

# Offering informed choice about breast screening: the English experience

Professor Amanda J Ramirez

*Director*

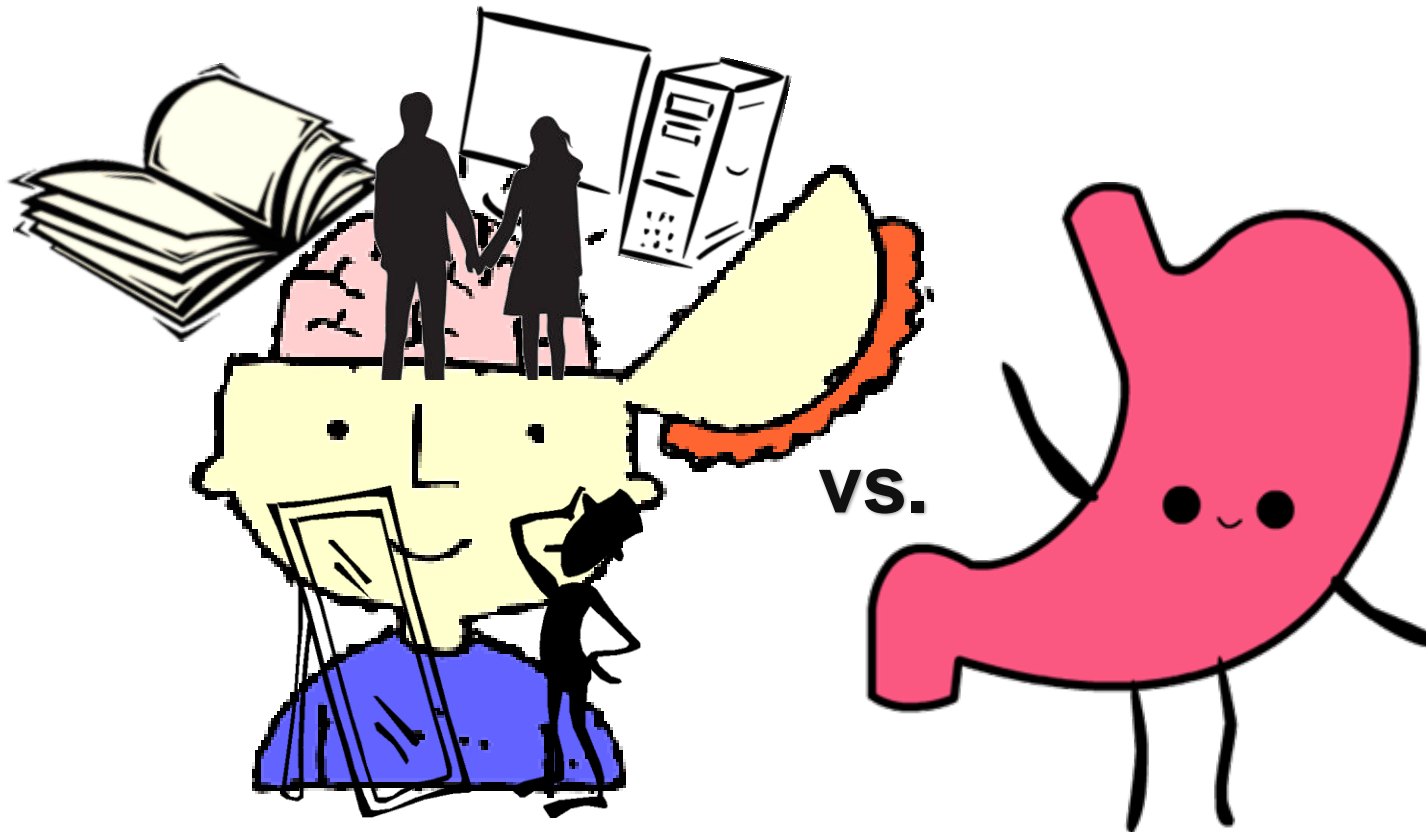
*Informed Choice about Cancer Screening & Promoting Early Presentation  
Group*

*King's Health Partners*

# 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



# 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

- » 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

# 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.

We invite you for NHS

date, time,

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.

Women aged 50 to 70 are invited to have breast screening every three years. [Some women aged 47 to 49 and over 70 are also being invited, as part of a study of screening older and younger women. Please see the enclosed leaflet *Extending the screening age range*, for more details.]

## 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.

If you have any questions about what breast screening involves, please phone the breast screening unit. If you would like help in deciding whether to have breast screening, please

## What happens

If you choose to have breast screening, you will be appointed to a breast screening unit. You will be asked to have a breast screening test. The leaflet is written by an independent team of information experts.

If you decide not to have breast screening, the breast screening unit will know your decision.

Yours sincerely

## 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

## THE LANCET

Search for  in All Fields  [Advanced](#)

[Home](#) | [Journals](#) | [Collections](#) | [Audio](#) | [Conferences](#) | [Education](#) | [Resource Centres](#) | [For Authors](#) | [About Us](#) | [Subscr](#)

The Lancet, Early Online Publication, 16 August 2010

doi:10.1016/S0140-6736(10)61152-X [Cite or Link Using DOI](#)

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

Prof Paul Farmer MD<sup>a</sup>, Julio Frenk MD<sup>b</sup>, Dr Felicia M Knaul PhD<sup>c</sup>, Lawrence N Shulman MD<sup>d</sup>, Josep-Alfonso Alleyne MD<sup>e</sup>, Lance Armstrong<sup>f</sup>, Prof Rifat Atun FFPHM<sup>g</sup>, Douglas Blayney MD<sup>h</sup>, Lincoln Chen MD<sup>i</sup>, Prof Richard Foa<sup>j</sup>, Henry Gospodarowicz<sup>k</sup>, Prof Robert Hogg<sup>l</sup>, Prof John Hens<sup>m</sup>, Prof John Hens<sup>n</sup>, Prof John Hens<sup>o</sup>, Prof John Hens<sup>p</sup>, Prof John Hens<sup>q</sup>, Prof John Hens<sup>r</sup>, Prof John Hens<sup>s</sup>, Prof John Hens<sup>t</sup>, Prof John Hens<sup>u</sup>, Prof John Hens<sup>v</sup>, Prof John Hens<sup>w</sup>, Prof John Hens<sup>x</sup>, Prof John Hens<sup>y</sup>, Prof John Hens<sup>z</sup>

**Scientific  
accuracy**

of the disease on human suffering. We challenge the public health community's assumption that... remain untreated in poor countries, and note the analogy to similarly unfounded arguments from more than a decade... against provision of HIV treatment. In resource-constrained countries without specialised services, experience has shown that much can be done to prevent and treat cancer by deployment of primary and secondary caregivers, use of off-patent drugs, and application of regional and global mechanisms for financing and procurement. Furthermore, several middle-income countries have included cancer treatment in national health insurance coverage with a focus on people living in poverty. These strategies can reduce costs, increase access to health services, and strengthen health systems to meet the challenge of cancer and other diseases. In 2009, we formed the Global Task Force on Expanded Access to Cancer Care and Control in Developing Countries, which is composed of leaders from the global health and cancer care communities, and is dedicated to proposal, implementation, and evaluation of strategies to advance this agenda.



**Readership**

## 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.

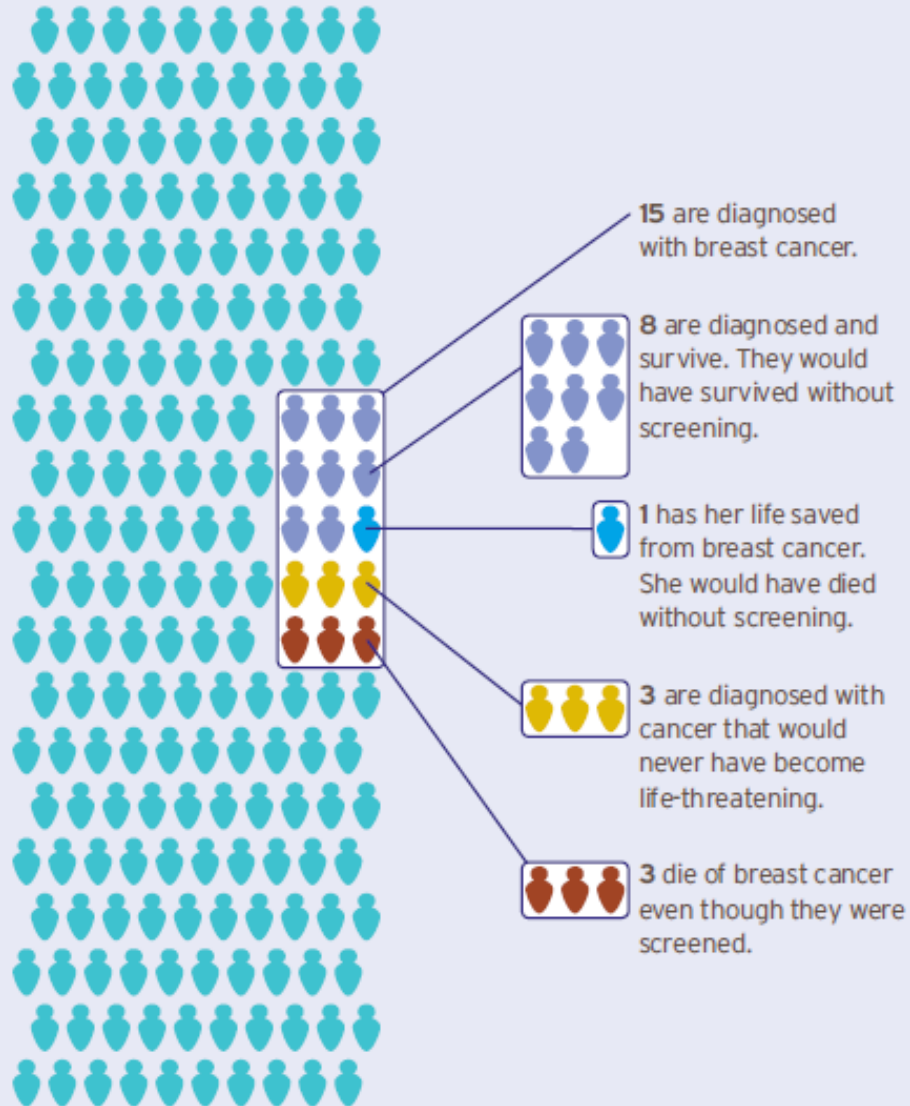
## **Finding cancers that would never have caused a woman harm**

- » 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...



# Acknowledgements

## In consultation with

- » NHS Cancer Screening Programmes
- » Cancer Charities
- » Experts in risk communication, patient & public involvement, cancer screening:
  - *Prof Angela Coulter*
  - *Prof Vikki Entwistle*
  - *Prof David Spiegelhalter*
- » Cancer Screening Advisory Committees



# Acknowledgements

## The Informed Choice about Cancer Screening Team

**Professor Amanda J Ramirez**, Director

**Dr Lindsay J Forbes**, Co-Director

**Louise Smith**, Programme Manager

**Elliann Fairbairn**, Project Manager

**Charlotte Blackmore**, Researcher

**Aradhna Kaushal**, Researcher

**Devon Spika**, Researcher

**Mary Ohene**, Administrator