

ORIGINAL ARTICLE

The value of information and support; Experiences among patients with prostate cancer

Siv Tove Aunan¹  | Gry Ciekals Wallgren²  | Britt Sætre Hansen^{3,4}

¹Faculty of Health Sciences, Department of Caring and Ethics, University of Stavanger, Stavanger, Norway

²Department of Haematology and Oncology, Stavanger University Hospital, Stavanger, Norway

³Department of Anaesthesiology and Intensive Care, Stavanger University Hospital, Stavanger, Norway

⁴Faculty of Health Sciences, Quality and Safety in Health Care Systems, University of Stavanger, Stavanger, Norway

Correspondence

Siv Tove Aunan, Faculty of Health Sciences, Quality and Safety in Health Care Systems, University of Stavanger, N-4036 Stavanger, Norway.
Email: siv.t.aunan@uis.no

Abstract

Aims and objectives: To explore and analyse prostate cancer survivors' experiences and critical reflections of information received during their cancer trajectory.

Background: Prostate cancer is one of the most prevalent cancers in men worldwide. Treatment causes side effects such as urinary incontinence, bowel changes and erection problems influencing sex life and manhood. Cancer pathways are designed to give patients and their relatives a predictable and as stress-free as possible treatment trajectory and minimise waiting time.

Design: Qualitative, explorative research design.

Methods: Focus groups with 16 prostate cancer survivors after having participated in an educational programme. The COREQ checklist was followed to ensure rigour in the study.

Results: The main theme, 'Help me stay in control', and three subthemes, 'To be met with interest and support, enough knowledge to understand what is happening and a plan to build the new life on', emerged from qualitative analysis and highlighted the participants' need for information and support, specially scheduled at critical times in the treatment trajectory: the diagnostic phase, the treatment phase and the life after treatment. They also highlighted the need for empathy and interest from health-care professionals and highlighted the need for arenas to discuss vulnerable topics. Contact with peers was perceived as supportive and encouraging.

Conclusion: Healthcare professionals must support prostate cancer survivors with empathy, interest and information tailored to their needs in three different phases. Continuity in information flow may increase trust and satisfaction among the prostate cancer survivors.

Relevance to clinical practice: PCa patients' need for information varied at critical times in their treatment trajectory. HCP should meet them with empathy and interest to be able to tailor their need for information and support.

KEYWORDS

cancer pathway, care, communication, coping, experiences, information, oncology nursing, patient education, prostate cancer, psychosocial needs, quality of life, support, well-being

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2021 The Authors. Journal of Clinical Nursing published by John Wiley & Sons Ltd.

What does this paper contribute to the wider global clinical community?

- Information should be given with interest and empathy and scheduled at critical times in the cancer trajectory.
- Continuity in the information process is important.
- Meeting points for information and networking help PCa survivors to be open for intimate discussions and learning
- PCa survivors need access to HCPs (a ON-driven outpatient clinic) to address their ongoing needs for supportive care and information.

1 | INTRODUCTION

Worldwide, prostate cancer (PCa) is among the most prevalent cancer types in men (Huntley et al., 2017; Jakobsson & Fransson, 2013; Jemal et al., 2011; Schantz Laursen, 2017; Siegel et al., 2019). Among men in Norway, 26% of all cancers diagnosed in 2019 were PCa (Cancer Registry of Norway, 2019).

The current overall five-year survival rate among patients with PCa is 95.5% (Cancer Registry of Norway, 2019). The prevalence of PCa is also increasing, mainly due to the rising population of older adults (Cancer Registry of Norway, 2019). Prostate-specific antigen (PSA) measurement is not recommended as a general population-wide screening method in Norway. However, the proportion of cases in which PSA testing leads to further examination is increasing and is the main rationale for subsequent biopsy (Cancer Registry of Norway, 2019; Paterson et al., 2015).

In suspected PCa cases, the general practitioner will refer the patient for further assessment by the specialist health service. The intention of national standardised cancer pathways is to minimise waiting times and to give patients and their relatives a predictable treatment trajectory that is as stress-free as possible (Cancer, 2016). Research shows that medical information is routinely given, but information and support regarding psychosocial issues arising from cancer remains unmet (Kelley et al., 2015; Levesque et al., 2015).

1.1 | Background

Most men with PCa survive (Jakobsson & Fransson, 2013). Mortality has decreased since 1996, possibly due to a combination of early diagnosis and better, more active treatments (Cancer Registry of Norway, 2019; Huntley et al., 2017). However, treatment causes side effects such as bowel changes, urinary incontinence, erection problems with consequent sex life effects, fatigue, changes in sense of self and a lack of control (Jakobsson et al., 2013; Schantz Laursen, 2017). Urinary incontinence and erectile dysfunction are the most common side effects and challenges associated with surgery (i.e. radical prostatectomy) (Carrier et al., 2018; Schantz Laursen, 2017). Such consequences adversely affect quality of life as it relates to psychosocial life, sexuality and intimacy (Schantz Laursen, 2017; Simpson, 2015). Dramatic changes in men's sexual function should be seen as a key

assessment in clinical interventions (Ezer et al., 2012), and nurses should focus on, and assess, emotional and social aspects during follow-up visits (Jakobsson et al., 2013). Men with PCa want to be independent and take part in their treatment decisions, but they need health professionals' help and support to regain control over their recovery and perceived health (Muntlin Athlin et al., 2018). Clinical nurse specialists play a key role in ensuring that patients receive individualised information and support (Basketter et al., 2018). Oncology nurses (ONs) are trained to provide these patients with predictability in an unpredictable life situation (Aunan et al., 2018).

More information and tools to improve coping and control among this patient population are needed. Empathy, care and individualised information are low-cost interventions, which can be enormously important (Huntley et al., 2017). Educational programmes are also needed because although patients want information about their diagnosis and treatment options prior to starting treatment, they find it difficult to absorb facts at this time (Huntley et al., 2017). During the threatening and stressful circumstances that often surround PCa, these patients may be challenged to absorb a range of information about their diagnosis and treatment. In such situations, patients may need information repeated or 'reinformation'. Mutual support and camaraderie with other men diagnosed with PCa appears to be a particularly important source of social support that helps them manage side effects (Hamilton et al., 2015).

The fact that meeting with fellow patients, such as in an exercise programme, is important to outcomes provides nurses with useful insight regarding common experiences, support and hope (Stenberg et al., 2016). Most men newly diagnosed with PCa want to be informed and involved in medical decision-making (Davison et al., 2014). Jakobsson and Fransson (2013) found that to make a difference in the lives of patients with PCa, nurses must bridge the gap between in-hospital treatment and everyday life beyond the hospital.

1.2 | The Norwegian National Prostate Cancer Pathway

The pathway for prostate cancer describes PCa treatment in relation to curable and incurable disease. Treatments vary from active surveillance by general medical services to treatment and follow-up by hospital-based specialists. Many patients' treatments combine surgery, radiotherapy and/or hormone treatment.

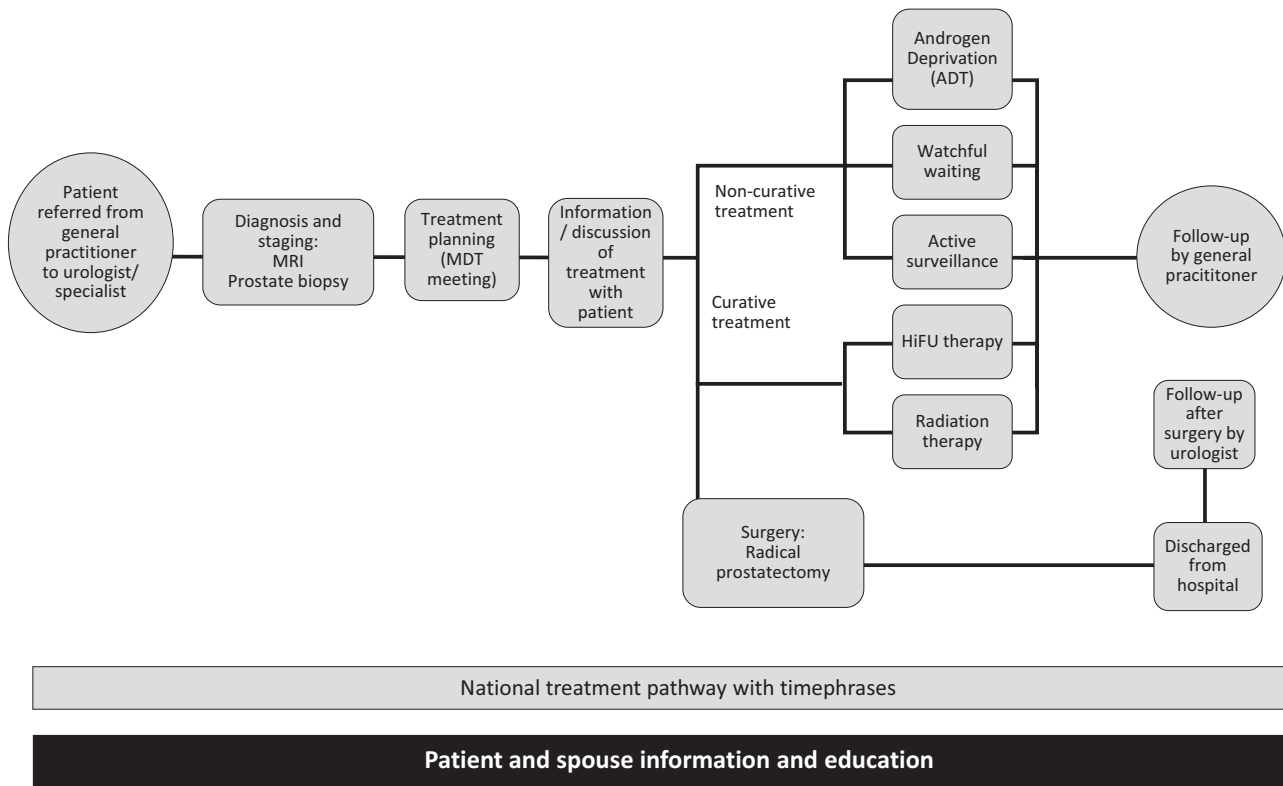


FIGURE 1 Simplified version of the local prostate cancer pathway, based on the national pathway (MDT meeting: multidisciplinary team meeting, HiFU: high-intensity focused ultrasound).

During the past few years, most PCa treatment in Norway has changed from inpatient- to outpatient-based. As outpatients, men with PCa must find new arenas in which to meet and learn from experts and fellow patients. Urologists/expert physicians oversee outpatient-based treatment and follow-up, based on the national clinical pathway (Figure 1). There are relatively few ONs, and according to the Norwegian National Prostate Cancer Pathway, their first and only scheduled meeting with patients with PCa is 12 months post-surgery. All PCa patients in Norway have access to a pathway coordinator for PCa patients whose role is to connect the patients with the hospital system. This coordinator is a member of the multidisciplinary team and responsible for individual information and continuity in follow-up. Most curative and follow-up treatments take place at the urology unit, while patients needing radiotherapy or chemotherapy are referred to the local cancer unit.

1.3 | The prostate cancer pathway

1.3.1 | The information pathway

The local and the national pathways are identical. According to this pathway, men with PCa receive information from a urologist when they receive the diagnosis and when they are admitted to hospital for the operation. The local pathway coordinator for PCa patients (a nurse) contacts all patients by telephone in the diagnostic phase

organising all appointments. Patients are invited to contact him/her by phone if they have questions during and after treatment. The information pathway is then discontinued 12 months after the completion of treatment. The PCa survivors are then contacted (telephone) by an ON. Inspired by the information and treatment pathway organised for breast cancer survivors with their own cancer nurses and oncologists as points of contact along the treatment pathway (Aunan et al. 2018), we wanted to explore how PCa survivors experienced information received along their treatment pathway.

We recruited participants from the local Prostate Cancer School (PCaS), a local information programme (2 days), designed as an offshoot of the Breast Cancer School (Aunan et al. 2018) to meet the PCa survivors' information needs. The PCaS is popular and has a waitlist that varies from 0–8 months. This waiting list and not the PCa survivors' need for information decides when they are admitted to the programme. In 2019, 120 PCa survivors completed the programme. The PCaS is organised by the hospitals' Centre for Patient Education.

Study aims

The primary study aim was to explore and analyse PCa survivors' experiences and critical reflections on the information they received during their cancer trajectory. Greater knowledge is needed regarding how patients with PCa experience the individualised and group-based information they receive throughout their PCa trajectory. Our review of the relevant literature revealed no similar studies; thus,

our findings may provide more insight into these important issues. Two research questions guided the study:

- How do PCa survivors experience their need for information and support during their cancer trajectory?
- How can this be improved?

1.4 | Ethical considerations

This research was approved by the hospital administration and Regional Committees for Medical and Health Research Ethics (REK) in Norway (No. 2018/1427), the University Hospital Data Protection Officer and the Unit Manager. The participants were given information about the study purpose and methods; they were also told that participation was voluntary, that they were free to withdraw at any time (The World Medical Association Declaration of Helsinki, 2013) and that full confidentiality was guaranteed (REK 2019). Written consent was obtained from each participant.

2 | METHODS

To gain knowledge and understanding of PCa survivors' experiences with information received during their cancer trajectory, a qualitative, explorative design was applied with focus groups to encourage the participants' critical reflections. Focus groups give participants a discussion forum in which direct evidence about similarities and differences in their opinions and experiences is gathered (Morgan, 1997). Open questions and time for discussion gave room for exchange of experiences and reflection. The participants were invited to describe their experiences with information and support through their cancer journey (Appendix 1).

2.1 | Participants and clinical setting

To capture the need for information described by the PCa survivors, the study participants were all PCa survivors recruited from four PCaS courses ($n = 80$). The first author informed them about the study and invited them to participate. The 16 participants who accepted the invitation were organised into four focus groups (with 5, 5, 2 and 4 participants in each, respectively). Due to organisational problems (finding suitable time), one focus group was conducted with 2 participants only. They were eager to participate and shared valuable information. The sixteen men in this study were aged 55–80 years. The focus groups took place in a room in a university building. All participants arrived as scheduled, despite some needing to travel long distances. The focus groups were moderated by the first author who is an experienced CNS and unknown to the participants, and an assistant observer who is an HCP and one of the organisers of the PCaS. To make the participants' comfortable,

the moderator opened each interview session with a broad question about their general experiences, followed by questions from the semi-structured interview guide (Appendix 1). Given the authors' preunderstanding that men are not in the habit of verbalising grief and worry to the same extent as are women, we were surprised—the participants willingly shared sensitive stories from their backgrounds to make the authors and their fellow patients understand what they had been through. The 60- to 70-minute discussions were friendly and lively, and direct language ('hard-on', an erection, etc) was used. They used humour especially when sensitive stories were shared. They underlined the importance of the study and were grateful for the opportunity to participate. Each interview was recorded using an audio tape recorder, which was later transcribed by the first author. The COREQ checklist was followed to ensure rigour in the study (Supplementary file 1).

2.2 | Qualitative content analysis

A qualitative content analysis was used, following several steps (Graneheim et al., 2017; Graneheim & Lundman, 2004) (Table 1). All focus groups ended with a summary of the key points as they were understood by the moderator and assistant. The participants were free to accept, correct or elaborate on these key points. The investigators are all female registered nurses, one of whom has experience in critical care and two of whom have experience in cancer care. All interviews were transcribed by the first author. All authors participated in the analysis, and each individually read the transcribed text several times. The authors met repeatedly to reflect on patterns, and identify similarities and divergences in the participants' descriptions of their need for information and support from HCP throughout their illness trajectory. After condensing the meaning units, still preserving their core meaning, they were labelled with a code. The codes were sorted into categories at a manifest level, and subthemes and themes were created through abstraction.

The first author and third author were invited to present the results from our study to PCa survivors attending a PCa café. These survivors confirmed the findings, strengthening the trustworthiness of our study, and shared new narratives with the café guests; they also expressed gratitude for our efforts to bring their experiences into political and patient safety discussions.

2.3 | Limitations of the study

Considering participant checking, we did not provide feedback from participants during or after the analysing process. Participant checking was carried out, in an ongoing way as data were collected to ensure that the participants' meanings are understood. The semi-structured interview guide was not piloted, but the interviewers were experienced with focus-group interviews.

TABLE 1 The analysis

| Theme: | A plan to build/base the new life on | | | | | |
|------------|---|--|---|--|--|--|
| Subthemes: | To be met with interest and support | | Enough knowledge to understand what is happening | | Use of humour, direct language | |
| Categories | To see, listen to and make sure information is tailored to their need | To bring along support to information meetings | Tailored information about treatment and consequences | Tailored information from specialists and peers about side effects and how to prevent them | HCPs to contact when in need for more information (reinforced) | Someone to contact when in need |
| | Hope and predict ability | | | | | Accept the new situation, body changes |
| | | | | | | Use own experiences to help fellow strangers |

3 | RESULTS

The primary study aim was to explore and analyse PCa survivors' experiences and critical reflections on their need for information and support during their cancer trajectory. To answer our research questions, the results are presented based on the theme and subthemes revealed in the analysis.

The main theme 'Help me stay in control' expressed the PCa survivors' overall need to stay in control of their lives. They also described their greatest challenge as a lack of information and information continuity. They put special emphasis on three information phases of their cancer trajectory: diagnostic, treatment and post-treatment phase (Figure 2). Their need for information and support to help them stay in control of their lives varied according to which of the three information phases they were experiencing (Figure 2). The main theme represented a unified need for a general information pathway with both group and individual meetings and for individual plans and individualised information throughout the cancer journey, to help patients stay in control of their lives.

Our exploratory approach indicated that there is no such thing as a standard patient with PCa, and no standardised way of informing and supporting them. The results identified diversity, uniqueness and differences in patients' needs. To be seen and considered as an individual was perceived as crucial. They underscored that they did not perceive their cancer trajectories to be linear. Rather, they described a process of moving back and forth and in circles.

As shown in Figure 2, the PCa treatment pathway focuses primarily on diagnostics and treatments. As noted by the arrows at the base of the figure, continuous informational support is provided. Our findings add a new perspective on this pathway, represented by the addition of three information phases emphasising different information needs along this pathway.

Our three subthemes emerge from the participants' description of three information phases in their cancer trajectory: *To be met with interest and support (phase 1)*, *enough knowledge to understand what is happening (phase 2)* and *a plan to build the new life on (phase 3)*.

3.1 | Subtheme 1: 'To be met with interest and support'

During the diagnostic phase (phase 1 in Figure 2), participants highlighted their need to be met with interest and support. The pathway to receiving a PCa diagnosis varied. Some participants went to their GP for a routine examination due to symptoms (e.g. urinary frequency, nocturia, difficulty passing urine). PCa was diagnosed using the PSA test, rectal examination and biopsy. The participants had different experiences and needs related to information and support when they received their cancer diagnosis. The diagnosis phase included the first meeting with a urologist, when they received information about PCa, examinations, follow-up and treatment options. This urology consultation was described in different ways. Some participants problematised the fact that

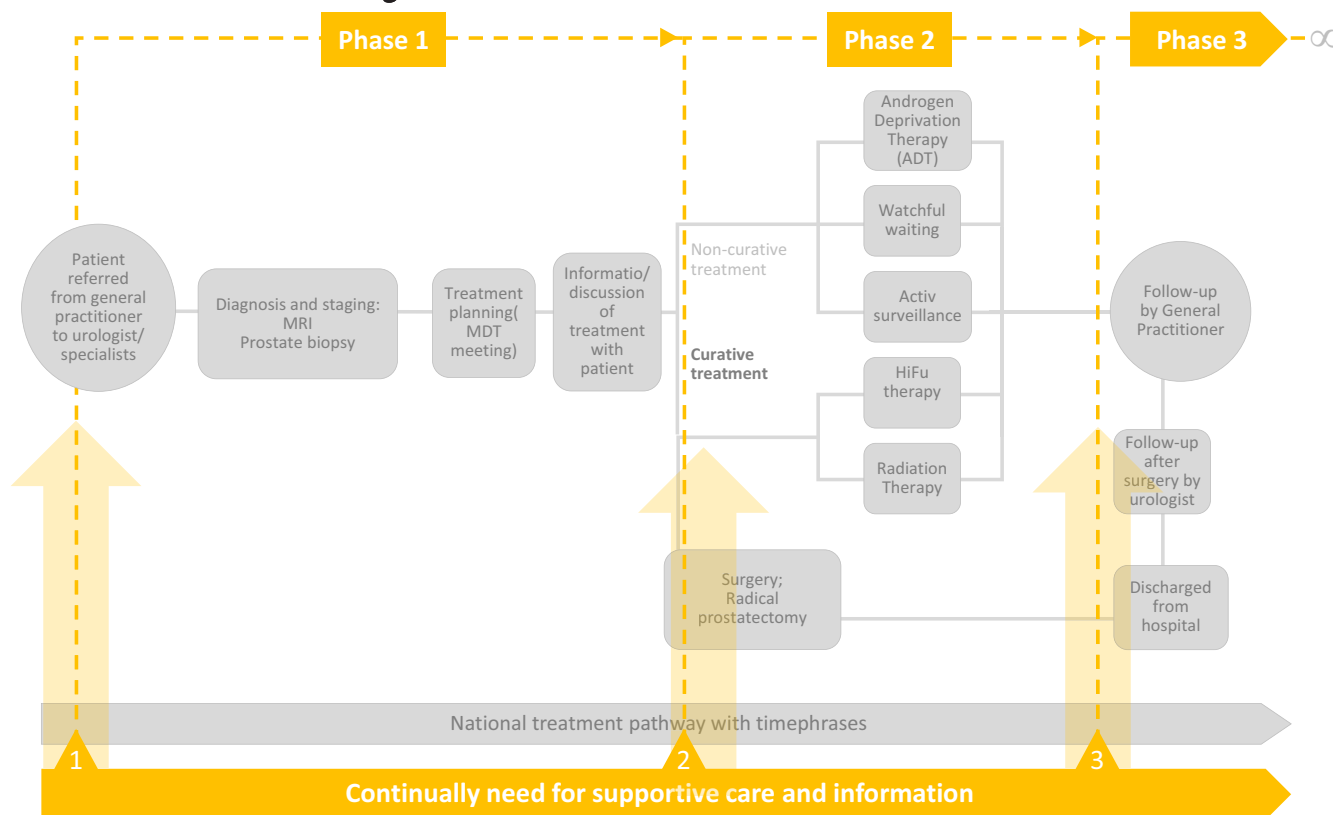


FIGURE 2 Special information needs along the treatment pathway.

they never saw the same urologist again. Some described being contacted by the pathway coordinator (telephone) as important and service-minded communication. Others could not recall being contacted. Some were satisfied with the information they received and how it was communicated, and others experienced the consultation as unpredictable and frightening. They emphasised that the way the consultation was conducted, providing information and support during this first phase, was crucial to establishing trust in their HCPs and the treatment system; it was also critical to providing the hope that would support their ability to cope with the situation:

It is in the first meeting you need all the extra information that can give you hope, I experienced the opposite, hopelessness...the information related to negative side effects such as urinary incontinence and a dysfunctional sex life was presented in a way I felt was very difficult. The way I got the diagnosis and the lack of follow-up and information felt quite brutal. (S.3.)

The participants highlighted a need to be treated with empathy by the HCP delivering their diagnosis. They experienced this as 'a terrible situation leading to challenging side effects influencing the rest of their lives'. They pointed out that spouses should attend these consultations. One participant described his difficult experience with receiving unexpected information from the urologist, alone:

The urologist said that the consequences of surgery would be that I will lose the erection and get a urinary leak. I did not bring my wife to this meeting, as it was just an information meeting. I experienced that this tough, direct and very unintelligent way of delivering information was quite brutal. (B.4.)

Other participants were satisfied with the information they received from the hospital urologist delivering their diagnosis with different treatment options and recommendations. Others drew attention to the support they received from the pathway coordinator.

Some described a feeling of being left alone to organise their own treatment appointments, while others experienced breached promises that affected their trust in the HCPs and treatment system:

The urologist said I could call if I had any questions after the consultation. I called, several times, but never got in touch. I was very disappointed. It felt like an assembly line because a doctor is so busy and unavailable. (K.3.)

3.2 | Subtheme 2: 'Enough knowledge to understand what was happening'

The participants' involvement in the decision-making process varied. Some were more informed and engaged than others and asked

questions regarding treatment choices and how to manage side effects. Others relied solely on their doctors' advice and prescriptions. Some expressed a desire to participate when urologists decided their treatment. The participants all stated that being provided with enough knowledge to understand what was happening was an important contribution at staying in control before and during treatment. They wanted their own needs to be included in the decision-making process. It was emphasised that after the treatment decision had been made, it was important to have enough information from the doctor and nurse about the treatment and its side effects and consequences:

At a meeting a week before the surgery they told me things I should have known months before. A nurse spent an hour explaining the treatment, the side effects and effect of the treatment. It was very good. The surgeon gave me the same information with a different approach. This was also very good, and the chances of a positive outcome were repeated. It was a very good meeting, but it came too late. If I had the information earlier—it would have made my life easier. (S.2.)

They wanted information and to understand and agree with the treatment choices. Participants understood 'active surveillance' in different ways as expressed in the following dialogue:

Active surveillance? I have never heard about that, is it a group of men with the same diagnosis discussing everyday challenges?' (J.1.) 'The doctor is watching the development, taking the PSA and seeing if it rises'. (O.1.) 'Then I have been through active surveillance... the doctor took many blood tests. The problem was that I did not know why. (J.1.)

Some participants felt better informed than others. There was no continuity in information as they met new urologists at every appointment. Some urologists recommended contacting a physiotherapist to learn how to prevent side effects such as incontinence while others did not. The participants received a list of physiotherapists and were expected to establish contact with one themselves. They described the value/utility of these meetings differently. Most of the physiotherapists recommended did not have the expert knowledge needed. One physiotherapist, however, was highly valued as an expert who was able to clearly explain the technical aspects of the surgery, its side effects and how to prevent them, but the waiting list was long.

All valuable information before the treatment operation I got from the physiotherapist. She explained the details about what would happen, how the surgery would affect me and why and how the pelvic floor movement treatment was important. I did not know anything about this. Until then I only knew about urinary incontinence and loss of erection. (S.2.)

Communicating with peer survivors promoted the participants' confidence and enhanced their ability to cope. However, they had to take responsibility for seeking information about support groups and charities. Social relationships with peer survivors were arenas in which men felt safe to share disease experiences, sexuality and masculinity ideals:

The most important thing throughout the process has been talking to others in the same situation, how others have experienced getting prostate cancer and side effects...several I have met who have had prostate cancer ask me 'how are you doing?', I think it's very reassuring to talk to others who have been through the same. (L.4.)

The Facebook PCa support group was an important resource for sharing disease experiences and side effects such as urinary and sex life problems. One participant urged HCPs to inform their patients about this digital peer help group, with which he had a positive experience:

In the Facebook group I found the best source of information in the beginning. I think the doctors could recommend this. It is not a scientific site, and one must be critical of what one reads but people talk about important things like sex and what they have been through. (B.4.)

The participants openly discussed dramatic treatment side effects. They also highlighted the need for more information about these significant changes, including how to prevent some and cope with the rest. They suggested a stronger information focus on these issues both before and during treatment:

I am treated with hormone tablets and injections every three months for two years and have many and dramatic side effects of treatment. I am putting on weight, four kg so far, I have sleeping problems, I have lost my sex appetite, I am fatigued, and I must struggle to exercise three times a week. My life has been changed, dramatically. I suggest more focus on this dramatic change in the information courses such as the Prostate Cancer School. I think many would open up for more sensitive discussions. (G.2.)

3.3 | Subtheme 3: 'A plan to build the new life on'

Most participants understood that they had a good survival prognosis. Their spouses were more anxious about development of metastases than were the men; the men's most significant challenges were sexual dysfunction and incontinence. The men highlighted having a plan to base their new life on as important in the post-treatment

phase (phase 3 in Figure 2). Side effects such as sexual dysfunction and incontinence affected their male identity:

It was not the cancer itself and metastases I was afraid of. They told me that my cancer was not the aggressive kind. It was the side effects I feared the most, the influence on quality of life and the mental part of it. Life changes quite a bit after cancer treatment, influencing control over urine and stools and changing one's sex life. I am not that old, but suddenly I felt very old, on my way over the hill so to speak. That was the biggest challenge for me. (S.2.)

Some participants found it difficult to talk about erection and incontinence problems with their spouse and friends. At the PCaS, men found it more natural to share their sense of self and intimate relations in a serious and humorous way. One man expressed his frustration with sexual dysfunction:

My sex life has been absent after surgery, not having sex in any form. There are some barriers...it is obvious that a man with diapers is not very attractive. (L.3.)

Identity challenges related to post-treatment sexuality, marital relationships, and masculinity were described as unexpected and very problematic. Even in the socio-cultural context with friends, some experienced a change related to virility and jokes:

The lack of erection due to hormone therapy is not my only problem. As a man in a man's culture, I now find it challenging to be a man in this culture. On weekend trips with buddies, I cannot laugh at 'gross' jokes like before. The erotic tension has disappeared, and this is a sad change. I have not spoken about this before. (T.2.)

The mental and physical changes make them vulnerable. The participants underlined the importance of learning to talk about the challenges represented by the side effects:

What we're talking about now is so sensitive that we don't talk about it to others. We can joke with friends, but we can thank ourselves for not talking about sexuality in the same way as women do. When we get into a situation as now and have reduced sexual health, we lose some manhood in a way. If I can compare it to women who must remove a breast due to breast cancer, they talk about their challenges in debates and on TV. We are just starting to talk about our challenges now. (O.2.)

Throughout the PCa trajectory, the need for someone to contact was stressed. They also believed that many PCa survivors would be open to talking more about their challenges and emotions with the pathway coordinator or the urologist if given the opportunity. Some urologists had invited them to call if they needed more information, and they did, without success. Others experienced that through talking and sharing experiences and relevant information, new knowledge led to changes in ways of thinking, thereby improving health and satisfaction. One participant described how he and his wife had found other means of showing affection and being close as a substitute for sexual intercourse, and he called it 'sexual health'. PCa experiences also led to advocacy activities, giving them recognition and satisfaction as peer supporters:

I find it difficult to talk about erection problems, urine leakage and things like that, but in my role as a support for my fellow patients in the PCaS, I found myself telling a story from a vacation with my wife. To support my erection, the physician advised me to bring along an injection to use when the time was right. The result was a terrible night (from 23.00–06.00) with cold towels to help reduce the erection. I wanted to prevent others from having the same situation (laughing). (E.4.)

4 | DISCUSSION

This study aimed to explore and analyse PCa survivors' experiences with, and critical reflections about, the information they received during their cancer trajectory by addressing our research questions 'How do PCa survivors experience information and support received during their cancer trajectory?' and 'How can this be improved?' Each individual participant shared from and discussed their information pathways, and how the information was provided and perceived. We found that information continuity and responsibility were not addressed in the treatment pathway, nor was there a system for evaluation and improvement of the pathway. Information was mainly presented by the interprofessional team, consisting of an urologist and the pathway coordinator. The overall results highlight the need for a systematic approach based on the expressed needs as suggested in Figure 2. Within this systematic information pathway, PCa survivors must be met both as a group and as individuals with different needs. PCa survivors experience supporting PCa survivors' ability to maintain control over their lives throughout their cancer journeys was important. Meeting with involved and interested HCPs, receiving and understanding relevant information and being included in individualised treatment and recovery plans were all highlighted. How these needs should be addressed varied from person to person, demonstrating that there is no such thing as a standard PCa survivor.

The participants in this study underscored the importance of being in control of their lives. Fear of death was not an issue, but quality of life was. Sexuality, masculinity and marital relationship were important issues; the need to encourage communication about these essential areas, throughout the trajectory, was emphasised repeatedly. Due to the complexity and several new treatments, the diagnostic and treatment phase can be complicated and disjointed, involving difficult treatment decisions and multiple care interventions by different HCPs (Jones et al., 2018).

To be seen and considered as an individual is therefore crucial. Through this lens of empathy and interest, relevant, tailored information should be presented throughout the cancer journey, to help patients maintain control over their lives. We also found that special information needs pertain to the three trajectory phases; the diagnostic phase, the treatment phase and the after-treatment phase (Figure 2). Like us, Schofield et al. (2016) divided the need for information into sequences scheduled at critical times in the treatment trajectory, when patients often experience increased information needs and distress. Their four consultation sequences, the beginning of treatment, after mid-treatment, after treatment completion and six weeks post-treatment, do not differ markedly from our three (Figure 2). Our subthemes represent how PCa survivors express these different information needs.

Being diagnosed with PCa was described as a shock. Our participants reported feeling alone and insecure. Patients with PCa whose prognosis was good did not consider the diagnosis itself to be threatening. For them, insecurity over considering treatments and possible side effects was more stressful. To be met with interest and support was crucial. According to Waldie and Smylie (2012), receiving a PCa diagnosis may be one of the most stressful events in a man's life. As illustrated in Figure 1, the prostate cancer pathway is complex, overwhelming and accompanied by a variety of treatment methods such as surgery, radiotherapy, active surveillance, watchful waiting and hormonal therapy. The participants expressed the need for supportive and caring meetings with HCPs as the treatment trajectory was planned and presented to them, considering their need for something to hope for in an unsafe situation. They also expressed the importance of being prepared for the first meeting with HCPs and being advised to bring their spouse or a family member/friend along. These first meetings were described as overwhelming for both the men and their families. Some participants experienced the first meeting with HCPs as positive, while others described hasty urologists delivering cold facts without empathy leaving them no hope which to cling. Previous research has shown that upon diagnosis, men and their family members begin an arduous journey of information gathering about PCa, its various treatments and their potential quality of life impacts; the resulting decisional conflicts require support (Waldie & Smylie, 2012).

There is value in having close contact with a specialist physician and an ON (Jones et al., 2018), and in being invited to contact your specialist physician or ON when in need (Aunan et al., 2018) rather than experiencing the frustration of repeatedly meeting new HCPs. Aunan et al. (2018) found that continuity in treatment and

information, provided by primary ONs and physicians in a structured way, is important to patients with cancer. Participants in this study described problems with understanding and remembering information they had received and, without a spouse by their side to help, felt lost. According to Huntley et al. (2017), information received in a stressful situation might be difficult to absorb. It is logical, sensible and in the patient's best interest to allow them to receive information in the right place and at the right time, when they feel ready to address the issues that may arise from undergoing treatment (Simpson, 2015).

Consistent with Huntley et al. (2017), our participants experienced HCPs' lack of understanding as disappointing and expressed a need for more empathetic, individualised approaches. The cancer coordinator (ON) in the urology department was perceived as caring and service-minded. Those who knew about and contacted her felt supported and could discuss their problems with her. ONs' roles in cancer information processes have been emphasised in several studies (Aunan et al., 2018; Basketter et al., 2018; Ezer et al., 2012; Muntlin Athlin et al., 2018) as providing patients with information and support. We found that patients with PCa and their families need ongoing support and information; we suggest these outpatient needs can be met by ONs (Figure 2). To improve support, the ON could be responsible for information regarding, for example, the PCaS and other safe information platforms during the first diagnostic meeting.

Some participants felt they were well informed about their treatment and possible side effects and were satisfied. Others described feeling vulnerable, experienced a lack of support and were not given the opportunity to participate in their treatment or care decisions. Decisions were made by experts and delivered to the patient without any explanation, or they were given a choice between surgery and radiology without the information they needed to make an informed choice. These men felt insecure and were often unprepared for either the side effects or how to manage them. Davison et al. (2014) found that most men newly diagnosed with PCa want to be informed and involved in medical decision-making. If patients fail to engage in systematic, informed decision-making processes, there is a greater chance they will regret the decisions that were made (Weeks et al., 2012).

They described needing someone to contact. Waldie and Smylie (2012) have argued that effective communication between the nurse, patient and family, the interprofessional team and community partners is the key to improving experiences among patients with PCa.

Our participants asked us how many urologists were employed at the hospital, because they believed they had met them all. They experienced no continuity and hasty information in the consultation process. This is consistent with another study in which follow-up was described as problematic because of difficulty establishing a confidential relationship, one in which discussing ones' sex life would feel natural, rather than with a 'disposable' physician or nurse (O'Brien et al., 2011).

A survey of over 1000 men across seven European countries showed that 81% had unmet supportive care needs, including psychological, sexual and health system information (Cockle-Hearne

et al., 2013). Consistent with previous work (Carrier et al., 2018; Holmes-Rovner et al., 2018), all participants in our study experienced treatment side effects, including physical, psychological and social impacts of urine leakage, sexual dysfunction, changed self-image and changed relationships with spouse and friends. We also found that they were uninformed about resources including national and international guidelines and information films, digital courses and literature that has been developed specifically for patients with PCa. Information and continuity in the information process may help ensure a better information trajectory. Although improving care coordination is the responsibility of all HCPs involved in these patients' care and should therefore be considered in their practice, we believe that an outpatient clinic for PCa patients (ON-driven) may represent the continuity in information flow and support needed in a fragmented healthcare system organising the experts' information required.

The post-treatment phase was described as challenging by the participants in this study. They had to learn to accept their new male identity and build a 'new way of living'. They needed support from family and peers and, sometimes, HCPs. According to Schofield et al. (2016), this last phase, or post-treatment sequence, deals with possible late sexual side effects of radiotherapy treatment and cancer survivorship issues including fear of cancer recurrence.

The participants in our study also underlined the importance of having a plan to follow and someone to contact, when needed, after they were transferred from the specialist to community-based health care and their local GP. Improving quality of life should be the ultimate aim of any healthcare treatment or intervention, and HCPs need to improve their understanding of the physical and psychosocial implications of PCa treatment from the men's perspective (Carrier et al., 2018).

All men in our study had participated in the PCaS during different phases of their cancer trajectories. Some felt that the course had come too late and that the information they received in the PCaS had been urgently needed earlier, when it might have made life easier. Previous research also emphasises the importance of arenas for information dissemination and discussion of vulnerable topics (Simpson, 2015). The PCa survivors in this study all strongly recommended contact with peers and reported feeling that this support helped them be open to intimate discussions, for example, about medication's effects and side effects regarding sexual function, and practical information regarding incontinence pads. Walsh and Hegarty (2010) found that contact with peers was perceived as the most important support for men going through radical prostatectomy as treatment for PCa. Using humour and positive thinking based on own experiences as a possible strategy in coping with the new situation was highlighted. Appleton et al. (2015) also found that viewing a situation in a positive light, using humour to diffuse the emotional nature of the diagnosis, can be helpful.

Some PCa survivors in our study felt they did not get the help and support they needed for building their new life from HCPs. To help and support others in the same situation, some of them engaged in

peer support to help others struggling with post-treatment side effects. They believed this was important for others and an important coping strategy for themselves—one that helped them regain control over their lives and allowed them to use their PCa and treatment experiences for something positive. Huntley et al. (2017) stated that men's supportive care needs to continue throughout their lives. It is therefore important that PCa care focus on longer-term care of men to determine which approaches are likely to be most effective.

In several studies (Basketter et al., 2018; Huntley et al., 2017; Waldie & Smylie, 2012), specialised nurses' roles are shown to be important to both patients with PCa and their spouses. Specialised nurses (i.e. ONs) can and should play a critical and highly rewarding role in providing continuity and care, information and support (Basketter et al., 2018). This was reflected by the positive statements from our participants who had contact with the ON. They felt informed, supported and confident about taking an active part in their recovery.

We suggest that ONs may play an essential role in educating patients about treatments, side effects and the impact of the disease on their lifestyle, as has been asserted by Basketter et al. (2018). ONs have specialist knowledge of both diagnosis and treatment and can safeguard continuity, and provide patients and their spouses with relevant reliable information. Nursing is the critical link for patient-centred, collaborative information exchange (Waldie & Smylie, 2012). We believe that an outpatient clinic with qualified HCPs (ONs) may add important contributions to supporting patients with PCa in reframing their new lives.

5 | CONCLUSION

Patients with PCa need varied information at critical times in their treatment trajectory: during the diagnostic, treatment and post-treatment information phases, including when recovery begins, and they are transferred from specialist-based to community-based health care and their GP. Herein, supportive needs were stressed as crucial, emphasising that HCPs should meet patients with PCa with empathy and interest. Bad experiences negatively impacted the quality of life of both patients and their families, while timely and tailored information made life easier. Lack of continuity in the information trajectory was perceived as problematic. It is in the patient's best interest to receive information when they feel ready to address the issues arising from treatment. PCa survivors need access to HCPs on an ongoing basis, to address their continuous need for supportive care and information.

ACKNOWLEDGMENTS

The authors wish to acknowledge Olaug Herborg Asheim Furnes, Kari Fredriksen and Roy Annar Norås.

CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

RELEVANT TO CLINICAL PRACTICE

PCa patients' need for information varied at critical time in their treatment trajectory. HCP should meet them with empathy and interest to be able to tailor their need for information and support.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Siv Tove Aunan  <https://orcid.org/0000-0003-4345-4718>

Gry Ciekals Wallgren  <https://orcid.org/0000-0002-9789-9774>

REFERENCES

- Appleton, L., Wyatt, D., Perkins, E., Parker, C., Crane, J., Jones, A., & Pagett, M. (2015). The impact of prostate cancer on men's everyday life. *European Journal of Cancer Care*, 24(1), 71–84.
- Aunan, S. T., Wallgren, G. C., & Sætre Hansen, B. (2018). Breast cancer survivors' experiences of dealing with information during and after adjuvant treatment: A qualitative study. *Journal of Clinical Nursing*, 28, 3012–3020.
- Basketter, V., Benney, M., Causer, L., Fleure, L., Hames, D., Jones, S., & White, L. (2018). The role of the CNS in the mCRPC patients pathway. *British Journal of Nursing*, 27, pS3–S8. 6p. 1 Chart.
- Cancer, P. (2016). *Prostate Cancer Pathway*. Norwegian Directorate of Health.
- Cancer Registry of Norway. (2019). Cancer in Norway 2019.
- Carrier, J., Edwards, D., & Harden, J. (2018). Men's perceptions of the impact of the physical consequences of a radical prostatectomy on their quality of life: a qualitative systematic review. *JBIM Database of Systematic Reviews and Implementation Reports*, 16(4), 892–972.
- Cockle-Hearne, J., Charnay-Sonnek, F., Denis, L., Fairbanks, H., Kelly, D., Kav, S., & Jensen, B. (2013). The impact of supportive nursing care on the needs of men with prostate cancer: a study across seven European countries. *British Journal of Cancer*, 109(8), 2121–2130.
- Davison, B. J., Szafron, M., Gutwin, C., & Visvanathan, K. (2014). Using a web-based decision support intervention to facilitate patient-physician communication at prostate cancer treatment discussions. *Canadian Oncology Nursing Journal/Revue Canadienne De Soins Infirmiers En Oncologie*, 24(4), 241–247.
- Ezer, H., Chachamovich, J. R., Saad, F., Aprikian, A., & Souhami, L. (2012). Psychosocial adjustment of men during the first year of prostate cancer. *Cancer Nursing*, 35(2), 141–147.
- Graneheim, U. H., Lindgren, B.-M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, 56, 29–34.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112.
- Hamilton, K., Chambers, S. K., Legg, M., Oliffe, J. L., & Cormie, P. (2015). Sexuality and exercise in men undergoing androgen deprivation therapy for prostate cancer. *Supportive Care in Cancer*, 23(1), 133–142.
- Holmes-Rovner, M., Srikanth, A., Henry, S. G., Langford, A., Rovner, D. R., & Fagerlin, A. (2018). Decision aid use during post-biopsy consultations for localized prostate cancer. *Health Expectations*, 21(1), 279–287.
- Huntley, A. L., King, A. J., Moore, T. H., Paterson, C., Persad, R., Sharp, D., & Evans, M. (2017). Methodological exemplar of integrating quantitative and qualitative evidence—supportive care for men with prostate cancer: what are the most important components? *Journal of Advanced Nursing*, 73(1), 5–20.
- Jakobsson, L., & Fransson, P. (2013). Patient reported outcome measure (PROM) of quality of life after prostatectomy—results from a 5-year study. *The Open Nursing Journal*, 7, 165.
- Jakobsson, L., Persson, L., & Lundqvist, P. (2013). Daily life and life quality 3 years following prostate cancer treatment. *BMC Nursing*, 12(1), 11.
- Jemal, A., Bray, F., Center, M. M., Ferlay, J., Ward, E., & Forman, D. (2011). Global cancer statistics. *CA: a Cancer Journal for Clinicians*, 61(2), 69–90.
- Jones, R. A., Hollen, P. J., Wenzel, J., Weiss, G., Song, D., Sims, T., & Petroni, G. (2018). Understanding advanced prostate cancer decision-making utilizing an interactive decision aid. *Cancer Nursing*, 41(1), 2.
- Kelley, S., DeCourtney, C., & Thorsness, J. (2015). Development and evaluation of a support program for prostate cancer survivors in Alaska. *International Journal of Circumpolar Health*, 74(1), 28605.
- Levesque, J. V., Lambert, S. D., Girgis, A., Turner, J., McElduff, P., & Kayser, K. (2015). Do men with prostate cancer and their partners receive the information they need for optimal illness self-management in the immediate post-diagnostic phase? *Asia-Pacific Journal of Oncology Nursing*, 2(3), 169.
- Morgan, D. L. (1997). *The focus group guidebook*, Vol. 1. Sage Publications.
- Muntlin Athlin, Å., Brovall, M., Wengström, Y., Conroy, T., & Kitson, A. L. (2018). Descriptions of fundamental care needs in cancer care—An exploratory study. *Journal of Clinical Nursing*, 27(11–12), 2322–2332.
- O'Brien, R., Rose, P., Campbell, C., Weller, D., Neal, R. D., Wilkinson, C., Mcintosh, H., & Watson, E. (2011). "I wish I'd told them": a qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Education and Counseling*, 84(2), 200–207.
- Paterson, C., Robertson, A., Smith, A., & Nabi, G. (2015). Identifying the unmet supportive care needs of men living with and beyond prostate cancer: a systematic review. *European Journal of Oncology Nursing*, 19(4), 405–418.
- Schantz Laursen, B. (2017). Sexuality in men after prostate cancer surgery: a qualitative interview study. *Scandinavian Journal of Caring Sciences*, 31(1), 120–127.
- Schofield, P., Gough, K., Lotfi-Jam, K., Bergin, R., Ugalde, A., Dudgeon, P., Crellin, W., Schubach, K., Foroudi, F., Tai, K. H., Duchesne, G., Sanson-Fisher, R., & Aranda, S. (2016). Nurse-led group consultation intervention reduces depressive symptoms in men with localised prostate cancer: a cluster randomised controlled trial. *BMC Cancer*, 16(1), 637.
- Siegel, R. L., Miller, K. D., & Jemal, A. (2019). Cancer statistics, 2019. *CA: A Cancer Journal for Clinicians*, 69(1), 7–34. <https://doi.org/10.3322/caac.21551>.
- Simpson, P. (2015). Prostatectomy: information provision and education for patients. *British Journal of Nursing*, 24(Sup9), S24–S28.
- Stenberg, U., Haaland-Ørverby, M., Fredriksen, K., Westermann, K. F., & Kvisvik, T. (2016). A scoping review of the literature on benefits and challenges of participating in patient education programs aimed at promoting self-management for people living with chronic illness. *Patient Education and Counseling*, 99(11), 1759–1771.
- Waldie, M., & Smylie, J. (2012). The Merck Lectureship: Communication: The key to improving the prostate cancer patient experience. *Canadian Oncology Nursing Journal/Revue Canadienne De Soins Infirmiers En Oncologie*, 22(2), 129–133.
- Walsh, E., & Hegarty, J. (2010). Men's experiences of radical prostatectomy as treatment for prostate cancer. *European Journal of Oncology Nursing*, 14(2), 125–133.
- Weeks, J. C., Catalano, P. J., Cronin, A., Finkelman, M. D., Mack, J. W., Keating, N. L., & Schrag, D. (2012). Patients' expectations about effects of chemotherapy for advanced cancer. *New England Journal of Medicine*, 367(17), 1616–1625.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Aunan ST, Wallgren GC, Hansen BS.

The value of information and support; Experiences among patients with prostate cancer. *J Clin Nurs*. 2021;00:1-12.

<https://doi.org/10.1111/jocn.15719>

APPENDIX 1

INTERVIEW GUIDE

The primary study aim of the study was to explore and analyse PCa survivors' experiences and critical reflections on the information they received during their cancer trajectory.

1. **How do you feel that the need for knowledge has been addressed from the time you were diagnosed and through treatment?**
 - Timing
 - Content in general/individually
 - Information form
2. **How has diagnosis and treatment affected your identity?**
3. **How do you feel about attending courses with others in similar life situation?**
 - Which time is best for you to attend the course (PCaS)?
 - How do you experience meeting peers?
4. **What will an optimal information arrangement look like for you?**
 - Do you have any suggestions for ways to organise an information pathway?
 - Do you need further follow-up with regard to information?
 - If so is the case, how can we meet your needs in the best possible way?