Offering informed choice about breast screening: the English experience

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Do women understand breast screening?

- A survey of 1000 women aged 49-64 (Webster & Austoker 2006)
  - 45% thought screening prevented breast cancer

- A survey of 5000 women across Europe (Gigerenzer et al, 2009)
  - 50% thought screening saved 50 lives per 1000 screened
  - 57% in UK, & 27% thought it saved 200 lives per 1000

- A survey of 895 Swiss women aged 40-80 (Chamot et al, 2001)
  - 80% thought screening prevented 25% of cancer deaths
What influences choice?
So far we have adopted two types of approach

**Be Screened**

**Analyse and Choose**
A third way........

Consider an offer
What do the public want?

- UK survey of 1964 adults aged 50-80 years
  - 47% preferred a strong recommendation
  - 37% a statement that the NHS recommends, but it is up to you
  - 16% wanted information with no recommendation

Waller et al, BJ Cancer 2012
What do the public want?

» UK survey of 1964 adults aged 50-80 years

- 82% trusted NHS to decide if a screening test was worthwhile
- Universal preference to receive all information on benefits & harms
- 87% said it was unethical not to inform about all possible risks of screening
- 29% did not need to know risks if research shows screening saves lives

Waller et al, BJ Cancer 2012
Consulting about how to develop cancer screening information

**Draft approach**

**Email circulation**
- Charities
- User forums
- Academics and citizens
- Screening services in England
- Cancer screening QA reference centres
- Cancer screening advisory committee members
- National Cancer Action Team
- Chairs of clinical commissioning groups
- National clinical leads for bowel, breast and gynaecological cancers
- The chief knowledge officer of the NHS
- The Department of Health

**Workshop with charities and patient organisations**

**Meeting with prominent critics of the breast screening leaflet**

**One-to-one meetings with:**
- Charity representatives
- Members of the cancer screening community
- Experts in informed choice and communicating with the public
85% of people want to receive a recommendation from the NHS when they are invited for cancer screening

88% of people said it should be up to them to make a decision about whether to have screening

94% want to understand the benefits and harms of cancer screening before making a decision

Consulting about how to develop cancer screening information

Draft approach

- Stakeholder feedback n=52
- 2 BME focus groups n=25
- Online opinion poll n=1085

Informed Choice about Cancer Screening

Integrated Cancer Centre
The way forward

We invite you for NHS breast screening on:

date, time, location, phone number

The NHS offers breast screening to save lives from breast cancer. Screening does this by finding breast cancers at an early stage when they are too small to see or feel.

Your choice

It is your choice whether or not to have breast screening. To help you make a decision we have enclosed a leaflet about the benefits and risks of breast screening and what it is like to have a breast screening test. The leaflet is written by an independent team of information experts.
Governance

Information production

» Has been in close collaboration with the NHS Cancer Screening Programmes
» Has been at arm’s length from the NHS Cancer Screening Programme to ensure impartiality
» Has been accountable to a new cancer screening information advisory committee to Public Health England & Department of Health
» Followed a rigorous & explicit editorial process, involving writers, editors, professionals in the screening programme & cognitive testing with women
Aimed at wide readership with scientific accuracy

Expansion of cancer care and control in countries of low and middle income: a call to action

Prof. Paul Farmer AO, MD, Dr. Felicia A. Hidalgo, PhD, Lawrence M. Shulman, MD, Michael A. V. Pettersson, MD, Lance Armstrong, MD, Prof. Alireza Amiri, MD, Shahram Alizadeh, MD, Lindis C. Chai, MD, Prof. Anthony Figg, MD, Dr. S. Colin Godbold, MD
How to present the benefits & harms data generated by the Independent Review of Breast Screening: recommendations from a Citizen’s Jury

» Express benefits & harms in terms of women attending rather than invited to screening
» Express benefits and harms alongside one another
» Use term risks NOT harms
» Use term overtreatment to overdiagnosis
» Include basic information on DCIS
» Use icon arrays with people, not bar or pie charts
» Acknowledge uncertainty, but unsure how to do this
Making a choice – the possible benefits and risks of breast screening

It is your choice whether or not you have breast screening. There are many different reasons why women decide whether or not to have screening. To help you decide, we’ve included information on the possible benefits and risks.
Benefits

Screening saves lives from breast cancer
These lives are saved because cancers are diagnosed and treated earlier than they would have been without screening.
Harms

Screening finds breast cancers that would never have caused a woman harm
Some women will be diagnosed and treated for breast cancer that would never otherwise have been found and would not have become life-threatening. This is the main risk of screening.

Doctors cannot always tell whether a breast cancer that is diagnosed will go on to be life-threatening or not, so they offer treatment to all women with breast cancer. This means that some women are offered treatment that they do not need.
Weighing up the possible benefits and risks of breast screening

Breast screening could save my life from breast cancer

Breast screening could mean that I am diagnosed and treated for a cancer that would never have become life-threatening
Uncertainty

There is debate about how many lives are saved by breast screening and how many women are diagnosed with cancers that would never have become life-threatening. The numbers on the next page are the best estimates from a group of experts who have reviewed the evidence.
Numbers

Overall, for every 1 woman who has her life saved from breast cancer, about 3 women are diagnosed with a cancer that would never have become life-threatening.
More Numbers

Saving lives from breast cancer
» Screening saves about 1 life from breast cancer for every 200 women who are screened. This adds up to about 1,300 lives saved from breast cancer each year in the UK.

Finding cancers that would never have caused a woman harm
» About 3 in every 200 women screened every 3 years from the age of 50 to 70 are diagnosed with a cancer that would never have been found without screening and would never have become life-threatening. This adds up to about 4,000 women each year in the UK who are offered treatment they did not need.
Tackling overdiagnosis

Researchers are trying to find better ways to tell which women have breast cancers that will be life-threatening and which women have cancers that will not.
If a group of 200 women all have breast screening, every 3 years from the age of 50 to 70, then by the time they are 80...

15 are diagnosed with breast cancer.

8 are diagnosed and survive. They would have survived without screening.

1 has her life saved from breast cancer. She would have died without screening.

3 are diagnosed with cancer that would never have become life-threatening.

3 die of breast cancer even though they were screened.
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