Research Square

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# Understanding experiences of recognising and reporting signs of recurrence following breast cancer: mapping behavioural determinants to optimise follow-up care

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## Abstract

# Purpose

Approximately 20% of people affected by breast cancer experience recurrence. Shifts to personalised stratified follow-up (PSFU) in the United Kingdom and internationally require individuals to initiate further appointments themselves if they suspect recurrence. We explored (a) breast cancer survivors' experiences in recognising and reporting signs of recurrence; (b) behavioural determinants underpinning recurrence-related self-management; and (c) views on interventions to optimise PSFU pathways.

# Methods

Qualitative interviews and focus groups were conducted with breast cancer survivors (n = 28). Data were analysed using thematic analysis and mapped onto the Theoretical Domains Framework and the Capability-Opportunity-Motivation-Behaviour model.

# Results

Participants reported limited information and support from healthcare professionals regarding recurrence recognition and reporting, alongside barriers to help-seeking. Key behavioural determinants of recurrence-related self-management behaviours included knowledge, skills, confidence, and the environmental context, influencing symptom recognition, breast self-surveillance and help-seeking behaviour. Participants with invasive lobular carcinoma reported specific challenges, including lower confidence and trust in healthcare professionals and mammographic screening, heightening recurrence fears.

# Conclusion

As PSFU or similar risk-stratified pathways become increasingly common globally, cancer survivors are expected to play a greater role in recognising and reporting potential recurrence. These findings inform how recurrence support can be optimally incorporated into PSFU pathways, which may be applicable to other cancer survivor groups. Key targets for interventions to optimise PSFU are highlighted. Improved recurrence education, self-surveillance support, clear guidance on help seeking and clinician training may increase confidence during survivorship. Tailored interventions are needed for individuals with invasive lobular carcinoma, who face unique challenges.

## Background

Each year, a breast cancer diagnosis affects approximately 56,000 individuals in the United Kingdom (UK) and affects 2.3 million individuals globally [1, 2]. Breast cancer is the most common cancer diagnosed in the UK, and its incidence continues to rise [1]. While breast cancer survival rates have improved [3], approximately one-fifth of individuals will experience recurrence [4]. The risk of recurrence varies between 10% and 41%, depending on multiple factors, and is either *local* (recurring in the same area), *regional* (recurring in the lymph nodes) or *distant* (secondary/metastatic cancer, recurring in distant parts of the body)[5, 6]. The risk of secondary cancer increases over time for some types of breast cancer [1, 5, 7, 8]. All types of breast cancer recurrence have significant psychosocial, emotional and physical implications as well as worsened mortality outcomes [1, 9].

Early detection of a recurrence is a key aim of breast cancer follow-up care to maximise overall survival [10, 11]. Due to increasing demand in the follow-up care system and patient demand for a pathway that better meets needs, personalised stratified follow-up (PSFU), (also termed patient-initiated follow-up (PIFU)[12], open access follow-up (OAFU) [13] or self-directed aftercare) has been widely implemented in the UK and increasingly internationally [12, 14–16]. This means that patients are required to recognise and report potential signs of recurrence themselves. Further implementation of the PSFU/PIFU pathway is one of the priorities of the new NHS National Cancer Plan for England to give patients more control and reduce unnecessary appointments [17]. Similar risk-stratified models of care are being explored globally, including in the Netherlands, Scandinavia, Canada and Australia [18–20]. The evidence to date suggests that PSFU pathways, which are associated with fewer clinical visits, have survival and quality of life outcomes comparable to those of standard follow-up care [21]. In the UK, most people treated for breast cancer move to the PSFU pathway several months after treatment completion (excluding endocrine therapy) [22, 23]. This means that patients no longer receive any routine oncology-based hospital appointments between yearly mammograms, so the responsibility of self-monitoring for signs of recurrence and initiating a hospital appointment, shifts to the patient. For PSFU pathways to be safe and effective, it is crucial that breast cancer survivors engage in active self-surveillance for potential signs of recurrence and help-seeking from their hospital team, as needed [12].

Recurrence risks and patterns vary by type of breast cancer. For example, approximately 15% of individuals affected by breast cancer have invasive lobular carcinoma (ILC) [24, 25]. Compared with the most common subtype (ductal breast cancer), ILC has distinct clinical features, particularly net-like growth with less typical symptoms (at initial and recurrence diagnosis)[24]. Mammography is offered to patients but is much less effective at identifying initial diagnoses and recurrences of ILC, as it is more likely to be occult on a mammogram [26]. Individuals with ILC are also at greater risk of late recurrence 10–15 years after diagnosis [27, 28], particularly younger survivors [29].

Review evidence highlights the limited evidence conducted to date on experiences of PSFU pathways [30]. Existing research shows that in PSFU pathways, individuals with breast cancer report a lack information about symptoms of recurrence and describe low self-efficacy (confidence in own ability) regarding how to check themselves, uncertainty about seeking help, and barriers to accessing support [31, 32]. Fear of cancer recurrence is also a key concern, although there is limited evidence on how this is impacted in PSFU [31–33]. Fear of recurrence can interfere with self-surveillance, either as a barrier to self-surveillance whereby patients ignore symptoms of possible recurrence or may prompt hypervigilance in checking [34–36], and can lead to increased health service usage [37]. In one UK survey, only 13% of patients diagnosed with secondary breast cancer reported receiving adequate information about symptoms of recurrence following their primary breast cancer [38]. There is a clear need for co-designed interventions that support recurrence-related self-management behaviours in individuals on PSFU or similar risk-stratified pathways [31, 39]. Although breast PSFU pathways are now implemented in the UK [12], there are limited evidence-based interventions to support cancer survivors with regard to recurrence [40]. Owing to the lack of research on individuals affected by the subtype ILC [41–43] and the unique patterns of recurrence, how this specific subgroup may experience the current PSFU pathway, as well as those with rare breast cancer subtypes, is unclear.

Our previous work highlighted gaps in service provision and support for breast cancer survivors on PSFU pathways at two UK centres [31]. As PSFU becomes increasingly adopted and relies heavily on patient self-management, this study explored experiences of recognising and reporting recurrence and managing fear of recurrence among breast cancer survivors on PSFU pathways across the UK. To inform future intervention development and model pathways, we aimed to identify key behavioural determinants of recurrence-related self-management behaviours required on PSFU by mapping data to behavioural theory [44–46]. Participants included individuals with and without recurrence experience and a range of breast cancer subtypes, enabling exploration of subtype-specific differences and groups that may require additional support on PSFU [18].

# Methods

## Ethical approval

The NHS Health Research Authority (HRA) and university ethics approval were obtained (North of Scotland Research Ethics Service, REC reference: 23/NS/0070, IRAS no: 316807). Informed consent was obtained from all individual participants included in the study. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used (see Supplementary file 1) [47].

## Design

A qualitative design was employed. The study protocol was registered on the Open Science Framework (DOI 10.17605/OSF.IO/6QZ4J). The Capability, Opportunity, Motivation and Behaviour (COM-B) model [46] and the theoretical domains framework (TDF) [48, 49] were both used to guide data analysis. These behavioural theories were employed, as understanding behaviour change through these models has been shown to be helpful at informing intervention development [50], including an existing self-management intervention for head and neck cancer survivors on PSFU [51]. The COM-B model proposes that behaviour is a result of an individual's capability (physical or psychological), opportunity (physical or social) and motivation (reflective or automatic) and is helpful at understanding barriers and facilitators to behavioural change, for example, self-surveillance for signs of recurrence or help-seeking [52]. The TDF provides a comprehensive structure for identifying the psychological, social, and environmental factors that influence behaviour, also informing intervention design [49].

## Patient and public involvement (PPI)

Two PPI members (JR, LT) were involved throughout the study design, including the development of the interview topic guides and patient information materials, and participated in all the research team meetings, contributing to discussions on all aspects of the study, notably discussions of the study findings as well as the authorship of the study.

## Recruitment

Participants were recruited through advertisements by UK breast cancer charities (including CoppaFeel, Breast Cancer Now, Lobular Breast Cancer UK), social media (e.g., X, Facebook groups), and breast cancer support groups. Potential participants were also invited through one NHS breast clinic in England, with several individuals from diverse ethnic backgrounds being specifically invited in person by their oncologist. Potential participants registered their interest and were contacted by HB or LM to arrange a convenient time for an interview or focus group. The participants eligible for inclusion were as follows:

- 18 years or over,
- Treated in the UK
- Any breast cancer subtype,
- Recurrence-free or diagnosed with a recurrence (loco-regional, distant recurrence),
- Up to 10 years after the completion of breast cancer treatment (excluding endocrine treatment).

## Qualitative data collection

Interviews and focus groups with participants were conducted via telephone or online, depending on their preference. These followed a semi structured topic guide (see Supplementary file 2) developed by the research team via literature, PPI input, and behavioural theory [46]. Topics included views towards information provided or accessed about recurrence symptoms, experiences of self-surveillance, barriers and facilitators to help-seeking, experiences of and coping with fear of recurrence, and views towards a future intervention targeted at addressing needs around recurrence in follow-up. The interview participants were asked to describe their demographic information and what they could recall of their treatment information. Focus group participants were not asked for specific demographic information but were asked to introduce themselves to the group (giving as much or as little information as preferred). All interviews and focus groups were audio recorded and conducted by experienced qualitative researchers, LM and HB (both White British females, with applied health and/or psychology, postdoctoral research backgrounds, with no previous relationship with any participants). A reflexive summary was written after each interview or focus group.

## Analysis

Audio recordings were transcribed verbatim and analysed using thematic analysis [53]. NVivo software (version 11) assisted with organising the data. Initial inductive analysis was conducted simultaneously with data collection. The analysis involved data familiarisation, and then, a selection of transcripts was coded independently by two researchers (HB and LM), who developed initial codes that were discussed with the study team. From this, a preliminary coding framework (Supplementary file 3) was developed, which was informed by the data, as well as some of the research questions. An iterative process involving further coding of additional transcripts further refined and developed the coding framework. The remaining transcripts were then coded by HB using the developed framework. Key themes and subthemes were then generated. The data were mapped by LM onto the TDF and COM-B model [46] to aid in the development of future interventions.

## Findings

## Participants

Study expression of interest (EOI) forms were completed by 38 potential participants, of whom 28 participated (reason for nonresponse to the research team either not given (n=9) or due to a possible recurrence investigation (n=1)). Participants were recruited via social media (n=10), charities (n=6), support groups (n=7), word of mouth (n=2) or ‘did not state’ (n=3), with no participants recruited via the NHS oncology clinic. Individual semi structured interviews were conducted with 16 participants, and 12 participated in 4 focus groups. Data saturation [54, 55] was reached, as no new themes emerged. All data collection took place between October 2023 and June 2024. The interviews lasted for an average of 48 minutes (range 26–88 minutes), and the focus groups lasted for an average of 100 minutes (range 77–105 minutes). All focus groups were conducted via Zoom, and interviews were conducted via either Zoom video calls or telephone. Among the 28 participants, 20 self-reported a primary breast cancer diagnosis, and 8 reported receiving a diagnosis of breast cancer recurrence (6 had local/regional breast cancer recurrence; 2 had metastatic breast cancer).

Full participant characteristics were obtained from the interview participants only and are presented in Table 1. Owing to the group format and issues of confidentiality, demographic data were not requested in the focus groups. The ages of the interview participants ranged from 39-70 years. A few were unsure of their breast cancer subtype diagnosis,

with most reporting a diagnosis of ductal breast cancer, 8 with ILC and 1 with triple-negative breast cancer. The time since primary or recurrence diagnosis ranged from 2016-2023. For the interviews, most (n=15/16) were Caucasian and n=1 was Black British, and in the focus groups, n=1 patient reported they were from a British Asian ethnic background. Seven (of 14 due to missing data) were educated at the postgraduate level or above. [insert Table 1]

## Results

# Themes

Four core themes with subthemes were generated and are presented below with illustrative quotes. Additional example quotes are provided in supplementary File 4. Where known by participants, subtype specific information is provided alongside quotations.

## Theme 1: Barriers to and facilitators of self-surveillance for breast cancer recurrence

### 1. *Knowledge of the signs of recurrence*

There was variation regarding the level of information participants reported receiving from healthcare professionals (HCPs) on signs or symptoms of recurrence. While a few patients recalled receiving some information on recurrence around the time of treatment completion or discharge to personalised stratified follow-up (PSFU), most reported that this information was lacking and was a key area of unmet need. Many reported a particular lack of information on signs of secondary breast cancer.

*"It was all a bit inconsistent, so there wasn't a smooth pathway to now your treatment's finished; there will be a series of support moving forward, what's secondary breast cancer, what to look out for"* (workshop 3).

Those who had received a recurrence diagnosis expressed disappointment and regret over the perceived absence of clear information following their primary treatment, which they felt could have empowered them to seek help sooner during follow-up.

*"So obviously that was a bit of a shock [diagnosis of secondary breast cancer after primary diagnosis], a bolt out the blue, although—with hindsight now, knowing what I know now, I understand that these were all symptoms, but when you're in the dark about what the symptoms are, you're kind of just going along with your GP, and maybe not pushing things as much as you should do."* P11 (secondary breast cancer)

Some had sought non-NHS sources of information, such as UK charity organisations, which were valued (e.g., Breast Cancer Now, Macmillan Cancer Support, ABCD, Lobular Breast Cancer UK); however, others were unaware of these resources or discussed misinformation from untrustworthy sources (e.g., certain forums based outside of the UK). The participants also sought knowledge from peer networks, including online forums, which one participant (P24) described as the only source of knowledge for checking for recurrence following a double mastectomy. Women felt that HCPs emphasised finding 'lumps', which were perceived to overshadow information on other signs or 'red flags' of recurrence (e.g., pain, dimpling, etc.), leading to uncertainty.

"*For my recurrence, I had pain, and I kept hearing this, the mantra that they keep telling you, pain is not a symptom of breast cancer"* (workshop 1)

Participants with ILC expressed a lack of ILC subtype-specific recurrence information from HCPs, including distinct differences in terms of recurrence symptoms and unique metastatic presentations.

*"I was never told that lobular might present differently in.. if it metastasises, that it might go to different places, including the GI tract, the peritoneum, it can be a different pattern, so I wasn't told any of that, so I've kind of worked that out for myself with the available information*." P6 (ILC subtype)

### 2. *Confidence regarding breast self-surveillance ('breast awareness')*

With respect to education on breast awareness and how to check themselves, some reported receiving nonspecific generalised advice from HCPs, such as *'look for anything new or unusual'*, which they felt often lacked clarity or enough detail. This led to a lack of confidence regarding what to look out for.

*"I have no idea because I don't know what it is I'm looking for. If I see or feel or touch something that's abnormal. I don't know what it is I'm supposed to be feeling - triggers with regards to the recurrence of breast cancer I wouldn't have 'a diddly squat*!"' P24 (ductal breast cancer)

Only a few participants recalled an in-person demonstration of how to check their breast area, which was typically from their breast care nurse. This was highly valued, as it helped them feel more confident in their ability to monitor their breast health. Conversely, those who had not received a physical demonstration felt that such instruction would have been beneficial and should be an integral part of follow-up care. This lack of guidance was particularly impactful for those who experienced ambiguous symptoms post-treatment, who described difficulty in distinguishing between post-treatment changes and potential signs of recurrence.

*"I think it is difficult to know what you're feeling… I got quite paranoid that I had found a lump in my other breast, and actually when I went to my GP "oh, it's just your rib". You can feel lumps and bumps, and it's that being able to differentiate between what's just part of your normal anatomy and what's actually a lump that you should be worried about, I think is tricky."* P12 (ductal breast cancer)

The participants' beliefs about the importance of regular breast self-surveillance also affected their behaviour. Some participants whose cancers were screen-detected or who had experienced atypical symptoms, including those with the ILC subtype, seemed to place less importance on breast self-surveillance during follow-up (compared with those who had self-detected their cancer), questioning the effectiveness of checking themselves ("*I doubt if I would spot something.... so,…No I don't bother checking*!" P5, ILC subtype). However, those who had found symptoms themselves before their diagnosis felt that continuing to check was worthwhile.

*"Because I found it so early, and so that's kind of why I do check now, because if it's gonna come back, I want to find it early again*." P21 (ductal breast cancer)

Some participants described using reminders from existing apps or phone calendars to prompt regular breast self-surveillance (or breast 'awareness') habits ("*I have a reminder on my phone"* P22, ILC subtype). These tools were seen as helpful at establishing habits, whereas barriers to regular engagement or avoidance with self-surveillance included a lack of routine.

## Theme 2: Barriers and facilitators to help-seeking regarding recurrence concerns

## 1. *Uncertainty regarding navigation of the PSFU pathway*

Most participants described being on a personalised stratified follow-up (PSFU) pathway, reporting yearly mammograms, but no routine hospital-based oncology appointments. The transition from active treatment to follow-up was challenging, with some perceiving a lack of support and guidance. Some were uncertain whether they were still under active care from the hospital and what would happen next.

*"It was something I was really concerned about, because basically it's like [HCP] kick you out of the nest and it's like 'young bird go fly!'"* P24 (subtype not known)

The participants who recalled a conversation about follow-up often described it as vague or lacking much detail ("*it wasn't particularly extensive guidance"* P6, ILC subtype) and did not provide sufficient clarity on who to contact with any concerns.

*"I feel a bit lost in the system… I'm still not clear really who should I go to."* P12 (ductal breast cancer)

Participants whose primary treatment was longer ago described feeling unable to directly contact their hospital team because of fear of '*making a fuss*' (P12). Instead, they described first re-accessing the system via primary care (e.g., their general practitioner, GP) to justify seeking help from specialist care, which introduced delays.

*"For me it was kind of like well if I go to the GP and the GP agrees there's something wrong I feel kind of validated in then going to secondary care and asking to be seen again …I didn't want to ring up the breast cancer team, knowing how much pressure they're under, if it was something that was something and nothing that the GP could deal with".* P12 (ductal breast cancer)

Some participants highlighted the value of having a trusting relationship with their breast care nurse as a positive influence on confidence in help-seeking, including being given explicit reassurance and clear invitations to get in touch if concerns arose.

*"I remember that was encouraged—that if there was a problem, I could contact the nurse, who was brilliant by the way. I felt that once she was there in the background, I felt reassured that I could approach her."* P48 (ductal breast cancer)

## 2. *Patient-, HCP- and system-level influences on delays in help-seeking*

The participants discussed a range of barriers, both current and anticipated, to seeking help regarding recurrence. System-level issues included difficulties accessing their hospital team, often due to administrative issues such as having to leave messages on answering machines. This process was perceived as anxiety-inducing, particularly when responses were delayed. A few participants recounted instances where they received no response from HCPs, which discouraged participants from future attempts to seek help. Another key barrier was the concern around burdening HCPs.

*"I'm now worried about it from the point of view of ongoing surveillance… The support is slightly less easy to access now, so there is a route; any concerns are sort of triaged by the breast care nurse. I have had occasions when, and it's very difficult to actually get to speak to someone in person in the first instance, so it's leaving a message on an answering machine, and I've waited weeks for callbacks - that's been quite a worrying process*" P6 (ILC subtype)

The experience of having previously raised concerns that they perceived to be actively dismissed by HCPs (including oncology staff and GPs) was also a barrier. These experiences left participants hesitant to seek support again, even when they experienced symptoms indicative of recurrence. This was particularly salient for those with ILC, who described feeling unsupported due to a perceived lack of expertise among HCPs (primary and secondary) in their breast cancer subtype regarding the unique symptoms and patterns of recurrence. This negatively impacts well-being (*"we kind of live under this little grey cloud"* P8, ILC subtype*)*.

*"There are times when you think to yourself that niggle, whatever, has been going on a little bit too long now, I wonder what that is, or there are times when you think that, and it makes you very despondent with lobular [Breast cancer] because you know you're gonna get brushed off or dismissed because people don't really know what you're talking about.* P8 (ILC subtype)

# Theme 3: Role of fear of cancer recurrence

## 1. *Influences on, and coping with, the fear of cancer recurrence*

Fear of cancer recurrence (FCR) played an important role in the recognition and reporting of recurrence, with its severity and impact varying both across and within participants. Awareness of being at low risk of recurrence and early-stage breast cancer influenced FCR, although some still experienced significant FCR despite being aware of their 'good' prognosis. Participants with challenges in symptom detection (rarer subtypes, dense breasts, atypical symptoms at diagnosis or scan-detected cancers) described ongoing difficulties coping with FCR.

*"That's probably the most difficult thing: is knowing that I didn't find this lump until it was about an inch first time round. I didn't have any other symptoms, I felt perfectly well, and knowing that, and then knowing that it's my responsibility to find a recurrence going forward, that may not have any symptoms, is very difficult*". P20 (triple-negative breast cancer subtype)

Few participants had encountered (or could recall using) risk-communication tools with HCPs, but those who had generally found them helpful in supporting treatment decisions, although some desired clearer explanations owing to difficulties interpreting statistical information (*"It would have been really nice to have it kind of in layman's terms a bit more"* P27). The results, while helpful, could also negatively impact fears ("*it was a little bit scary … but I think in some ways it was helpful.*" P22). For example, one participant with triple-negative breast cancer found the knowledge of her survival estimate upsetting.

*"I was quite shocked. I think the surgeon had led me to believe that although the tumour was large and the lymph nodes were affected, she was still treating it as curative, but when you see statistics like that, that your five-year survival estimate is 45 percent with all the treatment, it brings it into stark reality. It's maybe difficult for people like oncologists who're dealing with it all the time to appreciate… how somebody might react to that sort of information.*" P20 (triple-negative breast cancer)

Participants with the ILC subtype highlighted unique concerns around FCR, such as fears regarding the possibility of recurrence being missed (by HCPs, mammographic screening), which contributed to heightened emotional distress.

*"I think the reason that I feel really nervous already about recurrence is because I've got this lobular type of cancer, and because so much of it wasn't visible on the mammogram… It worries me that there could be cancer in there and I won't know until it gets big, and then it's like 'oh god, it's really late again'."* P22 (ILC subtype)

Systemic issues, such as the lack of widespread MRI scanning, could exacerbate fears and erode confidence in the healthcare system in those with the ILC subtype. As many were aware of the inadequacy of standard mammographic imaging for this subtype, the scan results did not provide reassurance that they were free from recurrence. One participant described how successfully advocating for MRI scans (not initially offered by her NHS Trust) significantly reduced her FCR through having greater confidence in this surveillance method.

*"What I didn't realise at that time was that lobular cancer is less likely to be picked up via mammograms. So I have very little confidence in mammogram as a means of screening, and also later on monitoring and surveillance, although I'm not, with any kind of surveillance now I'm never totally reassured by scan results [which] feed into my anxieties about recurrence with lobular in particular, because the imaging technologies are just not designed for it*." P6 (ILC subtype)

To better cope with FCR, the participants discussed the importance of making health behaviour changes, including physical activity, healthy eating, or avoiding alcohol. Knowledge of the importance of lifestyle modification for reducing recurrence risk was felt to be empowering; however, many had not received such information by HCPs ("*I don't think anyone had spoken to me about it"* P13), and some were fatalistic about their chances of having breast cancer recurring.

"*I've learned that myself, but I don't remember being told, even by my lovely Macmillan lead nurse about that. Yeah, I'm aware about nutrition, exercise, and how important that is really to lower the risk of recurrence*." P48 (ductal subtype)

In addition, some participants also discussed accessing NHS or private counselling or psychological services, support groups, charity workshops or courses, which were perceived as supportive of managing FCR. Peer support from others with breast cancer for recurrence concerns was also highly valued for supporting them with FCR concerns, as were general self-care strategies, such as mindfulness or gratitude practices.

*"One of the most helpful things has been getting support from other people that're going through the same thing, and I think those are the people that you can talk to about something like recurrence...and I think people that're going through the same uncertainty as you… it just makes you feel a bit better about it*." P22 (ILC subtype)

For some, FCR was less frequent but could be triggered by ambiguous symptoms ("*it comes in waves"* P48). Therefore, clear and specific guidance from HCPs (e.g., knowing how long to monitor symptoms of concern and how often to check their breasts) helped some participants avoid excessive anxiety surrounding self-surveillance and hypervigilance.

*"It's difficult to be so mindful of your body without causing it overanxiety, because my surgeon said to me only check yourself once a month, .... So, it's keeping that balance"* (workshop 3).

# Theme 4: Informing intervention co-design

## 1. *Need for a guided recurrence discussion at the start of PSFU*

While increasing patient empowerment and education about recurrence around the start of the PSFU was needed, this was thought to be a *'very fine balance to tread' (*P11, secondary breast cancer) in terms of the complexity of providing reliable recurrence information without increasing anxiety. Many expressed a strong desire for a guided discussion with a HCPs about recurrence, ideally with a breast care nurse, that was personalised to individual preferences and circumstances and delivered in a sensitive way. The participants also wanted an in-person demonstration of breast self-checking.

*"Being able to have a chat and voice your concerns and they say 'yes, that is something you can do something about, or no, or don't worry about that', or whatever... that would be great, and obviously nothing can beat that in a way"* (workshop 2)

The participants felt that a discussion with an HCP would give them the opportunity to discuss recurrence information and their fears and to receive tailored support and signposting, as many had not received this information.

*"I think what I would have found very helpful was the opportunity to maybe have almost like a sort of end of treatment consultation with someone and to be given a leaflet that sort of says where to signpost you for various things...I almost needed that kind of validation that even if your treatment is quite early, it's OK to feel anxious and to reach out for help."* P12 (ductal breast cancer)

Many felt that discussing recurrence during active treatment was inappropriate, as they would have been unable to absorb information. Instead, several months post-treatment or the start of PSFU was identified as an optimal time. As information on lifestyle modification was deemed empowering, some felt that the provision of lifestyle information and support to highlight ways they could reduce their recurrence risk was also needed.

*"I would have appreciated a bit more support during that time, as far as the conversations about lifestyle … just maybe if it was standard procedure for the breast care nurses to go through that with you"* P30 (ductal breast cancer)

Further training for HCPs was identified as important to ensure that they could effectively support and educate patients regarding recurrence and empathise with FCR.

2. ***Preferences for Information Delivery***

The participants expressed varied preferences when asked about the format of a future intervention to help with the recognition and reporting of recurrence. In addition to an HCP-guided discussion, the participants suggested digital apps (web or mobile), videos, and/or written materials (leaflet or booklet, prompt sheet). These could include a recurrence symptom tracker or diary (digital or paper-based), which would enable them to more effectively self-monitor any symptoms of concern and present this to HCPs (or some suggested that HCPs could see their information). To help with self-advocacy, the provision of a physical document or prompts to support confidence in conversations with HCPs was discussed. Another suggestion was a GP system that would automatically flag patients' breast cancer history via artificial intelligence ("*Artificial intelligence should be making those connections*" P11) if they were to present with possible recurrence symptoms.

*"For me, I find if I can take a bit of paper or somebody says something to me that I can take and say to the GP: this says you should take me seriously -I think it gives women confidence to raise concerns."* P12 (ductal breast cancer)

Regardless of the format, there was a clear desire for greater signposting and navigation to existing, trusted resources, ideally if these were all in one place. The participants also discussed the importance of social support via forums or support groups with respect to support with fears around recurrence.

## Key behavioural determinants of recurrence-related self-management behaviours

To summarise the overall findings, Figure 1 maps key behavioural determinants onto the COM-B model, illustrating how these determinants can act as facilitators or barriers to recurrence-related self-management behaviours on

PSFU. {***insert Figure 1***].

In Table 2, the findings are mapped to the TDF (v2) domains and COM-B components and linked to the corresponding behavioural determinants and potential targets for future interventions. ***[insert Table 2]***

## Discussion

This study applied behavioural theory to systematically examine how individuals affected by breast cancer recognise and report potential signs of recurrence within personalised stratified follow-up (PSFU) pathways. By mapping participants' experiences to the COM-B and TDF frameworks (see Table 2 for detailed intervention targets for optimising PSFU), we identified modifiable behavioural determinants underpinning recurrence-related self-management behaviours and corresponding intervention targets. These novel findings extend our previous work [31] and other research in breast cancer survivors on PSFU [32] by providing a theoretically informed foundation for intervention development. They also demonstrated how current breast cancer PSFU pathways could be optimised (see Box 1), with potential relevance for other cancer survivors or long-term conditions.

## Box 1: Key Components for a Model Pathway Supporting Self-management in Breast Cancer PSFU

**1. Recurrence symptom education & recurrence awareness**

- Well-defined, accessible information on red-flag symptoms including red flag signs of secondary breast cancer, as well as other types of recurrence (e.g. local, regional).
- Information on how long to monitor a particular symptom for before seeking help.
- Use of visual aids to support symptom recognition (e.g. videos, infographics).
- Tailored education based on cancer subtype, or other treatment or clinical features that impede ability or confidence to check (e.g. dense breasts, screen detected cancer, double mastectomy).

**2. Behavioural self-management support**

- Capability: Knowledge and skills for symptom monitoring.
- Opportunity: Access to supportive services and clear, accessible symptom-reporting pathways (e.g. which healthcare provider to contact for specific concerns).
- Motivation: Support for emotional barriers (e.g. fear of cancer recurrence, avoidance, and uncertainty).

**3. Role of HCPs**

- A physical demonstration of breast self-surveillance (how to be breast aware)
- Training in FCR-sensitive communication, discussing risk of recurrence and risk reduction strategies including healthy lifestyle modification.
- An HCP-led guided discussion around the end of treatment/start of PSFU to discuss recurrence and provide support and signposting to relevant interventions.

**4. Digital Support with written formats, depending on preferences**

- Symptom trackers with prompts for action e.g. SMS prompts.
- Digital (or written) postcards to prompt help-seeking.

A key contribution of this study is the novel identification of subtype-specific challenges faced by individuals with invasive lobular carcinoma (ILC), particularly in relation to symptom recognition, surveillance confidence, help-seeking and fear of recurrence (FCR). Participants with ILC described limited access to tailored information, reduced confidence in the effectiveness of mammographic surveillance to detect recurrence, and experiences of symptom

dismissal by HCPs, all of which negatively affected wellbeing and engagement with follow-up care. These unmet needs among individuals with ILC have not been explored previously, highlighting the importance of ensuring that PSFU or similar pathways are responsive to the needs of diverse breast cancer populations. Future work is required to explore in-depth experiences in people with rarer subtypes.

These findings build on previous literature highlighting unmet supportive care and information needs [31, 56] and demonstrate a clear need for interventions on PSFU that increase patient empowerment, including knowledge, skills and confidence to engage in active self-care and self-surveillance. The intervention targets identified (Figure 1, Table 2) have important implications for future intervention design for PSFU. Increasing *capability* may be achieved through education and guided discussions about recurrence, including a demonstration of breast self-surveillance, which is delivered by breast cancer nurses, alongside information provided in a variety of formats (e.g., videos, apps, infographics, and written information). *Motivation* could be enhanced by education on the importance of self-surveillance, prompt help-seeking, and lifestyle modifications to reduce the risk of recurrence. There is clearly a role for greater inclusion of a wider multidisciplinary team (e.g., physiotherapy, occupational therapy, dietitians, psychologists) to promote post-treatment wellbeing. Improving *opportunities* requires addressing systemic barriers within the healthcare system, particularly by improving timely access to clinical teams and supporting clearer navigation of services during PSFU. Digital innovation, including artificial intelligence, is likely to play an important role in enhancing future follow-up care, including service-level improvements to care navigation. For instance, automated flagging of a patient's breast cancer history within primary care records could prompt General Practitioner's (GPs) to investigate possible recurrence symptoms during follow-up [57], supporting earlier detection and timely referral.

The findings also highlight the importance of interventions that support cancer survivors in self-advocating during interactions with HCPs, particularly those with less common subtypes, such as ILC. Co-designed digital or printed tools (e.g., symptom diaries or checklists) could act as prompts to support communication and increase confidence when raising concerns about symptoms with HCPs. Self-management support is increasingly recognised as central to empowering cancer survivors [58, 59], and higher levels of patient activation (knowledge, skills and confidence) are associated with lower health service use [60]. Digital interventions have demonstrated effectiveness in supporting breast cancer self-management post-treatment [40, 61], reducing healthcare costs [62] and improving patient outcomes [61]. Further work is needed to develop such tailored tools and interventions, ensuring that non-digital options are available to avoid exacerbating health inequalities.

Given the importance placed on peer support, facilitating peer-to-peer support during PSFU should be a key component of future interventions. A review of peer support interventions for breast cancer patients highlighted many positive effects, apart from unmoderated online peer interventions [63]. One-to-one peer support and peer education have beneficial effects on health behaviours and quality of life; however, further research is needed to determine their effects on FCR [63]. In addition to education about recurrence, future interventions should address unmet needs related to FCR, a persistent concern among breast cancer survivors that negatively affects wellbeing [64, 65]. As higher FCR is associated with increased help-seeking, it is likely that supporting cancer survivors in managing FCR may promote more appropriate healthcare utilisation [66, 67] and improve quality of life. While psychologist-delivered interventions for FCR have shown positive effects [68], these interventions may not be suitable for individuals with lower levels of FCR or may be feasible given systemic constraints such as a lack of time, staffing or resources. Brief nurse- or clinician-delivered interventions for FCR have been shown to be acceptable to patients and HCPs [69, 70]. However, there may be challenges with implementation due to current staff workloads [70]. One Australian oncologist-delivered intervention [69] incorporates education on recurrence 'red flag' symptoms, prognostic information, normalisation and reassurance, advice on self-management and referrals where appropriate, representing a promising model for adaptation within PSFU or similar risk-stratified follow up pathways.

Although few participants in this study had received personalised recurrence risk information (e.g., using existing risk prediction tools), such information was sometimes reported to cause distress, highlighting the need for clear explanations via lay terminology by clinicians. The findings indicate the ongoing and increasing need for HCP communication skills education and training to support sensitive discussions about recurrence, including communicating risk as well as the specific needs of individuals with ILC, to reduce diagnostic delays. Research suggests that breast cancer survivors better understand their recurrence risk when clinicians supplement standard explanations with brief, structured multimedia tools, which also encouraged more engaged discussions [71]. Emotional factors, such as anxiety, influence how patients process recurrence-risk information, highlighting the need for clear, supportive communication [71]. To address the challenges identified in our study, Box 1 summarises key components for optimally supporting recurrence-related self-management within PSFU pathways. ***[insert box 1]***

**Limitations**

This study has several limitations. Individuals who are more willing to discuss recurrence may have been more likely to participate. We did not measure FCR in a questionnaire; therefore, descriptions of this are based on participants' willingness to talk about this topic. We also included individuals diagnosed up to 10 years previously, which may not reflect current practice in terms of the provision of end-of-treatment clinics. Individual differences and preferences should, therefore, be considered when the findings are interpreted. Despite targeted recruitment, the sample lacked ethnic diversity, and many participants had undergraduate-level education or higher, potentially limiting the applicability of the findings to more diverse or socioeconomically disadvantaged groups. There were also a few participants who were unsure of which breast cancer subtype they had been diagnosed with, as we relied on self-report. We also did not collect information on gender identity, and we recognise the lack of demographic data collected from focus group participants is a limitation.

## Conclusion

Using behavioural theory, this study mapped breast cancer survivors' experiences in recognising and reporting potential signs of recurrence to key behavioural determinants. We highlighted barriers to and facilitators of recurrence-related self-management behaviours within PSFU pathways and illustrated the unique needs of individuals affected by ILC. These findings make a significant contribution to future intervention development for both breast cancer survivors and HCPs, with the aim of improving recurrence recognition and reporting and the management of FCR. The results have important implications for service provision and inform how recurrence support can be optimally incorporated into breast cancer PSFU pathways, which may be adaptable to other cancer survivors in the UK and internationally.

## Declarations


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## Author Contribution

L.M, J.B and E.W wrote the funding application and study conceptualisation. H.B conducted study recruitment and administation. L.M and H.B conducted data collection, coding and analysis. Data interpretation was discussed with all authors. L.M wrote the main manuscript text, and all authors revised the manuscript. All authors reviewed and approved the final manuscript.


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# Data Availability

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.

# Declaration of conflicting interest:

The author(s) declare that there are no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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# Tables

## Table 1- Interview participant characteristics (n=16)

| Characteristics | N (N=16) | % |
|---|---|---|
| **Age (years)** | | |
| 30-39 years | 1 | 6 |
| 40-49 years | 2 | 12 |
| 50-59 years | 6 | 36 |
| 60-69 years | 6 | 36 |
| 70-79 years | 1 | 6 |
| **Ethnicity** | | |
| White: British | 15 | 94 |
| Black British | 1 | 6 |
| **Highest educational qualification** | | |
| A level/NVQ | | |
| Undergraduate degree | 3 | 19 |
| Master's or PhD level degree | 4 | 25 |
| Missing data | 7 | 44 |
| | 2 | 12 |
| **Previous Treatment (in addition to surgery)** | | |
| **Received Radiotherapy** | | |
| No | 4 | 25 |
| Yes | 12 | 75 |
| **Received Chemotherapy** | | |
| No | 9 | 56 |
| Yes | 7 | 44 |

## Table 2: Behavioural Determinants and Potential Intervention Targets for Optimising PSFU Pathways

| COM-B Component | TDF Domain | Behavioural Determinants | Potential Intervention Targets/strategies to optimise PSFU pathways | Exemplar quotes |
|---|---|---|---|---|
| Capability (physical) | Skills | • Confidence to perform breast self-surveillance (be breast aware, knowledge of what is normal and deviations from this) | • Offer a physical demonstration (and/or via video) with personalised feedback, on breast self-surveillance (how to feel for what is normal and what changes to look for), along with training and resources for patients. | *"So they have talked to me about checking my breasts, because I brought up with them about how I thought I was checking, and I obviously wasn't checking very well, and so we did have a chat about how to check properly, you know like the clock and kind of going all around, different positions to be in and things..."* P22<br><br>*"I do think that very practical thing of actually being shown how to do it was really helpful for me."* P6<br><br>*"we're not taught how to check your breasts, you have to learn for yourself, so maybe if we taught people more how to check in person." Workshop 2 patient* |
| Capability (psychological) | Knowledge | • Confidence to navigate the PSFU and healthcare system (e.g., who to contact for what).<br>• Awareness of key 'red flag' symptoms of recurrence, breast self-surveillance (including how to, how often to perform behaviour).<br>• Knowledge on lifestyle factors that may reduce recurrence risk and general wellbeing. | • Develop navigation guides and clear signposting for healthcare access during PSFU.<br>• Provide tailored, reliable information and education on recurrence symptoms, frequency of breast self-surveillance and the impact of lifestyle on recurrence risk reduction. | *"I do feel a bit confused about who I'm supposed to call, I've got several numbers in my phone, which kind of yeah, if you ask me now to call one I wouldn't be 100 percent which one to go for." Workshop 2, patient*<br><br>*"I don't really know what other symptoms there would be. So lumps, and nipple, strange nipples, and that strange chicken skin, but other than that I don't really know what the signs would be, if there are any others". Workshop 2, patient*<br><br>*"You mean like reducing your alcohol* |

| | | | | |
|---|---|---|---|---|
| | | • Feeling able to manage anxiety around recurrence. | | *consumption, exercising, that type of thing, nobody ever discussed any of those sorts of things with me".* P12<br><br>*"Quite often I think [HCPs] will say just keep an eye on it and come back to us if you've still got it in three weeks... And that's worked for me really well in terms of managing my anxiety, and also because the majority of new pains that I've had have actually gone away within three weeks, so it's stopped me going backwards and forwards to the medical team."* P6<br><br>*"I think just information on what to look for, how to look for it, where to go if you are worried, which sort of sites can help support you if you do have a recurrence, and maybe where… Also even if you haven't had a recurrence, just things you can do for your mental wellbeing, just to kind of sort of support you."* P4 |
| Capability (psychological) | Memory, Attention and Decision Processes | • Timing of recurrence information delivery affecting acceptability and ability to be receptive to it (e.g., not during active treatment). | • Timely information provision on recurrence, tailored to individual preferences | "*I think it depends on where you are. When you're going through all the treatment you're so bombarded by so many things going on and so many appointments, I think yet more information at that point is possibly just gonna be just yet more noise*." Patient, workshop 2<br><br>*"I think you'd have to be very careful about what information you give about secondary [Breast cancer], for people to remember at a certain time. So whether you would need to call people back after, I don't know, but there's so much* |

| | | | | |
|---|---|---|---|---|
| | | | | *information that you have to assimilate"* P5 |
| Capability (psychological) | Behavioural regulation | • Prompts as reminders to perform breast self-surveillance and habit formation, help raise concerns and support decision-making. | • Provide timely prompts and tools to support habit formation around breast self-surveillance (e.g. SMS reminders)<br>• Provide decision support tools for help seeking.<br>• Remote monitoring with recurrence symptoms flagged to HCP e.g. system level prompts.<br>• Provide a 'body change map' to enable changes from the normal to be tracked | *"Probably once a week now...CoppaFeel, I get the reminder once a month, so without fail I do it on the, I think it's the first working day of the month that it comes from CoppaFeel, so without a doubt I always do it then. But then quite often I'll do it at the weekend as well, just as part of my routine.* P12<br><br>*"Something that could be developed for people who can either download pictures to, can type in yes it looks like this, no it doesn't look like that, and once they hit a certain thing it gets flagged or gets sent to somebody and they make that phone call back to that person. ...Or that on that it then says to that person you have hit a trigger, please could you give this number of call, and they call through to that number or they go on to the app to put all that information in again, and then it gets reviewed at the end by a professional. So they know that they're doing something to help themselves."* P24 |
| Opportunity (physical) | Environmental Context and Resources | • Level of system-level barriers (e.g., poor access to MRI imaging for ILC; administrative delays with contacting hospital team during PSFU and HCP responses).<br>• A follow-up appointment post-treatment around the start of PSFU with an HCP. | • Improve system responsiveness and accessibility of hospital staff, and access to MRI scanning, where appropriate.<br>• Tools on GP system to flag history of Breast cancer.<br>• Schedule end of treatment/start of PSFU appointment to | *"there should be a system on the computers where if you've got a certain history, I think this would be invaluable tool…but if you've had primary breast cancer and you're presenting with pain in the hip or pain in your spine or breathlessness or whatever, that straight away that that computer… P11*<br><br>*"if I remember back, I think I was told I could contact a breast nurse, but I don't think I knew who my breast nurse* |

| | | | | |
|---|---|---|---|---|
| | | • Access to a range of accessible formats. | provide a guided, personalised discussion.<br>• Provide additional information alongside discussion in different formats (apps, websites, video, written materials). | *was...I've seen different breast nurses, and one gave me her e-mail and I e-mailed her and she never got back to me. And then the other one said oh, I'll ring you, and she never rang me"* workshop 4<br><br>*"it's in paper form, there's all these other apps, somebody just needs to be like what's out there already, is there a way [audio dropout] these all together and have something there that is flexible and adaptable, works for people." Workshop 4*<br><br>*"Think it needs to be both [digital and paper based], because some people are better with technology, some people are older, are deprived and don't have access to a smartphone or an internet connection, they may find it daunting to look at that". (workshop 4 recurrence)* |
| Opportunity (social) | Social Influences | • Peer support, to support with FCR and provide signposting to existing resources. | • Signposting to peer support networks and existing credible resources and facilitate reliable information sharing. | "I *think the best thing would be like-minded people, people that have either been touched by cancer, are going through treatment or are post-treatment and are willing and happy to be part of a forum or a group"* P24<br><br>"*I think for me the most, one of the most helpful things has been getting support from other people that're going through the same thing, and I think those are the people that you can talk to about something like recurrence…and when you talk to other people you can kind of do, it's that living with uncertainty, and I think people that're going through the same* |

| | | | | |
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| | | | | *uncertainty as you, it just, I don't know why but it just makes you feel a bit better about it."* P22 |
| Motivation (reflective) | Social/Professional Role and Identity | • Emotional support on recurrence from a HCP, tailored to individuals' preferences and circumstances.<br>• HCP awareness of ILC subtype (and other rarer subtypes). | • Train HCPs to support patients with recurrence concerns and how to recognise symptoms.<br>• Train HCPs on awareness of ILC and rarer subtypes, with regards to recurrence. | *"So it's maybe having a bit of a personalised chat with somebody...how much that would affect you, you know in terms of your histology, being very tailormade to your specific set of circumstances"* workshop 2<br><br>*"I think what I needed was somebody to sit me down and say other people who are in your stage, we see this, they worry, you're not unique. And nobody's ever said that to me, so then I continue with this feeling of like oh, it's just me, I shouldn't be worrying, and I know it all sounds a bit, it's silly, and I know that a lot of that's me, but yeah, I think it would help to have something from, maybe, yeah, I think maybe from the breast cancer nurse, but also just maybe training for consultants and things when they're talking to patients"* P12 |
| Motivation (reflective) | Beliefs about Capabilities | • Confidence with recognising symptoms that may indicate a potential recurrence.<br>• Confidence with reporting symptoms that may indicate recurrence and ability to interact with HCPs and self-advocate. | • Provide self-advocacy tools and symptom checklists (e.g., a document to present to HCPs) to increase confidence for knowing when and how to seek help. | *"As [breast nurse was checking her] she was sort of explaining what she was doing, and she was sort of educating me as I went along. So that was really helpful, and I think the fact that it was practical and she was actually examining my breasts at the time actually made all the difference*!" P6<br><br>*"I feel a little bit reluctant to go to the GP, which is really stupid and it's really not like me. I feel as though I want to go and ask for a particular type* |

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| | | | | *of scan, but I can't go and be that direct, because I may not require that or they may think I'm just overthinking it, and then I end up not going. I don't know, it's a bit mixed up...Yeah, and I'm also aware of how overworked they are, and bothering them too much and not wanting to be that type of patient"* P45 |
| Motivation (reflective) | Beliefs about Consequences | • Beliefs about the importance of breast self-surveillance, and prompt help-seeking to avoid delays in recurrence detection.<br>• Beliefs about the importance of making positive lifestyle modification at reducing recurrence risk. | • Provide education on the importance of breast self-surveillance and prompt help-seeking<br>• Promote lifestyle interventions and support for behavioural change. | *"certainly it's one of the ways that I've managed my anxiety around it, is actually getting the information and then putting it into practice for myself, so that at least I can think to myself OK, I'm not in control of what genetic kind of malfunction has led to this cancer, but I do know that if I do my exercise I do have… I think it was extraordinary, it was something like a 40 percent lower recurrence rate in women who did 300 minutes a week or more of exercise than in women who didn't do any exercise."* P6<br><br>*"[HCP] did show me that [check breasts], and then that's something that I have seen on websites, even on like TikTok and social media, yeah, there's quite a lot on there, things like that...So, and I do feel that's because I found it so early, and so that's kind of why I do check now, because if it's gonna come back I want to find it early again.."* P21 |
| Motivation (automatic) | Emotion | • Feeling reassured by HCPs and having concerns taken seriously (not dismissed).<br>• Feeling emotionally | • HCP training on supporting patients with recurrence without increasing anxiety.<br>• Deliver personalised | *"So that was really difficult for me, I said I want to speak to .. my breast care nurse, it goes to like answer machine or whatever, and.. never heard back. So all that was a bit stressful and very depressing."* workshop 1 |

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| | | supported by HCP team | information with emotional sensitivity and timing. | *"invasive lobular cancer - basically what turned out to be all over the breast, eventually. And that's been really quite difficult for me to deal with, that no-one, I feel that no-one listened to me, and everyone brushed off my symptoms because they didn't fit the normal pattern of symptom recurrence."* (patient with ILC in workshop 1) |

## Figures

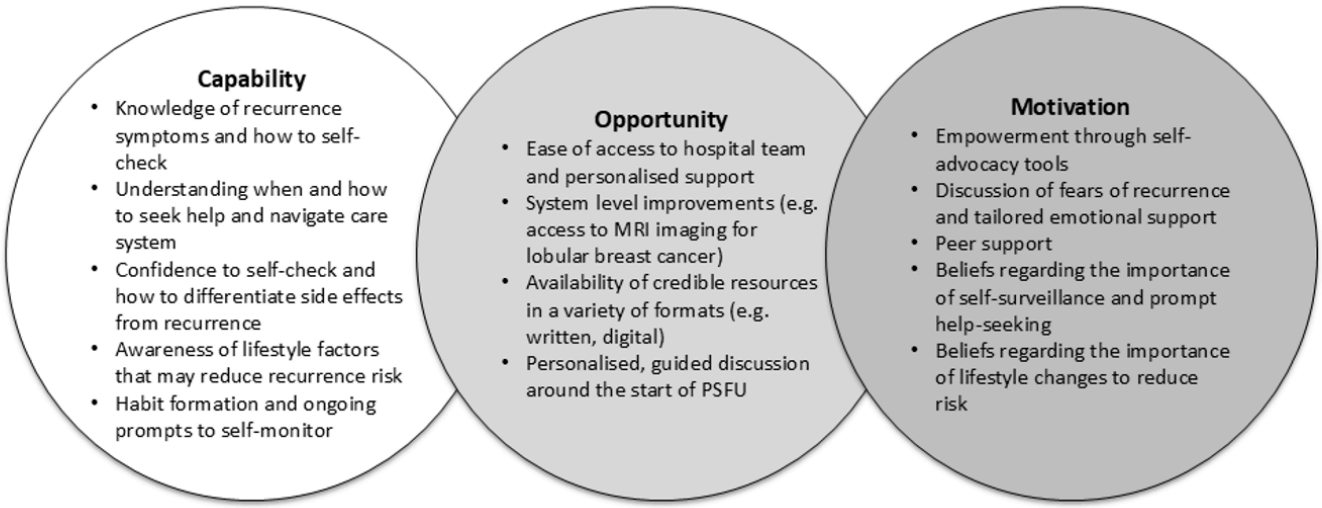



**Figure 1**

Key behavioural determinants of recurrence self-management behaviours on PSFU

## Supplementary Files

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- Supplementaryfile2Topicguides.docx
- Supplementaryfile3Codingframeworkforpatients.docx
- Supplementaryfile4additionalexamplarquotespatients.docx

- Supplementaryfile1COREQChecklistREPORTstudy.pdf