

Patients' experiences of a supported self-management pathway in breast cancer (PRAGMATIC)

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Background

There are few data on patients' experiences of entering and managing the Supported Self-Management (SSM) system for early breast cancer (EBC). PRAGMATIC aims to evaluate the experiences of EBC patients entering SSM and the impact on quality of life (QoL) and NHS service. We present the baseline and 3 month interview data here.

Methods

- 3 Surrey & Sussex BC teams identified eligible patients (Table 1)
- Participants completed QoL questionnaires (see abstract 3328)
- Subgroup interviewed at baseline, 3, 6, 9, 12mth to explore:
 - understanding of the SSM pathway
 - confidence in self-management
 - triggers to seek help
 - use of support services
 - impact of COVID-19 pandemic
- Ethical Approval Ref : 19/LO/1966
- Between Feb & Nov 2020, 110 patients were recruited; 32 of whom participated in interviews (Table 2 demographics)

Table 1: Participants' QoL alone / QoL & interviews by centre

	QoL	QoL & Interviews
Ashford & St Peters	34	13
Brighton	19	12
Worthing	25	7
Total	78	32

Table 2 Demographics	Sex (M; F)	Age Range			Partner (Yes)	Employed (Yes)	Endocrine (Yes)	Chemotherapy (Yes)
		<50	50-70	>70				
Interviews & QoL (n=32)	2; 30	7	21	4	25	19	26	10
QoL Assessments alone (N=78)	0; 78	12	50	16	48	34	60	25

Baseline Findings n=32

Patients' understanding of the pathway:-

- assume responsibility for their own follow-up **18 (56%)**
- save time & money for them & the hospital **14 (44%)**

"So that we can be kept an eye on & not abandoned & have a point of contact. Don't have to attend appointments regularly, makes it easier for us. Probably saves the NHS money as well"

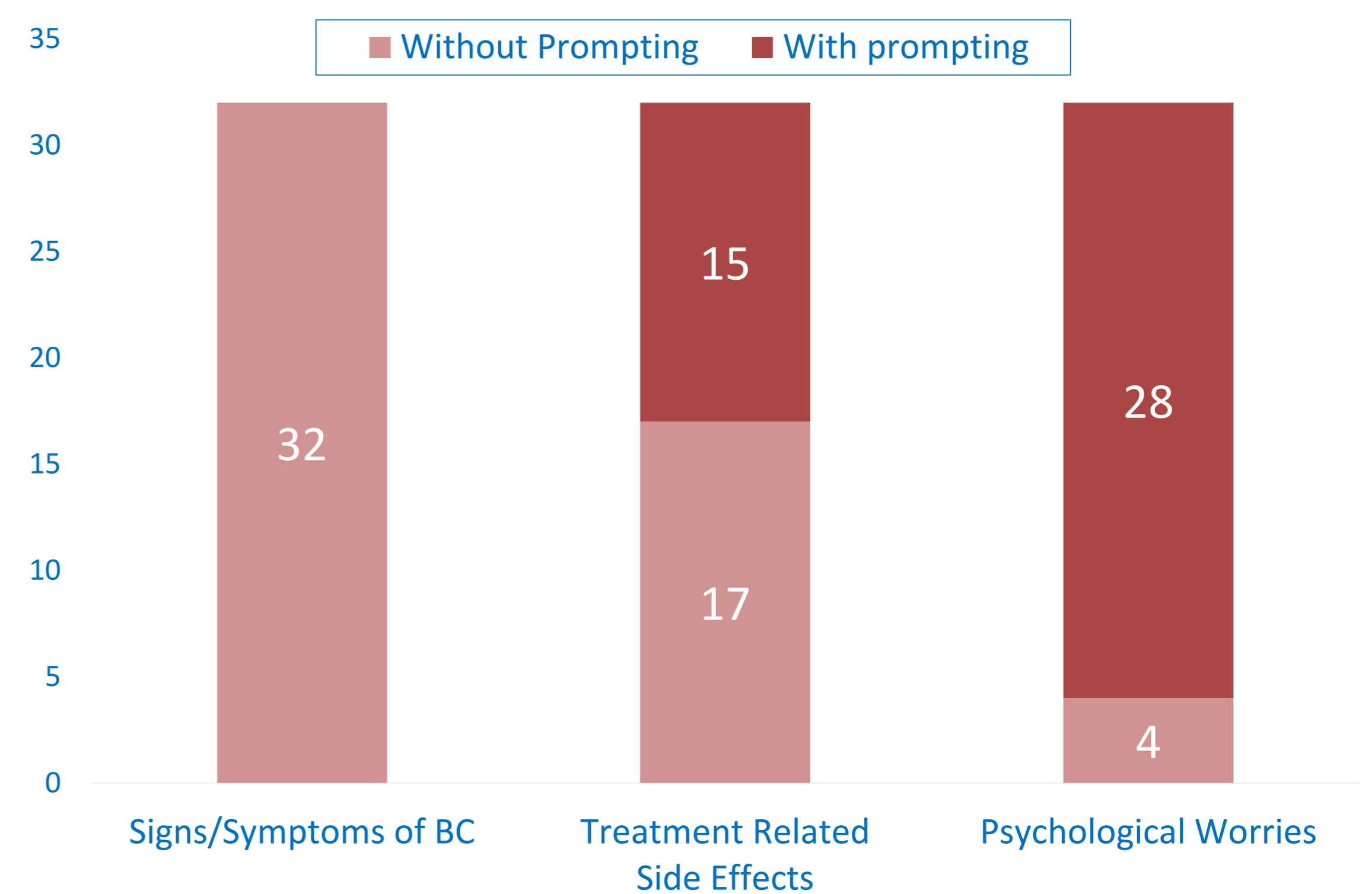
- 28 (88%)** had no concerns about starting the pathway
- 3 (9%)** had concerns about:-
 - Possible lack of face to face contact
 - Spotting a recurrence
 - Seeing a doctor as access is always via a nurse
- 1 (3%)** didn't realise she was on the SSM pathway
- 29 (91%)** very satisfied with the SSM introductory session
- 21 (66%)** recalled receiving written SSM guidance
- 13/21 (62%)** had read parts or skim read the written guidance

"It was geared mainly for women, so for a man it was a bit strange. It almost felt like you were invading their privacy."

Patients 'Very/Somewhat' Confident about:-

- managing breast cancer follow up care **31 (97%)**
- managing side effects of treatment **29 (91%)**
- identifying & reporting BC signs/symptoms **27 (84%)**

What concerns would trigger you to contact SSM?



3 Month Findings n=31

By 3 months

- 1** too anxious for interview - withdrew from study as awaiting scan regarding concerns about a recurrence
- 2** expressed concerns about the SSM pathway

"The lack of communication can make me feel a bit abandoned, feel like on your own a bit. Down to me to contact the breast team"

"It's in the back of my mind, due mammogram in August. I'm worrying about when it will be & the anxiety of having it & getting the results"

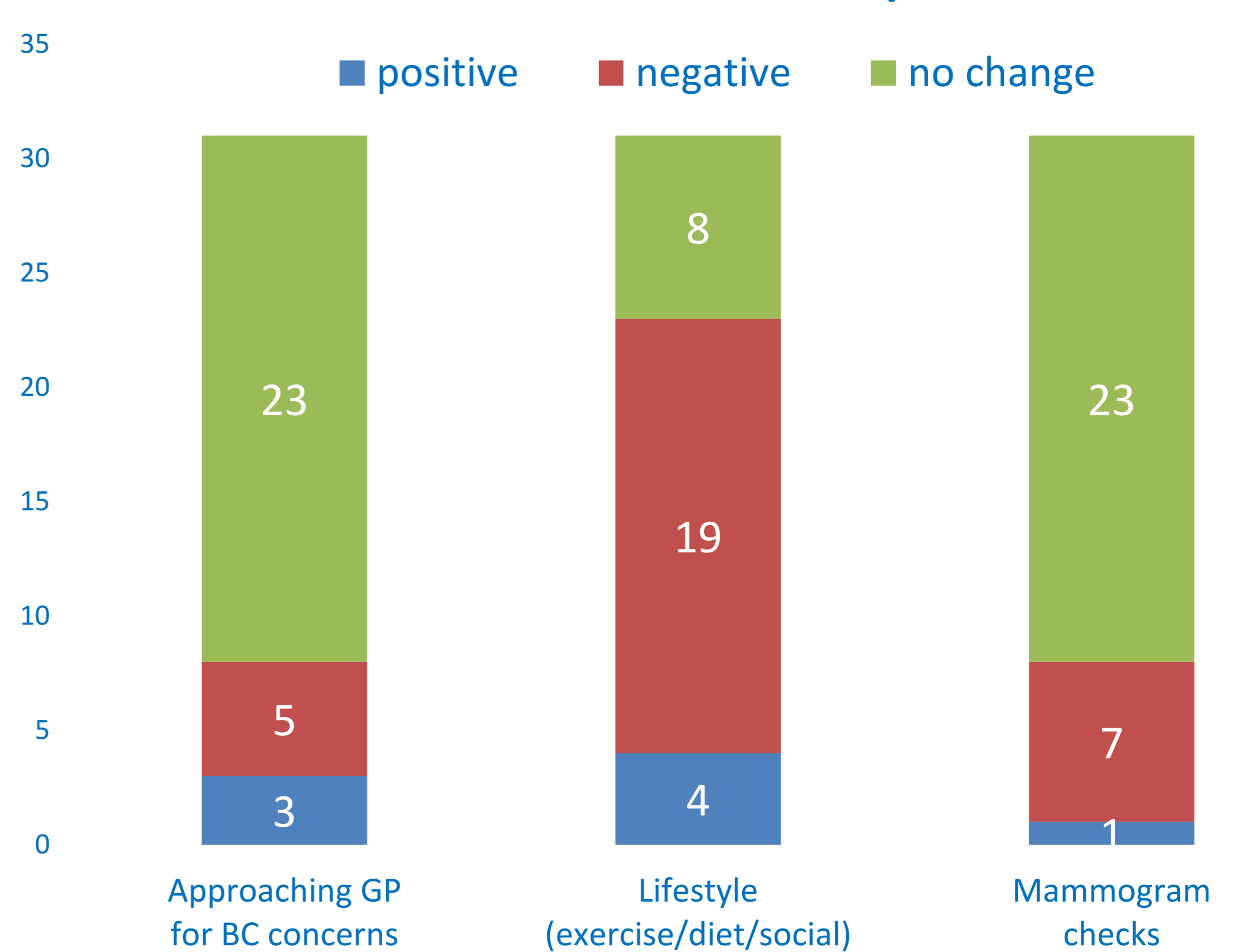
Helpline calls at baseline and 3 months:

- 13/32 (41%)** patients had made 15 calls to helpline & found it simple to use
- 9/15 (60%)** of calls returned within 24 hours
- 4/15 (27%)** calls were about BC signs & symptoms
- 2/32 (6%)** contacted the GP only for BC concerns

"Even though it wasn't an emergency. Nurse was really, really helpful. I didn't feel I was putting her out and she was happy to answer all my questions and discussed my case with a consultant"

- 4/31 (13%)** had referred to parts of the SSM handbook

What effect has the coronavirus pandemic had on :-



"Annual mammogram due beginning of May but postponed. I've had very mixed feelings about this, was quite worried about the delay, but then relieved that I didn't have to go to the hospital"

Conclusions

Initial findings show that during the first 3 months, many patients felt confident about managing their own breast cancer care. Those who accessed the helpline found it easy to use and responsive to their needs. The pandemic interfered in maintaining healthy lifestyle changes, and social interactions.