



## Optimising patient-initiated follow-up care – A qualitative analysis of women with breast cancer in the UK

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### ABSTRACT

**Purpose:** Current policy in the United Kingdom (UK) recommends that people with breast cancer (PWBC) are managed in follow-up pathways that suit their needs. With an increasing trend towards patient-initiated follow-up (PIFU) pathways for PWBC, this study conducted qualitative research exploring PWBC's experiences of a nurse-led PIFU service (termed 'Supported Early Discharge') to inform how PIFU pathways could be optimised. **Method:** PWBC on a PIFU pathway were recruited from two UK hospitals (one large cancer centre, one district general hospital) as part of a wider mixed-methods study (N = 118). Following completion of a series of surveys, a purposive subsample of 20 women were interviewed in-depth about their experiences. Thematic analysis was conducted.

**Results:** The majority of participants described positive views towards being on PIFU; however a significant minority struggled with uncertainties and difficulties related to: accessing ongoing care and support; performing breast self-examination (BSE); managing ongoing treatment side-effects; and fear of recurrence. Themes included: self-efficacy to manage own health; barriers and facilitators to help-seeking on a PIFU pathway; effective information sharing about side effects; preferences for personalised care; emotional wellbeing on PIFU-influences on fear of recurrence. A novel conceptual model is presented that highlights influences on self-management during PIFU.

**Conclusions:** Findings highlight ways in which PIFU pathways could be further optimised through greater and more effective education on BSE and recognising signs of recurrence, information on when and how to seek further help with any problems, targeted provision of psychological support, and clearer signposting to support for ongoing side-effects.

### 1. Introduction

Breast cancer (BCa) is currently the most prevalent cancer amongst women in Europe (Ferlay et al., 2018). Ten-year survival rates have almost doubled in the last 50 years in the United Kingdom (UK) (Cancer Research UK, 2021), mainly due to improvements in screening, disease management and treatment (Carioli et al., 2017). As the number of people living with and beyond cancer increase, BCa follow-up services are facing unsustainable demands. Traditional follow-up services,

whereby people with breast cancer (PWBC) routinely attend hospital appointments, offer limited clinical benefit (Montgomery et al., 2007). Recurrences are most often detected by PWBC at interval events between outpatient appointments (Grunfeld et al., 1996) with review evidence suggesting intensive follow-up is comparable in terms of survival rates and quality of life outcomes to less intensive follow-up (Moschetti et al., 2016).

In England, personalised risk-stratified follow-up approaches to cancer care, with supported self-management for 'low-risk patients' has

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**Box 1**

## Interview topic guide

**Key questions summary.**

Do you feel you have any specific unmet needs following cancer treatment?

What are your main concerns moving forward following treatment?

How is your life “different” to your life pre-cancer diagnosis?

Pick up specific concerns from questionnaires e.g. anxiety/depression, long term sequelae of treatment, work, financial concerns etc.

Do you have concerns your cancer may return?

What are your views and experiences of supported discharge follow-up?

Have you required re-access to breast services? How did this work? Did you receive suitable care?

Specifically related to your breast cancer-have you used other health services?

How could the service be done differently-any suggestions for different delivery methods?

been advocated by policy-makers for several years (NHS, 2019; NHS Improvement, 2012; NHS Improvement, 2016). This means follow-up care that includes a holistic needs assessment (HNA) and care plan to meet patient’s physical and psychological needs, with signposting to health and wellbeing events (NHS, 2019). Patient-initiated follow-up (PIFU, also referred to as supported early discharge, patient-led, open access, or point of need) aims to help empower patients to manage their condition by taking responsibility for initiating appointments themselves when they need it. In BCa care, PIFU pathways have been in place in some areas for almost 10 years in the UK, and delivering PIFU is a key part of the NHS pandemic recovery plan (NHS, 2020). PIFU pathways, when compared to consultant-led follow-up across different disease types, have shown to have similar outcomes in terms of depression, anxiety, quality of life, relapses, and patient satisfaction (Whear et al., 2020; Batehup et al., 2017; Frankland et al., 2019). However, to date, few studies have evaluated PIFU pathways in PWBC (Brown et al., 2002; Sheppard et al., 2009; Kirshbaum et al., 2017; Chapman et al., 2009; Chadha et al., 2014; Koinberg et al., 2002, 2004), but evidence suggests no differences between PWBC on PIFU compared to routine appointments regarding quality of life, psychological morbidity, or detection of recurrences (Sheppard et al., 2009; Kirshbaum et al., 2017; Taggart et al., 2012; Koinberg et al., 2004). PIFU follow-up has been perceived as more convenient for patients compared to conventional follow up (Brown et al., 2002). However, published studies with PWBC have seldom reported in-depth, qualitative evaluations of experiences of PIFU (Koinberg et al., 2002), nor explored barriers to help-seeking on PIFU.

The standard PIFU pathway involves a HNA and End of Treatment Summary (EoTS) through nurse-led clinics followed by discharge from hospital around six-months following the end of adjuvant treatment; open access to appointments (within two weeks); annual mammography for five years. A mixed-methods research study has been conducted of PIFU services at two study sites and herein we report the qualitative evaluation. We aimed to explore in-depth patients’ experiences of nurse-led PIFU services, to identify ways of optimising future services.

**2. Methods***2.1. Ethical considerations*

Ethical and regulatory approvals for the study were obtained from Oxford Brookes University and NRES approvals from Oxford Research Committee A (Ref: 17/SC/009). R and D site-specific approvals were obtained from two NHS hospital trusts. Written informed consent was obtained from all participants, and confidentiality of data assured. Due to the sensitive nature of the questions asked in this study, respondents

were assured raw data would remain confidential and would not be shared.

*2.2. Design*

A mixed-methods study design was employed involving the collection of survey and interview data. All patients with a primary BCa diagnosis were considered for PIFU, unless they were deemed not suitable for PIFU by their consultant (NHS Improvement, 2016), such as patients with: learning difficulties; mental health issues; endocrine therapy only; secondary/metastatic or locally advanced disease; recruited on clinical trials. PWBC (females only) diagnosed with stages 1–111 BCa on PIFU were identified through NHS records at one cancer centre (CC) and one district general hospital (DGH) in the South of England.

*2.3. Recruitment*

At both centres, PWBC had a face-to-face appointment with the BCa nurse at the end of treatment. At the DGH, the PIFU pathway (termed ‘Supported Early Discharge Follow-up’ at both centres) began at typically six months post treatment - when patients had their appointment with the nurse; however some patients had to wait up to 12 months for this appointment due to staffing issues. At the CC, PIFU commenced at the time of appointment with the consultant (surgeon or oncologist), which was around three months after the nurse-appointment. Patients were invited into this study during the nurse-appointment when they were given a study information pack with an expression of interest (EOI) form. Patients returned the EOI form to the study principal investigator (LM) who posted out the first questionnaire. Completed surveys were returned via post to the PI. Survey respondents were asked if they would participate in an interview. Respondents who were willing to participate in an interview were invited following final survey completion (via telephone or email). Purposive sampling was conducted, so that interviewees included a range of ages, BCa treatments and levels of needs and concerns as reported on the survey (physical, psychological, satisfaction with care).

*2.4. Data collection*

Semi-structured interviews were conducted via telephone and were audio-recorded. Informed consent was obtained immediately prior to the interview. Interviews were conducted by an experienced health researcher with an academic psychology background who was not involved in any way with patient’s clinical care (LMa, female, Research

**Table 1**  
Interview participants' demographic information (N = 20).

Participant characteristic	N	%
<b>Age</b>		
Under 40 years	2	10
40–55 years	7	35
Over 55 years	11	55
<b>Marital status</b>		
Married	12	60
Widowed	4	20
Single/divorced or separated	4	20
<b>Work</b>		
Working (full or part-time)	9	45
Voluntary work	1	5
Unable to work (due to ill health)	1	5
Retired	9	45
<b>Treatment type</b>		
Mastectomy and hormones	4	20
Mastectomy, radiotherapy and hormones	2	10
Mastectomy, chemotherapy, radiotherapy and hormones	3	15
Lumpectomy, radiotherapy and hormones	5	25
Lumpectomy, chemotherapy, radiotherapy and hormones	4	20
Lumpectomy and hormones	1	5
Lumpectomy and radiotherapy	1	5
<b>Ethnicity</b>		
White British and Caribbean mixed race	1	5
White British	19	95

Fellow in Supportive Cancer care). Interviews lasted approximately 30–45 min (range 25–60 min). The interview topic guide (Box 1) included open-ended questions regarding the impact of BCa on the participants' lives (physical, psychological, social), and their health care experiences and views about PIFU. Reflections from each interview were recorded (by LMa) in a reflexive research diary throughout the entire research process, and any initial themes were explored in subsequent interviews.

2.5. Data analysis

Interviews were transcribed verbatim. A thematic analysis approach was employed (Braun and Clarke, 2006). This involved familiarisation with the transcripts by re-reading them several times. Transcripts were then coded systematically (by LMa), involving line-by-line coding. As the analysis progressed, themes and sub-themes were inductively developed. Several transcripts were reviewed by EW and LM, and initial themes were discussed at team meetings (which included multi-disciplinary clinical and academic members including a breast cancer clinical nurse specialist). Relationships between themes were explored, as well as convergence and divergence between and within participants. Data was organised and managed using Microsoft Excel. Analysis was an iterative process as themes and sub-themes were constantly revisited. Data saturation for major themes was achieved.

3. Findings

146 women completed expressions of interest forms for the survey, of which 118 completed survey 1, 117 completed survey 2 and 83 completed survey 3, so the overall response rate to the survey was 73% (n = 318/438 completed all 3 surveys). Twenty participants were interviewed, and all were female. Sample characteristics are presented (see Table 1). Women were interviewed between February–September 2019 and were 2–3 years on average post diagnosis. Five key themes are described, relating to the impact of being on a PIFU regimen. A conceptual model was developed from the interview data to indicate the influences on self-management during PIFU (see Fig. 1). A conceptual model was developed to illustrate the key challenges for patients on PIFU, as well as the contextual and potentially modifiable factors (patient and health-care related) that seemed to influence self-management of BCa-related challenges during PIFU. These were developed from the interview data.

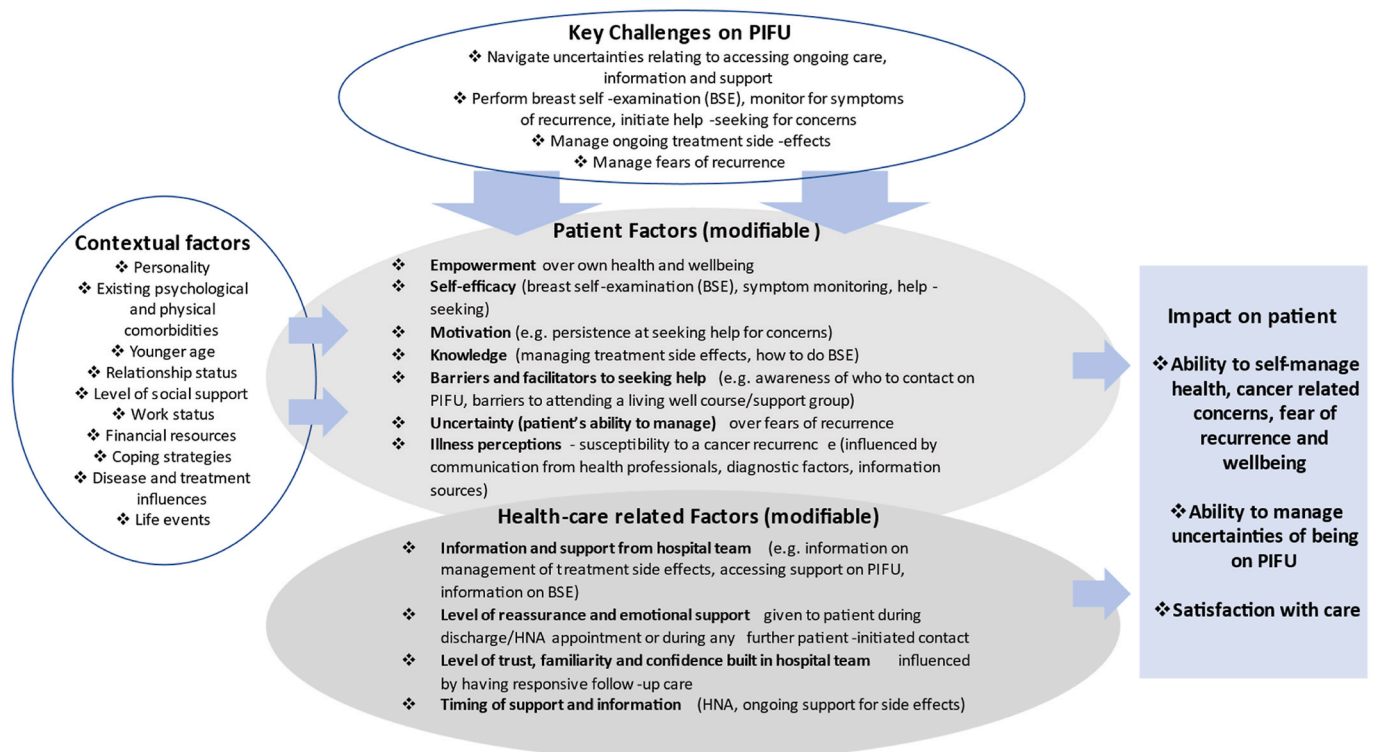


Fig. 1. A conceptual model of influences on self-management during patient-initiated follow-up (PIFU).

### 3.1. Theme 1: Self-efficacy to manage own health

The majority of women described positive views and satisfaction towards being on a PIFU pathway, appearing confident to manage their own health without the need for additional contact with the hospital team (“*It seems to be efficient*” H2.22; “*It’s [PIFU] beat my expectations actually*” H2.26; “*I have found it to be excellent*” H1:12). Some felt being on a PIFU regimen empowered them to take control and responsibility for their health, through monitoring their body and performing breast self-examination (BSE). Other positive benefits of PIFU that were mentioned included not having to attend hospital appointments, and greater capacity for other patients who need to be seen by the consultant. One younger participant felt PIFU fitted with her desire to get on with life after cancer and felt she would be able to raise any concerns earlier, rather than waiting until her next appointment:

*“In terms of [PIFU], it will suit me down to the ground, in that I kind of want to, as best as possible, move on from it, and this allows me just to actually pay attention to my body and if something’s wrong I flag it up, whereas I think if I had to wait once a year for my check-up I would just wait for my check-up if I thought something was wrong .... It just forces you to take responsibility for your health a little bit and pay attention a bit more. I just wanted to get it done and dusted and out of there. I don’t want to be followed up really. I don’t want to be reminded that it happened.”* H2.32

However, not all women appeared to feel confident to self-manage. Some described difficulties initially adjusting to the lack of appointments, although these appeared to be transient. A significant minority reported ongoing unmet needs and struggled with side effects and/or psychological issues. In a few women, confidence in checking their breasts appeared to be low as they experienced uncertainty over knowing what their normal was as this kept changing (“*It’s no good saying just get used to your new normal, because there is no normal, it keeps changing*” H1.76). Women who had not originally detected a lump themselves prior to diagnosis, appeared less confident at performing BSE than those who had.

*“As I understand it wasn’t that there was a lump that I could have felt [at diagnosis], it was something that only showed up on a mammogram ... in terms of examining my breasts, I’ve got scars and things so it’s quite difficult for me to know how it should feel ... I don’t feel confident that I can check and know what my body should feel like, in terms of self-examination”* H1.08

Therefore, a few reported a desire for more effective patient education in how to detect a recurrence to reduce their uncertainty and be able to differentiate between normal lumps and bumps. Greater advice on specifically how to perform BSE was wanted by some (delivered at living well courses or at a specific training session), as well as more information on what to expect in terms of ongoing treatment side-effects and symptoms of recurrence.

*“No, they [living well courses] didn’t really tell you how to check [BSE]. I think they kind of expected you to know how to check. I mean they do tell you the importance of continually checking..”* H1.30

### 3.2. Theme 2: Barriers and facilitators to help seeking on a PIFU pathway

One of the key facilitators to help-seeking on PIFU was women’s confidence in accessing support. Some women expressed confidence and trust in their health care team, and a sense of having a health care ‘safety net’ (“*It’s just nice to know that number’s there for support if I do find anything*” H2.26). This seemed to be due to having been really encouraged to call their hospital team, having coherent information and advice in a reassuring manner, and awareness of having rapid access back into the hospital system should they need an appointment (“*[hospital team]*

*say if you have any problems whatsoever, get in touch and you can go and see them. .... if I did have any worries at all I would be in touch”* H2.19). In some cases, women expressed confidence in their local primary care doctor (General Practitioner- GP) for whom some preferred as their first point of contact for any concerns. Those with positive experiences of having their concerns addressed when contacting the hospital helpline felt confident that any future concerns would also be addressed responsively.

*“They [nurse helpline] were brilliant when I rang them. And they saw me quickly and they followed up. So they were great. I am reassured that if I am concerned they’re there and they will see me and they will fit me in as quickly as they can”* H1.76

However, a few women discussed barriers to help-seeking from the hospital on PIFU. These included: perceived ‘busy-ness’ of hospital staff; not wanting to waste their time or make a ‘fuss’; perceived lack of significance of symptoms; uncertainty over the purpose of the helpline and for the type of concerns they could call for; as well as reluctance to call the hospital after discharge and feeling they instead had to see their GP (“*it feels like you can’t call the nurses once you’ve been discharged, you’re just like you’re discharged, now you’re back at the GP, so go and see them*” H1.10). This was sometimes due to having a long-standing and trusting relationship with their GP, and also perceiving the process of accessing the GP as easier than accessing the hospital. Other practical barriers to calling the hospital included a dislike of leaving an answerphone message, rather than getting an instant response on the helpline, as waiting for a response could provoke anxiety. Therefore, some thought better manning of the helpline when calling up with concerns on PIFU was needed.

*“Those experiences [of calling the hospital helpline] that I found aggravating my anxiety, so I would be more likely to try to speak to my GP, rather than leave a message on an answering machine for someone who .. might not call back for a few days, and when they do ... what could be a very simple question become aggravated by the days of anxiety of not getting an answer.”* H1.8

Having alternative ways of contacting the hospital, such as through email or text, were discussed as potential facilitators to help-seeking during PIFU. One participant described downgrading the importance of her concerns following difficulties with getting a response:

*“It would be really handy to have an e-mail address, or even a number that you could text, not expecting an instant answer ... because by the time you’ve rung two or three times and they’ve not picked up and you don’t really want to leave a message, you get to the point where you think maybe it’s not that important, and I won’t ring again ... So it’s more an access issue, in that in your own head you can quite quickly downgrade it if you don’t want to be a problem and they are obviously very busy”* H1.76

A few participants described having to be persistent and motivated when calling the hospital helpline regarding ongoing side effects. One participant described the challenge of having to call the helpline several times before getting satisfactory support:

*“I did know something was wrong and kept ringing the [hospital helpline] but it took them quite a while to actually listen to me”* H1.11

Some women also felt they would have liked more reassurance and encouragement that they could call the hospital. While some hadn’t needed to call the helpline, this participant discussed the importance that patients were able to call a nurse who was trusted and known to them, as this existing relationship was thought to be a potential facilitator to help-seeking.

*“I think it would be much more useful if they already had some contact with that nurse, and then they’re much more likely to phone the [helpline] if they’re anxious or they need something, not if they don’t know anybody or recognise anyone”* H2:21

### 3.3. Theme 3: Effective information sharing about side-effects

The impact, duration and severity of side-effects varied. For women on adjuvant endocrine therapy (AET), common side effects included hot flushes, muscles aches, fatigue, insomnia, and sexual difficulties. Some women experienced lymphoedema and psychological needs due to an altered body image and invasive treatment. Uncertainty was evident in some as to whether symptoms were due to AET, or to ageing or other long-term conditions. Some sought help from their GP rather than the hospital helpline, sometimes due to ambiguity or to uncertainty over whether they could ask the hospital team about these issues. This could also sometimes be due to the ease of access to the GP and their trusted relationship with them. While some women felt well supported with ongoing side effects on PIFU (“when I changed my [AET] pills ... they rang me back, and I went in and saw the oncologist.. so, I'd say they were very good” H1.30), a few discussed unmet needs regarding the support and guidance for AET in particular and wished more effective information had been given to better prepare them on PIFU following discharge. One woman described a lack of information about sexual dysfunction:

*“What they don't then say is actually that's going to impact on your sex life and the impact on your relationship. Nobody had that discussion with me. So nobody said that if you take [AET] obviously you're not going to have any oestrogen and it's going to be really tricky and difficult to have sex. Nobody mentioned.”* H2.21

Some women expressed uncertainty regarding what would happen in the future with their AET, with a few mentioning occasional non-adherence due to difficulties with side effects. A few participants felt that, as part of PIFU, an additional appointment could be on offer to patients who needed it, or an annual medication review with someone from their hospital team might help with managing ongoing treatment issues.

*“Even if it was just a 20-minute appointment, to bring out any things that you don't want to go to the doctors [GP] to talk about ... I think I'd prefer face-to-face.. it should maybe have been in about 18 months from [last appointment] it would have been good to see someone”* H2.22

### 3.4. Theme 4: Preferences for personalised care

In those who could recall having a HNA (a few could not recall this), the timing of these appointments varied between several months to up to a year following discharge. Views towards HNAs were mixed, with some reporting it was valuable before starting on PIFU, others felt it was a brief, ‘tick box’ exercise with little purpose. This was sometimes due to the timing of the HNA, which was sometimes felt to be too late at 9–12 months approximately since finishing treatment. Some would have preferred to have had a HNA in the first few month's post treatment.

*“I felt the follow-up [HNA] was far too late after the end of treatment. Because all my sort of concerns or worries I'd addressed myself at that point, or the majority of them”* H2.21

While most reported continuity in care regarding the nurses they had contact with, a few would have liked to have had a HNA with a health professional they had an existing relationship and rapport with, so they could feel comfortable discussing their concerns. The HNA was also thought to be an opportunity for nurses to continue to reassure patients about being able to call the hospital helpline on PIFU.

*“[I] felt like it was more of just a tick box, we're signing you off, there you go, bye. Just little comments could have helped to make it feel like we're still here, we are always here ... And I know that is open to me, so that if I felt concerned or worried I could ring [hospital helpline] and I could go on in, but it just didn't feel like it on the day [of HNA]”* H1.30

Most women recalled being signposted to Living Well support

programs; however uptake was very low (n = 2 had attended). Barriers to attendance included: having good existing support networks; practical barriers of distance; being busy; or a dislike of formal groups.

### 3.5. Theme 5: Emotional wellbeing on PIFU - influences on fear of recurrence

Some participants reported good emotional wellbeing since having BCa. However, for some participants fear of recurrence (FOR) was a concern to varying degrees and was seemingly influenced by several factors previously discussed such as positive perceptions of having a health care ‘safety net’.

*“I don't dwell on the fact that if it comes back it comes. If the cancer comes back then I know that I will be looked after to the best of their abilities, so no good worrying about it ... I was so well looked after, and so prompt”* H1.12

Whereas the lack of appointments and perceived lack of information on detecting a recurrence on PIFU was described as negatively influencing FOR in one participant:

*Once you're discharged you don't sort of have any backup for potential reoccurrence, and I almost feel out on a limb. Every lump and bump, you know, you're not trained to say oh, that's a fatty lump, there's no information there to help you. So every time you get a lump and bump you just go into oh my god, here we go .... it's that void afterwards, that that is my only criticism, because, it's almost like it's a loaded gun and you're waiting for somebody to fire the bullet.* H1.10

A greater perceived susceptibility towards a recurrence also seemed to negatively influence FOR, with a few assuming recurrence was inevitable. Perceptions appeared to be influenced by information from health professionals. Some had discussed risk of recurrence with a health professional and had been informed that the likelihood was generally low, although this information did not always mitigate women's FOR. Others had not discussed their level of recurrence risk with a health professional at any point, sometimes preferring not to know.

*“[risk of recurrence information] was offered ... and decided that it's probably better that I don't know ... Because of how I might act...I've got a rough idea; a bit of quick maths tells me what will probably be my likelihood. ....but I think I've come to some weird conclusion that I'm probably not going to make it that far into my forties..”* H2.32.

Some sought web-based information or information from peers with BCa about the risk of recurrence. Web-based information could cause alarm (“it's quite a high probability [of recurrence]” H1.10) and negatively impact on FOR. A few expressed fears of metastases and appeared not to have discussed these fears with health professionals.

*“I do think about it [recurrence] daily .... I would say I'm frightened the cancer's going to pop out somewhere else. I don't feel quite in control of it .... I'm confident that they've done everything they can for me, but it's the psychological thing that once you've been diagnosed with it, it never actually goes away..”* H2.26

Contextual factors were acknowledged as influences on women's general emotional wellbeing on PIFU. Several factors appeared to have a more positive influence, including: personality (e.g. optimism); social support (e.g. network of friends, BCa peer support); coping strategies (e.g. avoiding rumination); having financial resources; employment status (e.g. retirement). Other factors appeared to have a negative influence, including: being younger (e.g. burden of care for young family); being unpartnered (e.g. concern for future relationships); existing mental or physical comorbidities (including previous cancer diagnoses); disease and treatment factors (e.g. symptom burden); life events (e.g. bereavement). A few expressed unmet needs for greater psychological support generally and ongoing support for FOR. Greater reassurance was wanted



over their risk of recurrence, that they could call the hospital helpline at any time to discuss FOR, gain emotional support, as well as raise physical concerns.

*“You feel with the [helpline] it’s if you’ve got worries about your physical health, whereas actually maybe saying contact us if you feel you do need psychological support afterwards as well ... having availability of psychological support, a year, 18 months down the line ... that can possibly be the time that really you need the psychological support more”* H2.38

#### 4. Discussion

Cancer centres in the UK have been employing PIFU pathways for PWBC for several years. However, very few studies to date have provided an in-depth qualitative evaluation of patient’s experiences of PIFU (Koinberg et al., 2002). Our findings illustrate that many participants in our sample were generally satisfied with this pathway. Perceived benefits included feeling able to get on with life, empowerment over managing BCa and a sense of control and responsibility for monitoring their health. These findings echo those reported in a previous mixed methods study of endometrial cancer survivors, where PIFU was well received by the majority of women (Kumarakulasingam et al., 2019). Our qualitative findings provide an in-depth insight into the unmet needs that a significant minority of women reported in terms of health care, physical, and psychological issues. Unmet needs in some women centred around difficulties navigating uncertainties (as well as practical difficulties) related to accessing ongoing care and support, performing breast self-examination (BSE), managing treatment side effects and fears of recurrence.

Women described varying levels of self-efficacy regarding managing their health, including performing BSE, monitoring for symptoms of recurrence, and seeking help on PIFU. This confidence appeared to influence satisfaction with PIFU as well as self-management behaviours, also echoed previously (Kumarakulasingam et al., 2019). Our findings therefore highlight the need for more effective information sharing about breast awareness, BSE and symptom monitoring for PWBC on PIFU. In order to be more effective, patient education on self-management, such as BSE, might include peer education interventions and peer support (Hu et al., 2019; Hoey et al., 2008). Our findings about confidence levels also suggest a need to assess a person’s self-efficacy and patient activation (NHS England, 2018) when they are considered for suitability for PIFU, in line with recent guidance (NHS Improvement, 2016; NHS, 2020).

Although some women felt well supported with treatment side effects, a few expressed unmet needs regarding support for dealing with side effects of AET. There is strong evidence AET reduces the risk of recurrence and death when taken for 5–10 years; however it can result in significant side effects for some women (Early Breast Cancer Trialists’ Collaborative Group, 2015). Unmet support needs whilst on AET have been demonstrated in women receiving conventional clinical follow-up, and have been shown to influence non-adherence to AET (Harrow et al., 2014; Brett et al., 2018a, 2018c; Moon et al., 2017). In a previous study of women on PIFU, unmet needs following the end of treatment were shown to be highest in those receiving AET (Capelan et al., 2017). It is, therefore, important that more effective information and support regarding AET is provided to PWBC on PIFU. One intervention currently in development is aiming to support PWBC receiving AET and improve adherence and quality of life (Watson et al., 2020; Brett et al., 2018b). PIFU pathways could be optimised by providing clearer signposting to support for PWBC, so that they are clear about who to contact with different concerns, such as AET.

Our findings also highlight patients’ barriers and facilitators to help-seeking for concerns during PIFU, adding to the limited literature on this topic (Beaver et al., 2020; Kumarakulasingam et al., 2019; Koinberg et al., 2002). Previous studies highlight that worry over wasting the nurses time is a barrier to help-seeking (Kumarakulasingam et al., 2019)

as well as fear of recurrence (Kumarakulasingam et al., 2019). Sometimes this fear of wasting nurses time (and other reasons) led women to seek the support of their GP, which for some was due to ambiguity over who to seek help for particular issues. However for some participants, it was unclear whether they had been told to go to primary care by their hospital. Thus, PWBC on PIFU need effective patient education on when, how and who to contact following any concerns, and potentially further resources could be developed for patients at the discharge appointment. Potential facilitators to help-seeking included therapeutic relationships based on familiarity, confidence and trust, often influenced by having a responsive and supportive care team. Accessibility and trust in the nurse has also been shown previously as important for patient satisfaction and sense of security for those without routine follow-up appointments (Koinberg et al., 2002). Additionally, trust in their GP was also why some women seemed to prefer going to primary care for any ongoing concerns during PIFU. Some were also discouraged from seeking help by the systems in place at the hospital (e.g. answerphone system), suggesting improvements could be made to how patients can access their hospital team during PIFU.

Our findings also suggest a need to increase the level of reassurance and encouragement offered to patients on PIFU pathways, as well as information given at discharge. Having alternative ways of contacting the hospital, such as through email or text, were suggested as ways that help-seeking during PIFU could be optimised. Future research could, therefore, explore the implications of alternative ways that patients can contact their hospital team, such as text or email messaging. Other strategies might simply include the nurse providing reassurance and encouragement to the patient that they can call them about anything (physical and psychological issues) and through normalising their anxiety when they are discharged onto the PIFU pathway. This approach might generate anxiety over increased workload for health professionals who are struggling to manage caseloads; however evaluation of such a service change might identify a decreased workload if patients escalate concerns sooner which in turn reduces the need for hospital-based care. The Covid-19 pandemic has changed the delivery of follow-up services in the UK, with clinics being conducted via telephone (Dalby et al., 2021) and/or video call. One advantage of virtual health care can be a reduction in treatment burden for the patient (Alsadah et al., 2020). Widespread innovation using digital technology and virtual health care provision, much of which will continue beyond the current pandemic, will require ongoing evaluation.

Our study indicates that some PWBC on PIFU are benefitting from receiving the comprehensive model of personalised care (NHS, 2021b); however some felt this wasn’t delivered in a timely way or preferred not to access health and wellbeing events. Therefore, for HNAs, it is important that these are delivered at a useful time for the patient, as some felt their HNA was too late in the period following treatment completion. In addition, assessing a person’s holistic needs must result in a meaningful plan of care rather than be perceived as being a tick-box activity – ensuring that patients receive a care plan that is meaningful to them and supports their ability to self-manage underpins personalised care.

For those who want to know, it might also be helpful to provide personalised recurrence risk information (e.g. using the Predict tool (NHS, 2021a) around the time of discharge or final consultant appointment, as some women did not understand that their risk of recurrence was low. It is important that illness perceptions regarding susceptibility to a recurrence are addressed and challenged, where necessary. However, it is possible that some higher risk PWBC are also included in PIFU pathways, so tailored information is needed. Effective communication about risk between health professionals and patients is important, as a lack of discussion about risk has been associated with women either overestimating or underestimating their risk (Janz et al., 2017). Our findings indicate that there is a need for psychological screening as some PWBC have anxiety from fear of recurrence (FOR); however we did not have evidence in this study that this was specifically

**Box 2**

## Key recommendations for optimising PIFU care provision

- Ensure patients understand what to expect on a PIFU pathway and are clear who they can contact and how they can do so, if they need further support. This could be in the form of information as well as verbal reassurance given to women at their HNA/or discharge appointment, where barriers to help-seeking can be addressed.
- Greater and more effective patient education about breast awareness and self-examination and how to recognise potential signs of a recurrence (could be delivered via peer educators, health professionals or through digital/written information and support resources).
- Greater and more effective information sharing about treatment side-effects.
- Psychological assessment, screening and referral where appropriate, and targeted psychological support to help patient's manage fears of recurrence (FOR).
- Greater signposting to support available (including support for symptom management, where to get support from for a range of concerns, peer support and non-NHS/charitable organisations).
- Implementation of the comprehensive model of personalised care: agreeing and providing personalised care and support plans following a holistic needs assessment, and conducting an end of treatment summary and cancer care review. The timing of personalised care and support planning should happen throughout a person's cancer pathway and not be isolated to single time points.
- PIFU discharge appointment conducted with a health professional known and trusted by the patient, where possible.
- Personalised recurrence risk information discussed with the patient at discharge or final consultant appointment, if wanted, to provide reassurance over risk of recurrence and where necessary, challenge and address patient's illness perceptions regarding susceptibility to a recurrence.

related to being on PIFU. Previous research shows that around a fifth of BCa patients experience persistent FOR, and younger women and those less satisfied with medical treatment are more likely to have higher FOR (Custers et al., 2020). Therefore, targeted psychological support is required for PWBC struggling with FOR.

Overall, our findings provide rich insight into the experiences of PWBC in a PIFU pathway. We have suggested some recommendations to optimise PIFU pathways (Box 2). Our conceptual model could inform the development of future interventions designed to improve patient's ability to self-manage during PIFU. Digital technologies, such as websites and mobile apps could be developed to increase self-efficacy and reporting of symptoms and concerns.

#### 4.1. Limitations

Our qualitative evaluation is limited by a relatively small sample; however we aimed to get an in-depth insight into women's experiences. While we had a diverse sample in terms of gender, age and marital status; only one participant was from a non-white ethnic background, which reflects the lack of diversity in our wider survey sample. Further research is needed to explore the experiences of people of colour on PIFU regimens. It is possible that wider contextual issues may also impact patient's adherence to, and acceptability towards PIFU, such as their level of trust in health professionals which seems to be an important facilitator to help-seeking during PIFU. Mistrust in the health care system is more widely evident in minority ethnic groups (Bazargan et al., 2021); therefore further exploration of views towards PIFU is required in specific ethnic groups. Alternative strategies (Howcutt et al., 2022) may be needed for optimising recruitment strategies for diverse ethnic groups in future studies, such as recruiting through key leaders from within community faith networks. Other strategies might include using alternatives to written materials such as audio-consent, having a researcher from within a specific community to reach out to groups, or recruiting via local radio, newspapers or posters displayed in key places for specific groups (Farooqi et al., 2018).

We also did not collect data on socio-economic status or health literacy, which we acknowledge is a limitation of the study. For example, it is possible that patients with low health literacy may have specific needs during PIFU which need further exploration in future work. From our data, it is not possible to say whether issues such as fear of recurrence were greater than if women had been in routine follow-up care. It is, therefore, possible that aspects of women's experiences may be similar to those on routine follow-up care, so larger trials comparing routine vs

PIFU are required. There is a chance that due to the time delay in interviewing patients (2–3 years post diagnosis), there may have been issues with recall bias. Future studies are required to explore PWBC's experiences who are closer to the time of their discharge appointment.

## 5. Conclusions

Findings highlight how PIFU models could be further optimised for PWBC and potentially other cancer patient groups. Our conceptual model indicates important considerations for designing future interventions, particularly how self-examination and help-seeking behaviour could be promoted to improve patient's satisfaction with care and self-management of disease during survivorship. Future interventions and research will need to consider the views of diverse ethnic and socio-economic groups.

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## CRedit authorship contribution statement

**Lyndel Moore:** Conceptualization, Methodology, Formal analysis, Investigation, Resources, Writing – review & editing, Project administration. **Lauren Matheson:** Formal analysis, Investigation, Writing – original draft, Writing – review & editing. **Jo Brett:** Writing – review & editing, Supervision. **Verna Lavender:** Conceptualization, Methodology, Writing – review & editing, Supervision. **Anne Kendall:** Conceptualization, Writing – review & editing, Supervision. **Bernadette Lavery:** Conceptualization, Writing – review & editing, Supervision. **Eila Watson:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision, Funding acquisition.

## Declaration of competing interest

None declared.

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