

Mammo-50



LIVING BEYOND THE DIAGNOSIS OF EARLY BREAST CANCER - PATIENTS' PERSPECTIVE FROM THE MAMMO-50 TRIAL

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on behalf of the Mammo-50 Trial Management group

Trial Schema

Female patients aged >50,
previous treatment with curative intent for breast cancer and
3 years post curative surgery

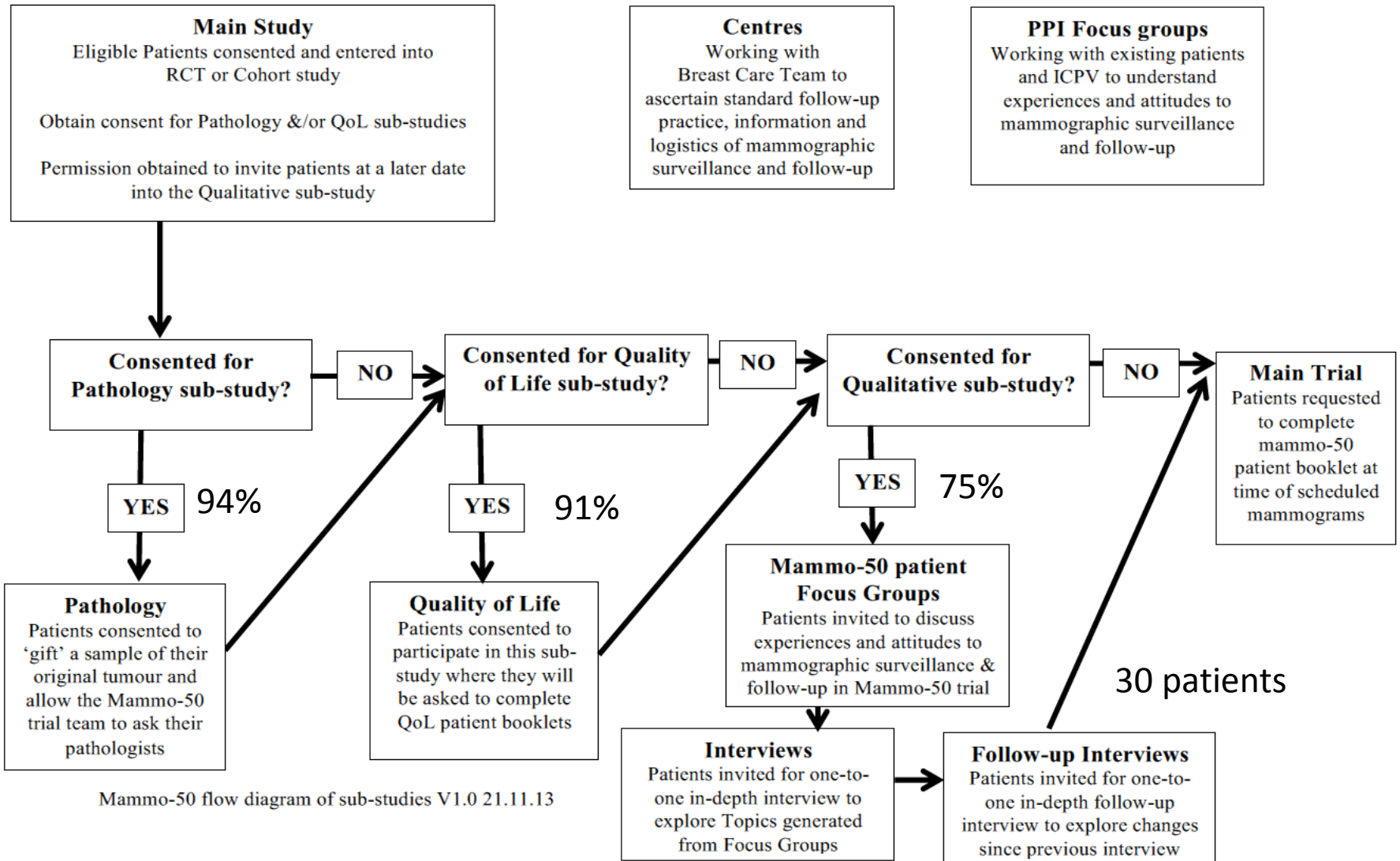
Randomisation

Arm A (N=2500)
Annual surveillance
mammography up to 9 years
post curative surgery

Arm B (N=2500)
Less frequent mammography:
2 yearly for conservation patients
3 yearly for mastectomy patients
Up to 9 years post curative surgery

- Event data form recurrence, new primary or death
- Mammo-50 patient booklet at time of scheduled mammogram

Flow diagram of Mammo-50 Main trial and Sub-studies



Mammo-50 User perspective & involvement

Initial focus groups prior to trial:

- Three workshops with patients assessing QoL scales
Lots of the scales did not capture the information of patients living with and beyond the diagnosis of cancer
- Three PPI focus groups were held for women who are living after diagnosis of breast cancer
They provided an insight into the perspectives' of follow-up and mammography held by women who have breast cancer

Mammo-50 patient focus groups:

- Five focus groups with Mammo-50 patients

ICPV:

- Patient-led survey on experiences of follow-up

Initial Focus groups

Patient-led follow-up – general agreement that there are “several people are looking out for us” but need to know:

- Who to contact and how quickly they would be seen (one woman had ‘tested’ the open access system)
- When to contact; “Is it serious enough?”
- Suggestion that a ‘drop-in centre’/similar would be less frightening than going back to hospital
- The importance of continuity in follow-up was stressed

Initial Focus groups

Debate about how they felt about mammograms and follow up:

- Confident with mammograms if cancer detected that way
- Need to maintain clinical follow-up
 - Lack of confidence in self-examination
 - Unsure what to look for
 - Effects of scar tissue
 - Lymphedema
 - Videos only use women with unrealistic size & shape!

Mammo-50 patient focus groups

- Main findings from 5 patient focus groups indicate the surgeon and clinical team absolutely key to how the patients feel
- Diagnosis is key to confidence of mammograms
- Important as to how results are given
- Advocates of continued mammographic surveillance
- Diagnosis is key to type of preferred follow-up
- Confidence driven by experience & information given
Although many still not sure about self examination

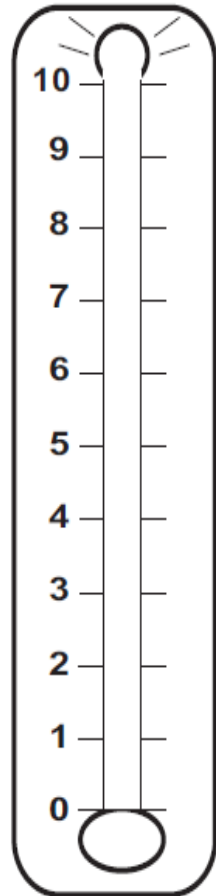
QoL BOOKLET

1. Distress Thermometer
2. Assessment of Survivor Concerns Fear of Recurrence questionnaire
3. The Warwick-Edinburgh Mental Well-being Scale
4. FACT B
5. Blank page at the back asking about patient journey

Questionnaire relevance, booklet completion time and any other information

QoL: Distress Thermometer (1)

HIGH
DISTRESS



THERMOMETER

NO
DISTRESS

RANKING	Physical Problems	RANKING	Practical Problems
	<input type="checkbox"/> My appearance <input type="checkbox"/> Bathing or dressing <input type="checkbox"/> Breathing difficulties <input type="checkbox"/> Passing urine <input type="checkbox"/> Constipation <input type="checkbox"/> Diarrhoea <input type="checkbox"/> Eating or appetite <input type="checkbox"/> Fatigue, exhaustion or extreme tiredness <input type="checkbox"/> Feeling swollen <input type="checkbox"/> High temperature or fever <input type="checkbox"/> Getting Around (e.g walking) <input type="checkbox"/> Indigestion <input type="checkbox"/> Sore or dry mouth <input type="checkbox"/> Nausea or vomiting <input type="checkbox"/> Pain <input type="checkbox"/> Dry, itchy or sore skin <input type="checkbox"/> Sleep problems and/or nightmares <input type="checkbox"/> Tingling in hands and/or feet <input type="checkbox"/> Changes in how things taste <input type="checkbox"/> Hot flushes <input type="checkbox"/> Memory or concentration <input type="checkbox"/> Speech problems <input type="checkbox"/> Wound care after surgery		<input type="checkbox"/> Caring responsibilities <input type="checkbox"/> Finance, work or housing <input type="checkbox"/> Transport or parking <input type="checkbox"/> Questions about my illness / treatment <input type="checkbox"/> Communications with NHS staff Family Problems <input type="checkbox"/> Relationship with my children <input type="checkbox"/> Relationship with my partner <input type="checkbox"/> Relationship with other relatives/friends Emotional Problems <input type="checkbox"/> Loneliness or isolation <input type="checkbox"/> Sadness or depression <input type="checkbox"/> Worry, fear or anxiety <input type="checkbox"/> Anger or frustration <input type="checkbox"/> Difficulty making plans <input type="checkbox"/> Guilt <input type="checkbox"/> Hopelessness <input type="checkbox"/> Sexual Concerns Spiritual/religious concerns <input type="checkbox"/> Loss of faith or other spiritual concern <input type="checkbox"/> Loss of meaning or purpose in life <input type="checkbox"/> Not being at peace with or feeling regret about the past

Other concerns (e.g. other medical conditions, etc)

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Distress Thermometer (2)

Score	Trial (%)	Cohort (%)	Total (%)
0 - 4	2730 (76)	315 (74)	3045 (75)
5-7	651 (18)	75 (17)	726 (18)
8-10	226 (6)	37 (9)	263 (7)
Total	3607	427	4034

Main Causes of distress	N (%)
Fatigue	528 (53)
Sleep	463 (47)
Worry, fear or anxiety	453 (46)
Memory/Concentration	379 (38)
Hot flushes	376 (38)
Pain	328 (33)

ICPV patient survey

2/3rds of patients in follow-up have unmet needs.

Common themes included:

- Feelings of abandonment
- Fear of recurrence
- Lack of confidence in recognising signs of possible recurrence
- Wanting more reassurance
- Wanting more advice on what to look for and how to deal with it

- Limitations with standard QoL scales used in clinical trials
- Mammo-50 patient focus groups reinforced importance of follow-up and need for continued contact with clinical team
- From the Distress thermometer:
 - 25% patients had raised levels of distress; 7% very high level
 - Fatigue, sleep, worry/fear, memory/concentration, hot flushes, pain
- ICPV survey – 66% patients report unmet needs;
37% want different follow-up
- Take home message – when asked, patients report things causing them distress but which may go unnoticed in routine follow-up

CIs:

Janet Dunn,

Peter Donnelly, Andy Evans

PPI & ICPV members:

Maggie Wilcox, Sophie Gasson

Radiologists:

Anthony Maxwell

Oncologists:

Peter Barrett-Lee, David Cameron

Statisticians:

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HE:

Claire Hulme, Peter Hall

Nursing:

Sue Hartup, Annie Young

Pathology

Sarah Pinder

Surgeons:

Adele Francis, Riccardo Audisio

Alistair Thompson

Qualitative:

Eila Watson

Come to instructional session at 11am