cancer-specific surveillance (Earle, Burstein, Winer, & Weeks, 2003; Earle  
5 & Neville, 2004). However, a British RCT found no significant differences in reoccurrence and  
6  
7 death rates, QoL, psychological well-being and satisfaction with care between GP-led and  
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9 surgeon-led follow-up for colorectal cancer survivors (Papagrigoriadis & Koreli, 2001).  
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14 Studies have found that lack of time and resources in primary care in the UK was of  
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16 concern to GPs and nurses (Mitchell et al., 2012; Watson et al., 2011) and participants in our  
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18 study expressed similar concerns, particularly in connection with funding. Participants also  
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20 reported being unable to schedule appointments that were long enough to address patient  
21  
22 worries and were concerned about additional increases to an already heavy workload, echoing  
23  
24 issues identified in studies focusing on general and colorectal cancer care (Papagrigoriadis &  
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26 Koreli, 2001; Roorda, Berendsen, Haverkamp, van der Meer, & de Bock, 2013).  
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31 The majority of our participants described problems and difficulties in communication  
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33 with secondary care, commenting on the inadequacy of discharge letters and lack of clear  
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35 information. This finding echoes the concerns of GPs in a UK study (Mitchell et al., 2012) who  
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37 wanted improvements in written communication, and GPs in a Danish study who complained  
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39 that discharge letters tended to focus solely on technical aspects of treatment and not on the  
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41 more holistic issues that concerned them and their patients (Guassora, Jarbaek, & Thorson,  
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43 2015). Our participants suggested a range of approaches to overcome the difficulties they  
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45 experienced, including improvements to guidelines provided by hospitals, better and quicker  
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47 access to specialists and extra training. There was also a view that hospitals should prepare  
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49 patients for discharge from their follow-up care, which would make GPs' work easier and more  
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51 successful. The issue of communication between primary and secondary care has been raised  
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53 by a number of studies, with delays and lack of clarity frequently noted (Kripalani et al., 2007).  
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#### Implications for practice and research

The findings of this research highlight the urgent need for preparation for discharge from secondary care, which should include information about the next steps in the follow-up care, such as management of side-effects, as well as clear instructions and guidelines relating to the role and responsibilities of GPs. This should include specification of the content of the information provided to the GPs and the provision of guidance concerning how this can be achieved in a timely fashion and delivered in a supportive manner. In particular, there should be clear and detailed guidelines for GPs about their role following discharge to avoid potential confusion about the respective roles and functions of GPs and hospital specialists, which can result in patient distress and dissatisfaction.

The process of discharge and the appropriate steps and conditions required for its successful implementation need to be clearly specified and the discharge process should be formalised within the care pathway.

Improving communication between GPs and specialists is likely to improve patient care after treatment. A shared care model and survivorship care plans would enable all members of the cancer care team to coordinate and deliver the best care and address the lack of clear guidelines about the role of GPs (Earle, 2006; Grunfeld & Earle, 2010; Nissen et al., 2007; Skolarus et al., 2013).

Additional funding to provide infrastructure support, such as an IT recall system, could help GPs to manage the extra workload. In addition, primary care could modify established GP practice approaches and recall systems that have been successfully used for other diseases and follow-ups such as smear tests.

Late-occurring and long-term physical and psychosocial side-effects require on-going management and GPs may require support for updating knowledge and skills in order to

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4 deliver appropriate care in this regard. Future guidelines should focus not only on the  
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6 provision of PSA tests by GPs but also on the provision of follow-up care relating to side-  
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8 effects. GPs should be aware of and prepared to provide support and advice concerning the  
9  
10 management of side-effects and their impact. Given the evidence from previous research  
11  
12 concerning the challenges that men experience when raising concerns and expressing  
13  
14 emotions with GPs it would be useful to provide guidance and information to GPs concerning  
15  
16 gender, masculinity and communication management. This would support GPs in delivering  
17  
18 the holistic care endorsed by our participants.  
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23 Future studies should recruit GPs practising in areas with large African-Caribbean and  
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25 Africa communities. Men of these ethnic backgrounds are at a higher risk of developing  
26  
27 prostate cancer and do so at a younger age, so they are likely to have particular needs. For  
28  
29 example, a recent study (Margariti et al, 2019) found African Caribbean prostate cancer  
30  
31 survivors believed that lack of knowledge among GPs about aspects of PCa that were of  
32  
33 particular relevance to them was problematic. While our study did not seek to address the  
34  
35 issue, it is known that gay men with PCa report low satisfaction with PCa health care (NHS,  
36  
37 2014), and studies have reported that particular sources of dissatisfaction include assumptions  
38  
39 of heterosexuality, lack of interest and lack of appropriate knowledge among healthcare  
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41 professionals (e.g. Rose, Ussher & Perez, 2018). Future studies should explore this further in  
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43 the context of UK GP-based care.  
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48 Research should also address the views of nurses in primary care given their important  
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50 role in providing follow-up care  
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53 London Cancer is an integrated cancer system serving North East and Central London  
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55 and West Essex aiming to deliver comprehensive and seamless cancer care to all patients from  
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57 diagnosis, through treatment, to living with and beyond cancer. They have recently published  
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4 guidelines for stratified follow-up care of prostate cancer including discharge guidance so it  
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6 would be useful to repeat this study in the relatively near future to determine whether these  
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8 have impacted on the GP experience (UCLH Cancer Collaborative Annual Review, 2018)  
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11 While the importance of providing psychosocial support to cancer patients throughout  
12  
13 their follow-up has repeatedly been emphasised (Rubin et al., 2015), few participants in this  
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15 study were involved in providing such support.  
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### 21 **Strengths and limitations**

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23 A particular strength of this study is that all participants were working in the UK. Most  
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25 previous studies were conducted in countries whose health care systems differed from the UK  
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27 making any generalization from these to the UK system problematic.  
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32 Given the recent guidelines and recommendations from UCLH Cancer Collaborative, the  
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34 concern of the NHS, cancer communities and charities is about addressing the needs of cancer  
35  
36 survivors and growing the involvement of primary provision in their follow-up care. This study  
37  
38 addresses an important contemporary issue and its findings could be useful and contribute to  
39  
40 the examination of this phenomenon in the UK and the development of policies.  
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44 The data were self-reported with no objective confirmation of an alternative perspective  
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46 on issues. The sampling method may have been biased towards GPs who had a particular  
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48 interest in prostate cancer and the views expressed by participants may not represent the  
49  
50 national population of GPs In addition the research was limited to urban geographical areas  
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52 and the findings may differ in regional, rural and remote areas.  
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## Conclusion

Findings from this study support previous research that GPs expressed a lack of confidence and knowledge in relation to following-up cancer survivors and their miscommunication with secondary care. The novel finding is that this study identifies a preliminary effective systematic approach to provide the GPs what they require in order to be prepared in managing prostate cancer survivors. In addition, GPs shared the need for oncology specialists to provide a disease-specific recommendation on cancer recurrence symptom monitoring as well as post-treatment survivorship issues. The findings from this study strengthen the call for better communication pathways to be developed for GPs and oncology specialists to improve the follow-up care they provide to prostate cancer survivors.



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**Table 1. Interview topic guide**

- Could you tell me your opinion about the transfer of prostate cancer survivors from hospital-based care back to the primary care setting?
- What experience have you had of providing care to survivors of prostate cancer?
- Do you think that you receive adequate information from the hospital about these patients?
- What information would you like to receive from the hospital concerning these patients?
- Could you tell me how well-prepared you feel is the main healthcare provider for a prostate cancer patient after his discharge?
- Can you tell me if you have any concerns or reservations about having this role?
- What do you anticipate will be the demands and the expectations of prostate cancer patients from you following their discharge?
- Do you feel that you require any kind of additional support/training or information in order to assist you in providing effective care to these men? If so, what would be the best way of providing this?

**Table 2. Demographic characteristics of the GPs who participated in interviews**

Demographic characteristics	N
<i>Gender</i>	
Male	10
Female	10
<i>Years of working experience</i>	
1-10	6
11-20	6
21-30	4
31-40	4
<i>Special interest or qualification in prostate cancer</i>	
Yes	5
No	15



**Table 3. Themes developed through analysis of the data**

Theme	Description	Representative quotes
1. Care provision and follow-up	This theme presents participants' current involvement and role in prostate cancer patients' follow-up care after their discharge from hospital care. Participants shared their opinion and experience in providing follow-up care to these men and what they consider as follow-up care.	<i>"We just do the PSA surveillance, and then we refer back to the hospital when the PSA has reached a certain level."</i>
2. Preparedness for assuming responsibility.	This theme presents the professional beliefs and views that participants expressed about their preparedness for assuming the role of the main healthcare provider in prostate cancer patients after their discharge from secondary care. Participants described whether they felt well-prepared and confident or not.	<i>"I would be worried about the monitoring; the responsibility of the monitoring being done totally in primary care. I think of the risk people getting lost follow up, because people, you know people move around, they could get lost. My other reservation would be that GPs don't know how to interpret the test results."</i>
3. Challenges for primary care	In this theme, participants described the challenges in primary care at this present time to assuming this role	<i>"The hospital's discharge summaries are pretty inadequate cause all they</i>

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	and taking over the “burden” of follow-up care.	<i>give is the diagnosis, and then they give a recommendation about PSA and follow-up, they don't give any other, to my experience, any other recommendation about managing other aspects of these men.”</i>
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For Peer Review