

## Patients' experiences of a suppoRted self-manAGeMent pAThway In breast Cancer (PRAGMATIC)



NHS Surrey and Sussex **Cancer Alliance** 

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### Background

- Cancer has become a chronic condition, with an estimated 2.5 million people living with this disease in the UK<sup>1</sup>
- The routine clinical follow-up of such large numbers is hugely problematic in the NHS
- Traditional breast cancer (BC) follow-up involves clinic visits that may be impractical for many
- ❖ The NHS is prioritising support pathways to help survivors live well beyond their diagnosis
- Supportive Self-Management (SSM) allows patients to report symptoms as and when necessary
- Some hospitals in Surrey and Sussex have implemented SSM pathways for BC but not formally assessed the impact for patients

#### Aims

Measure

- ❖ To describe the Surrey and Sussex SSM pathway in BC at the 4 centres in Table 2, in terms of :-
  - Patient experience
  - Quality of life (QoL)
  - Confidence and ability to recognise and report symptoms related to BC
  - Resource implications and costs

### Patient population & Inclusion Criteria

- ❖ 100 BC patients (women/men) who have completed hospital treatment
- Attended an end of treatment workshop or one to one appointment prior to SSM
- Stratified by age & treatment one third chemotherapy, two thirds endocrine therapy

Baseline 3

❖ Able to read & understand English, willing and able to provide consent

### Table 1 – Measures and time points

		months	months	months	months	T
nal Assessment of Therapy-Breast 3) <sup>2</sup>	100					S
						В
Roles and sibilities Scale	100					F
Health nnaire-12 2) <sup>4</sup>	100					R T
ic Health Related of Life EuroQol-5D – Q5D-5L) <sup>5</sup>	100					•
al Self-Efficacy Scale	100	_				C
e use questionnaire	100					*
rviews	30/ 100					<b>R</b> 1 2

#### **Methods & PRAGMATIC Study Flow Chart**

Clinical team identify those who have completed secondary care for BC and due to attend an end of treatment workshop / one to one appointment about the SSM pathway

Potential participants receive the study information sheet following end of treatment workshop / one to one. Clinical nurse specialist forwards contact details of those interested to SHORE-C with a completed expression of interest form

SHORE-C researcher makes contact a minimum of 24 hours later to answer questions, and explore which part of the study they wish to join (either questionnaires alone or interview plus questionnaires)

Consent obtained by SHORE-C researcher prior to data collection or prior to first interview

Questionnaires (n=70)

Baseline, 3, 6, 9, and 12 months

Interviews & questionnaires (n=30)

Baseline, 3, 6, 9, and 12 months

# Table 2 – Sites participating in the PRAGMATIC Study

Site	Recruitment target
Ashford & St Peter's Hospitals NHS Foundation Trust	25
Brighton and Sussex University Hospitals NHS Trust	25
Frimley Health NHS Foundation Trust	25
Western Sussex Hospitals NHS Foundation Trust	25

## Results

The study will:

- Describe the challenges and benefits of the SSM pathway
- Generate patient experience data
- Provide QoL data
- Identify those who are more comfortable with recognising BC related symptoms and reporting them
- Identify the characteristics of those who need more support
- ❖ Provide further details about areas that need to be addressed to ensure that the pathway functions smoothly and to the benefit of patients

## Conclusions

- ❖ There are few data on patients' experience and their emotional and psychosocial well-being in a self-management pathway
- The information generated in this study will provide a valuable insight into patients' interpretation of the SSM pathway

### References

- 1. Macmillan, Fact Sheet., <a href="https://www.macmillan.org.uk/">https://www.macmillan.org.uk/</a> images/cancer-statistics-factsheet tcm9-260514.pdf. Accessed 12/09/2019
- 2. Brady, M.J., et al., Reliability and validity of the Functional Assessment of Cancer Therapy-Breast qualityof-life instrument. Journal of Clinical Oncology, 1997. 15(3): p. 974-986.
- 3. Shilling, V., et al., Development and validation of the patient roles and responsibilities scale in cancer patients. Quality of Life Research, 2018. 27(11): p. 2923-2934.
- 4. Goldberg, D.P., & Williams, P. A user's guide to the General Health Questionnaire.
- 5. Herdman, M., et al., Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation, 2011. **20**(10): p. 1727-1736.
- 6. Schwarzer, R., Jerusalem, M., Generalized Self-Efficacy scale. Measures in health psychology: A user's portfolio. Causal and control beliefs ed. SWJ Weinman, & M Johnston. 1995, Windsor, UK NFER-NELSON. (pp. 35-37).

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