

# **Living with Secondary Breast Cancer**

Health and Wellbeing days for patients living with active disease

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**Macmillan Secondary Breast Cancer CNS**

**The Christie**

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## Background

- Average survival for patients with SBC - 3 years
- Living with physical burden of active disease
- Living with psychological burden of life limiting diagnosis
- Services focus on diagnosis and end of life
- SBC patients feel uncomfortable accessing H+W days alongside primary patients and needs differ

## Service aim

- To create a support pathway for patients with secondary breast cancer

## Challenges

- Implementing recovery package for advanced disease
  - Ensuring patient and staff engagement
  - Lack of funding
  - Finding time away from existing clinics
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## First year after diagnosis – a minimum of:

- HNA at nurse led clinic within 6 weeks of diagnosis
- Stratified nursing follow up dependent on need
- Telephone follow up if appropriate
- Health and wellbeing day to educate and promote self management and living well
- Easy access to key worker team

## Innovation funding opportunity

- Macmillan and Manchester Cancer
- 12 month project ideas
- Application December 2014
- H+W project with one day a week CNS lead and administrative support
- £20,000

## Aim

To offer Christie patients with SBC and their significant others across Manchester the opportunity to attend a health and wellbeing event about “Living with Secondary Breast Cancer”

## Objectives

- To increase awareness of common symptoms and available services
- To increase confidence in achieving a good quality of life
- To offer support from professionals and other patients about living with uncertainty and living well with SBC
- To reduce isolation

## Method

- 3 events delivered in 2015-16
- The Christie Secondary Breast Cancer Patient Focus Group asked to help plan programme
- Programme included speaker sessions in the morning, information stalls at lunchtime and breakout sessions in the afternoon
- Patients invited via out patient clinics and events also advertised via local BCN's, chemotherapy units, Macmillan information centres and social media
- Expert speakers and facilitators invited
- On the day and pre and post event questionnaires evaluating impact

## Living with Secondary Breast Cancer (SBC) programme

09:30-10:00	<b>Meet and greet, tea and coffee</b>	
10am-10:05	<b>Welcome</b>	Claire Gaskell, Christie Secondary Breast Cancer CNS
10:05-10:15	<b>What is SBC? A patient's perspective</b>	Ali Metcalfe, SBC patient
10:15-10:40	<b>Red flag symptoms, what do I need to know?</b>	Claire Gaskell
10:40-11:00	<b>Diet and SBC</b>	Dr Michelle Harvie, Senior Research Dietician, Genesis Centre
11:00-11:40	<b>Current treatment and developments in research</b>	Dr Sacha Howell, Consultant Medical Oncologist
11:40-12:00	<b>Open microphone question session with expert panel</b>	
12:00-1:00	<b>Lunch with stalls in foyer offering information from different service providers</b>	
1:00-1:30	<b>Supportive Care</b>	Tracey Coleby, Breast Palliative Care CNS and Geneva Rhodes, SBC patient
1:35-2:20	<b>Break out session 1</b>	
2:20-2:30	<b>Tea/coffee</b>	
2:30-3:15	<b>Break out session 2</b>	
3:15-3:30	<b>Guided mindfulness/relaxation exercise</b>	Anita Mehrez, Lead Complimentary Therapist
	<b>Summing up and close</b>	

### **Breakout sessions**

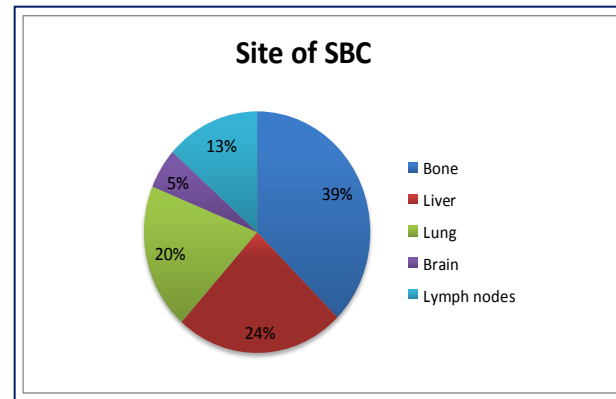
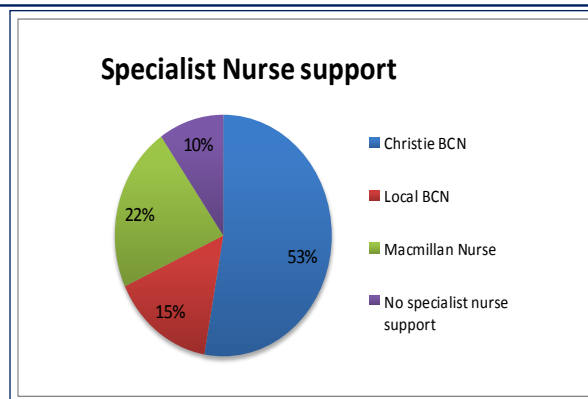
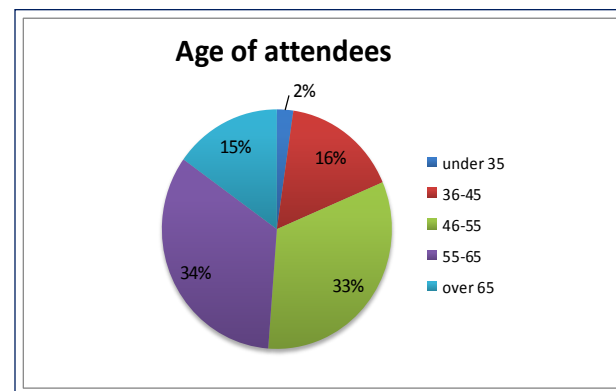
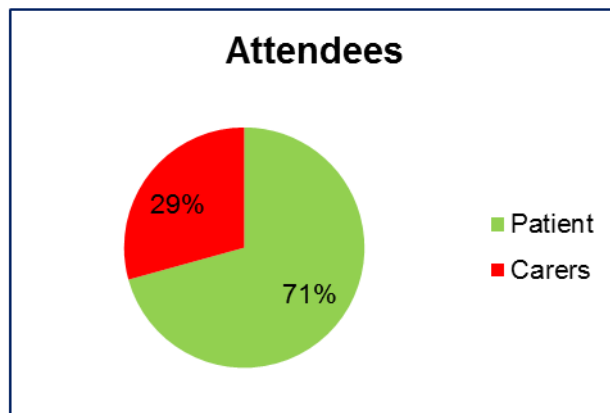
**45 mins each. Choose 2 prior to event, each breakout session will be delivered twice.**

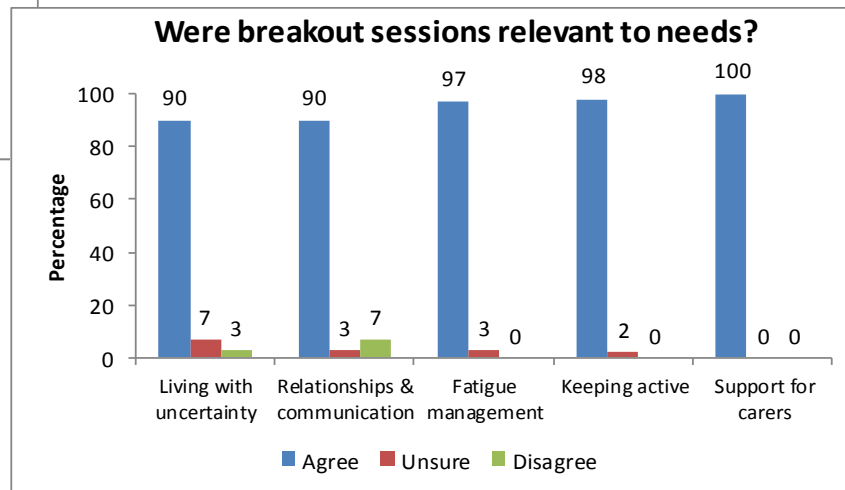
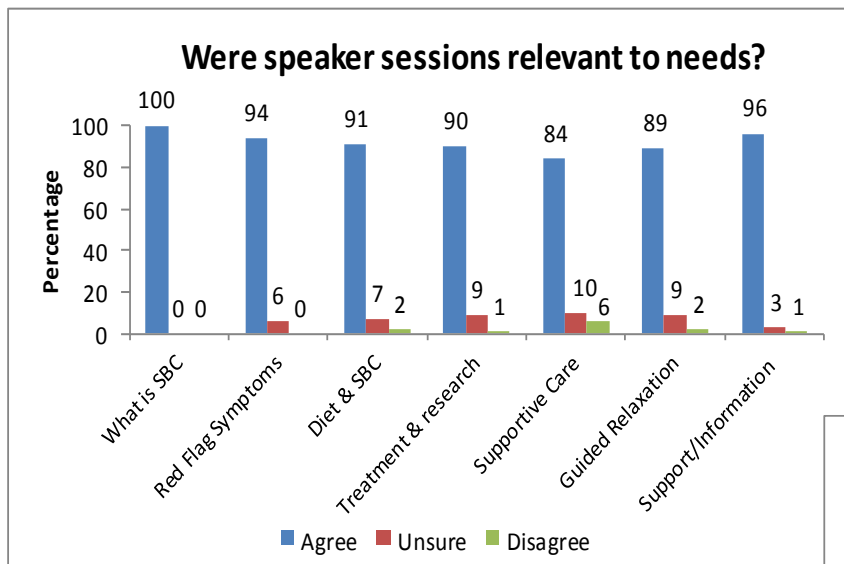
1. Living with uncertainty – lead by Psycho-oncology team
2. Relationships and communication – lead by Beechwood, TLC and/or Winstons Wish
3. Fatigue Management – lead by Occupational Therapist from St Anns Hospice
4. Keeping Active with Secondary Breast Cancer – lead by Macmillan Active
5. Support for carers – lead by Psycho-oncology and Macmillan SBC CNS

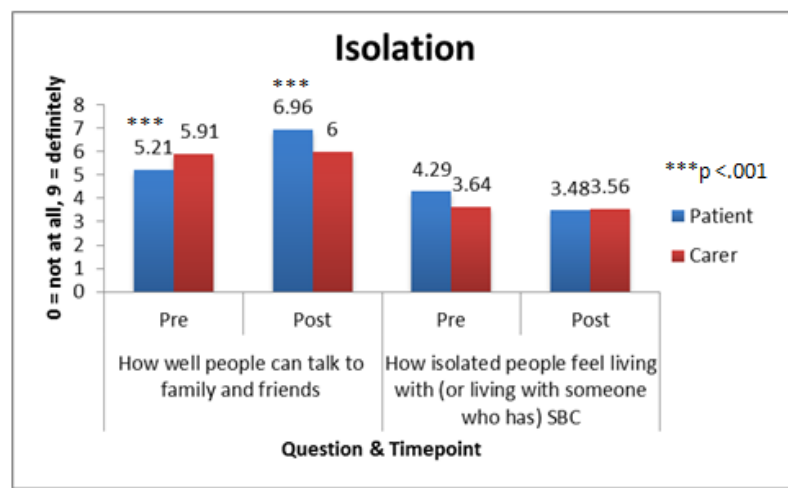
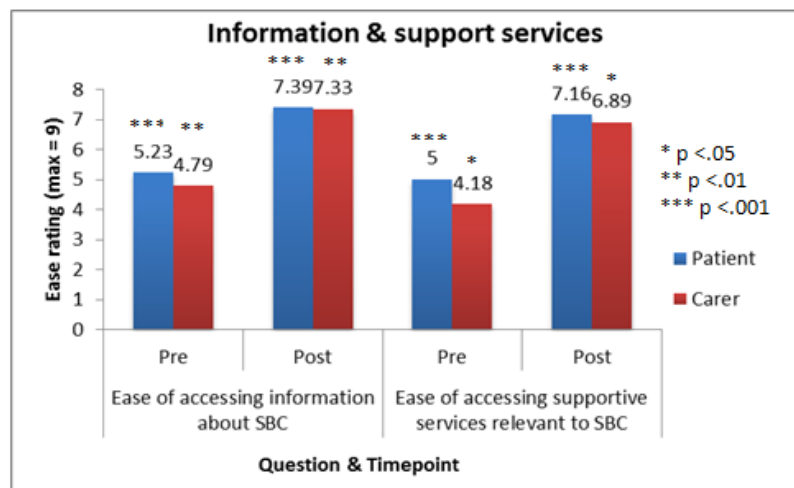
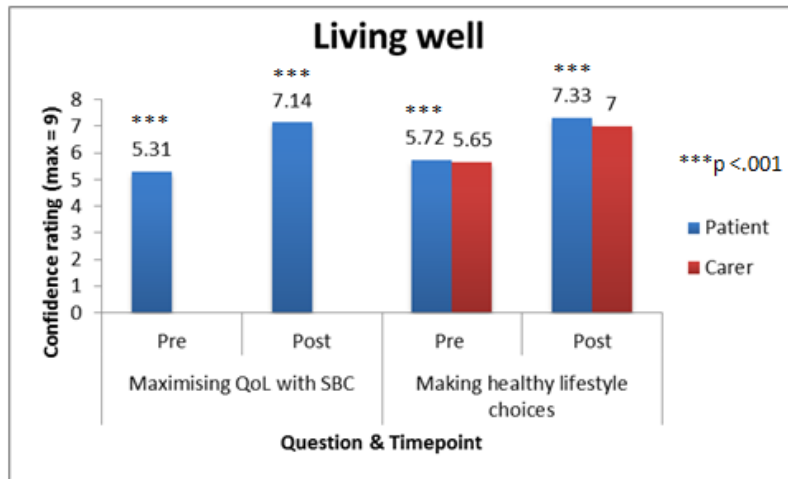
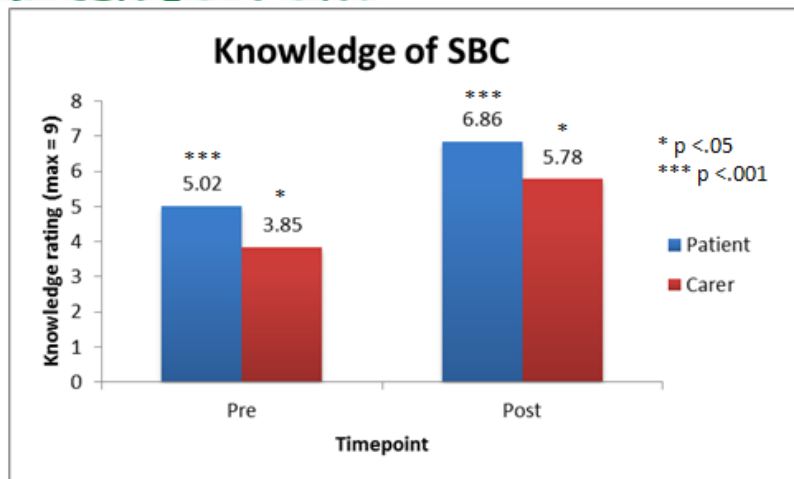


# Results

Bolton	3
Bury	3
Leighton	12
Manchester	5
Oldham	6
Rochdale	2
Salford	4
Stockport	13
Tameside	3
Trafford	21
Wigan	5
Other	11







**All results except those measuring isolation were statistically significant**

*“I felt so much more knowledgeable after the event and less anxious.”*

*“Fact and myth busting was very useful. Great to get access to experts.”*

*“Excellent support and knowledge, meeting others, knowing it’s not just me.”*

*“...it empowered me to take more control of my health and treatments and to ask more questions.”*

*“Excellent but too fast! Need two days!”*

*“Meeting more people in the same situation of talking openly about SBC – priceless!!”*

## Costs

- Initial project under budget
- Approx £600 per event – catering main cost

BUT...

- Expectation staff see as part of their role
- No cost for rooms as patient event
- Services/charities need a reason to support
- Admin support needed for a few weeks pre event

## Funding

- Macmillan (MCIP) x2
- Educational grant (pharmaceutical) x2
- Commissioning needed but cannot replace OPA

## Progress since initial project

- 3 further H+W days delivered
- March and October
- Provided as part of a structured pathway of care
- Opt out rather than opt in – personal invitations
- 40-50 patients and carers attending each event
- Further evaluation planned as part of a research study to attempt to influence long term commissioning

## Acknowledgements

Christie SBC Patient Focus group

Dr Carole Farrell, Nurse and AHP Research Fellow, School of Oncology, Christie

Sarah Bellhouse, Research Associate, School of Oncology, Christie

Sharon Foy, Ros Fox, Bethan Daniel - Christie Macmillan Secondary Breast Cancer CNS team

Kath Rashed, BCN secretary, Christie

Tracey Coleby, Macmillan Breast Palliative Care Project lead, Christie

Dr Sacha Howell and Dr Anne Armstrong Consultant Medical Oncologists, Christie

Dr Michelle Harvie and Mary Peggington, Research Dieticians Genesis Centre, Manchester

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Fiona Sanderson, Palliative Care OT, St Anns Hospice, Manchester

Kay Jackson, Key Worker, Neil Cliffe Centre, Manchester

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Carol Townsend and Steph Brayford, Breast Cancer Care

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Ambokile Bell, Macmillan Active, Manchester

Maxine Cumbo, Senior Physiotherapist, Christie

Polly Sangar, Relate, Manchester

Christie Information Centre, Christie benefits advisors

Sinead Collins, Maggie's Manchester Centre Head, Maggie's Centres

Jo Taylor, ABCD diagnosis support (website)