

# Development of an online surgical decision aid for young women newly diagnosed with breast cancer

Dr. Alejandra Recio-Saucedo, Dr. Claire Foster, Sue Gerty, Dr. Ramsey Cutress, Prof. Diana Eccles

Contact: C.L.Foster@soton.ac.uk

## Introduction

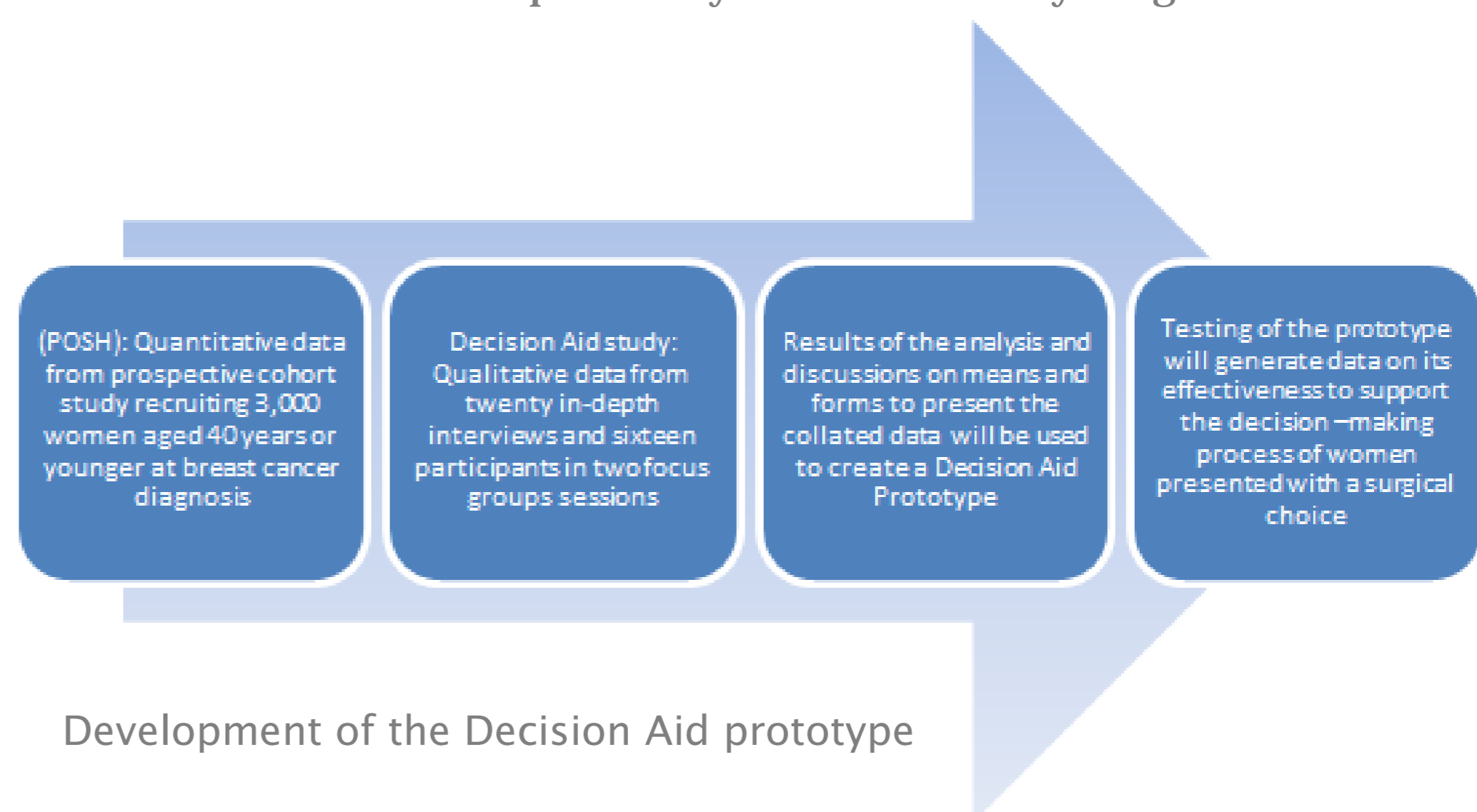
Breast cancer is the most common cancer in women aged 40 or under (Zhou and Recht 2004; Peate, Meiser et al. 2009). The psychosocial impact of this disease is magnified when diagnosed at an early age as it affects women during the reproductive and child rearing phases of their lives (Hickey, Peate et al. 2009). Most women present with potentially curable cancer. Most will have a choice between mastectomy or breast conserving surgery. However, making a surgical decision presents a difficult challenge for women (Whelan, Levine et al. 1999; Whelan, Sawka et al. 2003).

Decision aids are tools that help to convey disease and treatment information in an interactive way. They improve patient understanding, reduce uncertainty and lead to greater satisfaction with the decision made (O'Connor, Fiset et al. 1999; O'Brien, Whelan et al. 2009; Belkora, Volz et al. 2012). Service User groups confirm that information to support decision-making specifically in younger women with breast cancer is lacking and is a priority for research (Peate, Meiser et al. 2011). In collaboration with predominantly younger service users, this pilot study will use age-specific outcome data to formulate a decision aid aimed specifically at women with young-onset breast cancer.

## Aims

**Aim (1)** To determine the influence of family history and age on surgical treatment outcomes and survival for women aged  $\leq 40$  years at diagnosis.

**Aim (2)** To develop and test a surgical decision aid that will provide age relevant information aimed at helping young women better understand treatment choices and outcomes.



## Methods (1)

- Correlation and descriptive statistics will be used to summarise the pathological and radiological features, clinical presentation, demographic data, family history, ethnicity and treatment data.
- Cox proportional hazards multivariate regression analysis will be used to determine the effects of age and family history on surgical outcome (local recurrence and new primary cancers) and Distant Relapse Free Survival (DRFS) (adjusted for all other known prognostic factors listed).
- The primary outcomes of interest will be relapse-free survival, local recurrence and contralateral new primaries.

**Decision Aid for  
Young Women with  
Breast Cancer**

## Methods (2)

- Systematic review regarding information that young women with early onset breast cancer would like to know when potentially facing a surgical choice between mastectomy and breast conserving surgery.
- Twenty semi-structured interviews that will explore the retrospective decision making experiences of women regarding their surgical treatment.
- Two focus group discussions will explore the key information resulting from the analysis of the cohort data in Aim 1 and the key themes from the interviews around decision making. They will explore how information can most usefully be presented to women to aid decision making.

Research for Patient Benefit Programme

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## Analysis

Transcripts from the interviews and focus groups will be analysed using a framework approach. The findings will provide a description and interpretation of women's experiences of making decisions about surgery and their views and recommendations for how information could be most helpfully presented to women.

## Outcome

The deliverable will be an online interactive decision aid that is relevant to younger women diagnosed with breast cancer. The decision aid will be developed and piloted in collaboration with the Breast Cancer Care Service User Research Partnership which will provide access to users both to develop and evaluate the decision aid.

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