

How can we offer choice about cancer screening?

Professor Amanda J Ramirez

Director

Informed Choice about Cancer Screening & Promoting Early Presentation Group

King's Health Partners

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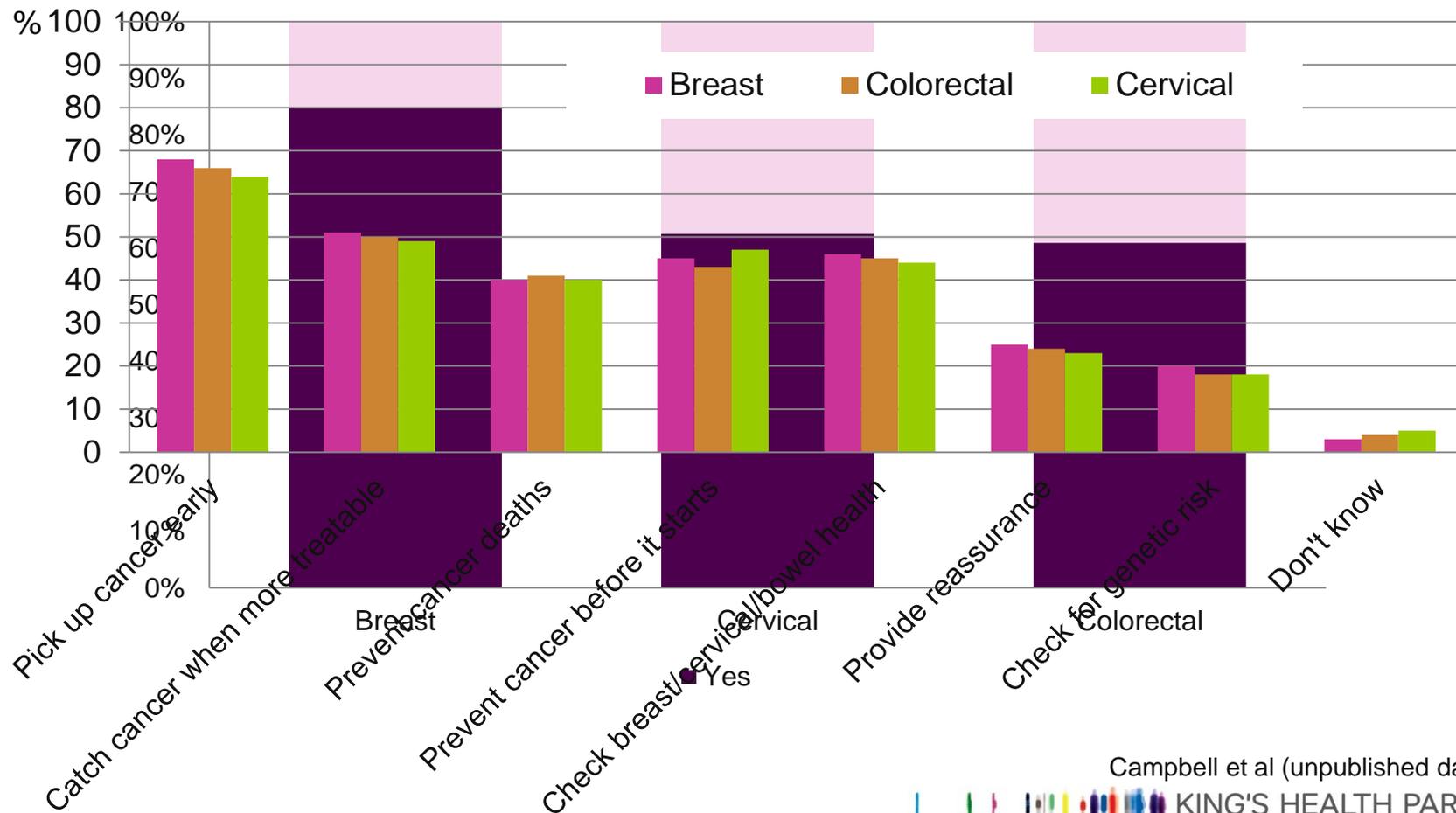
National Clinical Lead for Cancer Patient Information

Public attitude to cancer screening

- » Highly favourable, particularly within age groups eligible for screening
- » Believe cancer screening services should be provided by the National Health Service
- » But the many barriers reflected in screening participation rates

What do the public understand about cancer screening?

Awareness of the NHS and the UK's Other Cancer Screening Programmes



Campbell et al (unpublished data)

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

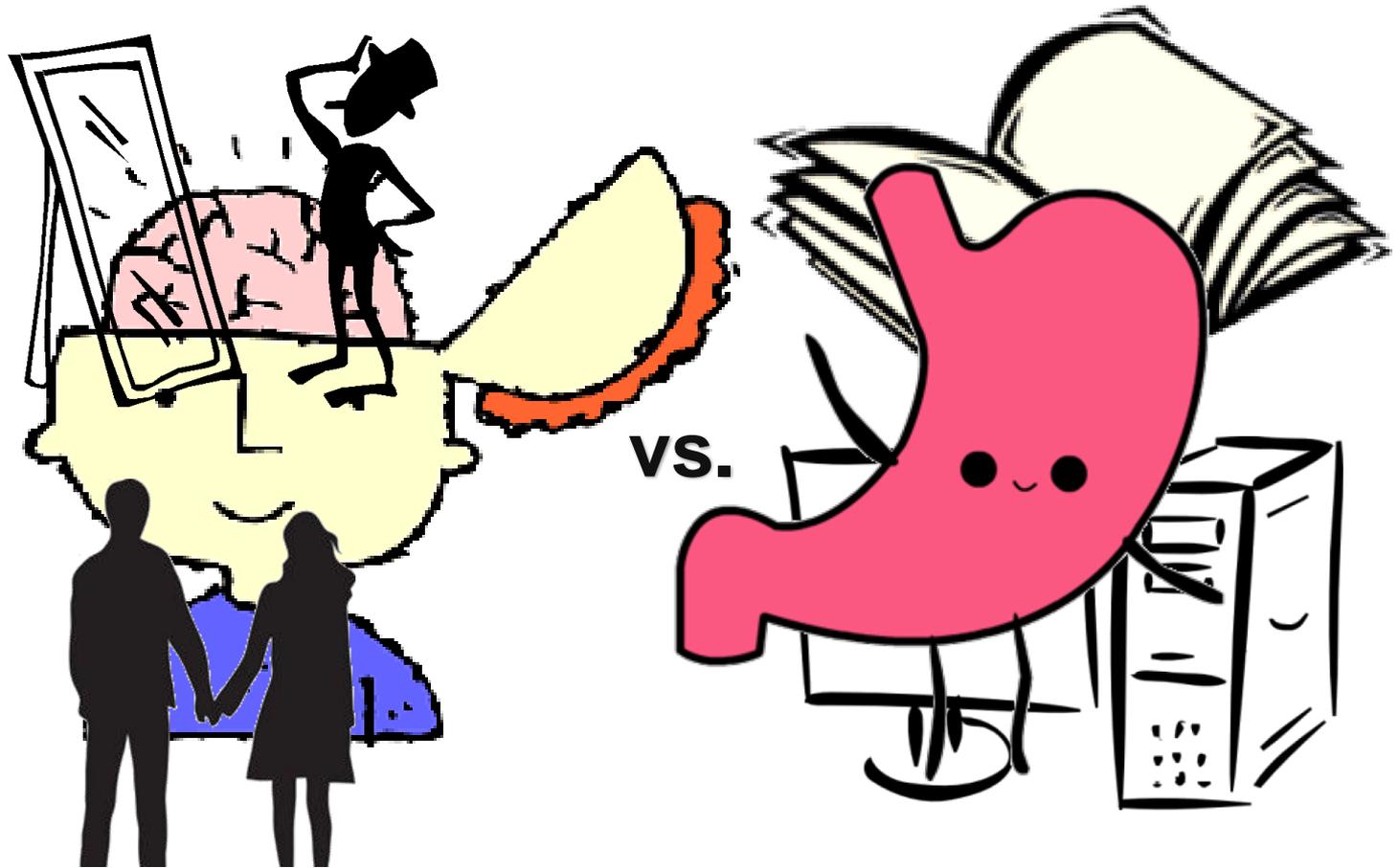
- » A survey of 895 Swiss women aged 40-80 (*Chamet et al, 2001*)
 - 80% thought screening prevented 25% of cancer deaths

Why women go for breast screening

Enthusiasm for testing	<p>I feel that it is very important whether you are 30 or...80 [that] you have any tests that you can.</p> <p>I do know that an intelligent person needs the tests routinely, just to make sure everything is cool.</p>
Value of reassurance	<p>[The] greatest benefit is learning you don't have cancer.</p> <p>It makes you really happy when you get that piece of paper that says you don't have anything</p>
Attitudes to risk	<p>If someone objected to having it done, why they're taking their own life in their hands I guess.</p> <p>Even if statistical risk [of getting breast cancer] is low I still want screening, there is still a chance.</p> <p>Better to be safe than sorry.</p>
Trust vs. scepticism	<p>It must be really good, otherwise they wouldn't have it.</p> <p>I interpret it that they're lying, pure and simple, [when they say] that it's not useful.</p> <p>If the experts can't agree, it's worth doing a screening.</p>
Perceptions of sensitivity	<p>...whereas mammography, you know nothing was missed.</p> <p>I always wondered if something could have been missed...</p>

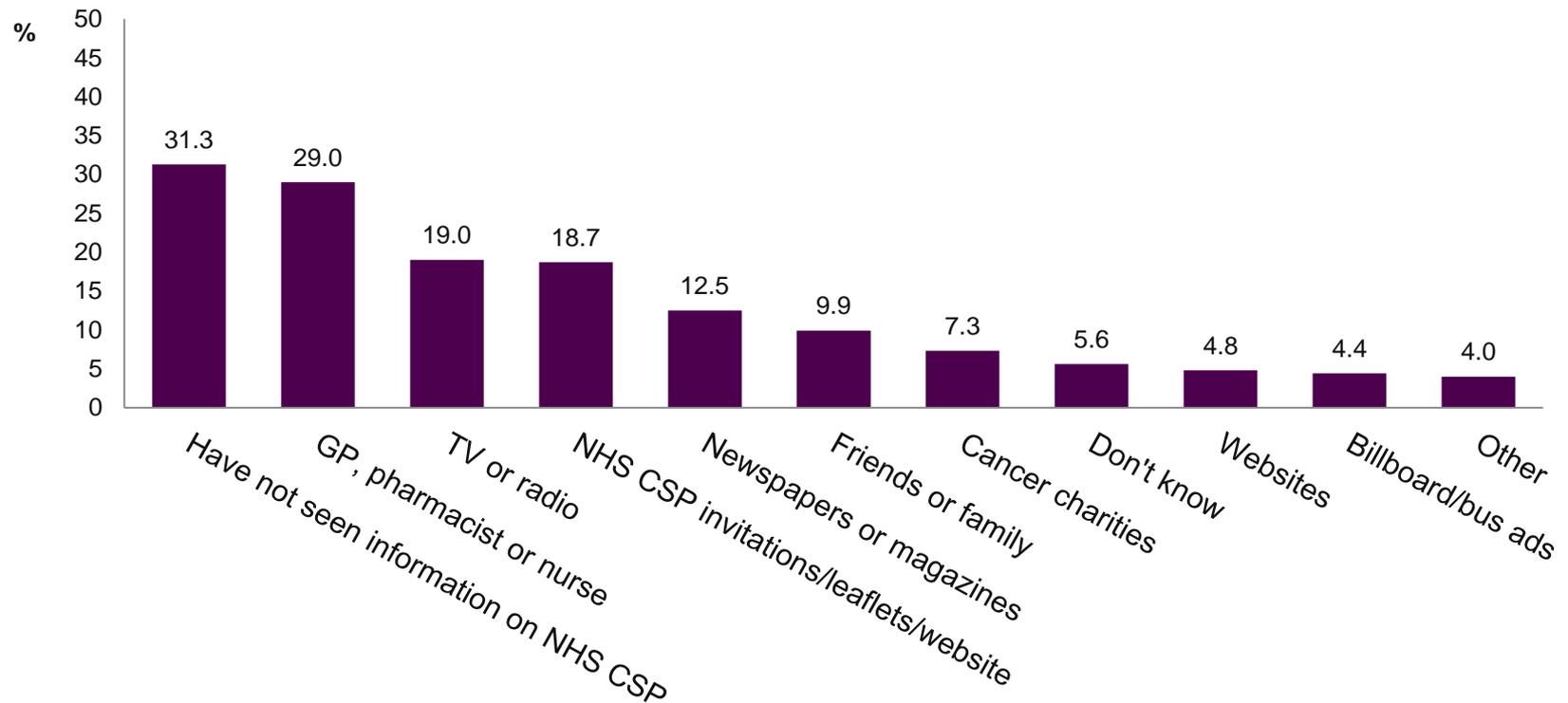
Hersch et al (2011)

What influences choice?



Where do people get information on cancer screening?

Sources of information about NHS Cancer Screening Programmes in the last 2 years



Campbell et al (unpublished data)

So far we have adopted two types of approach

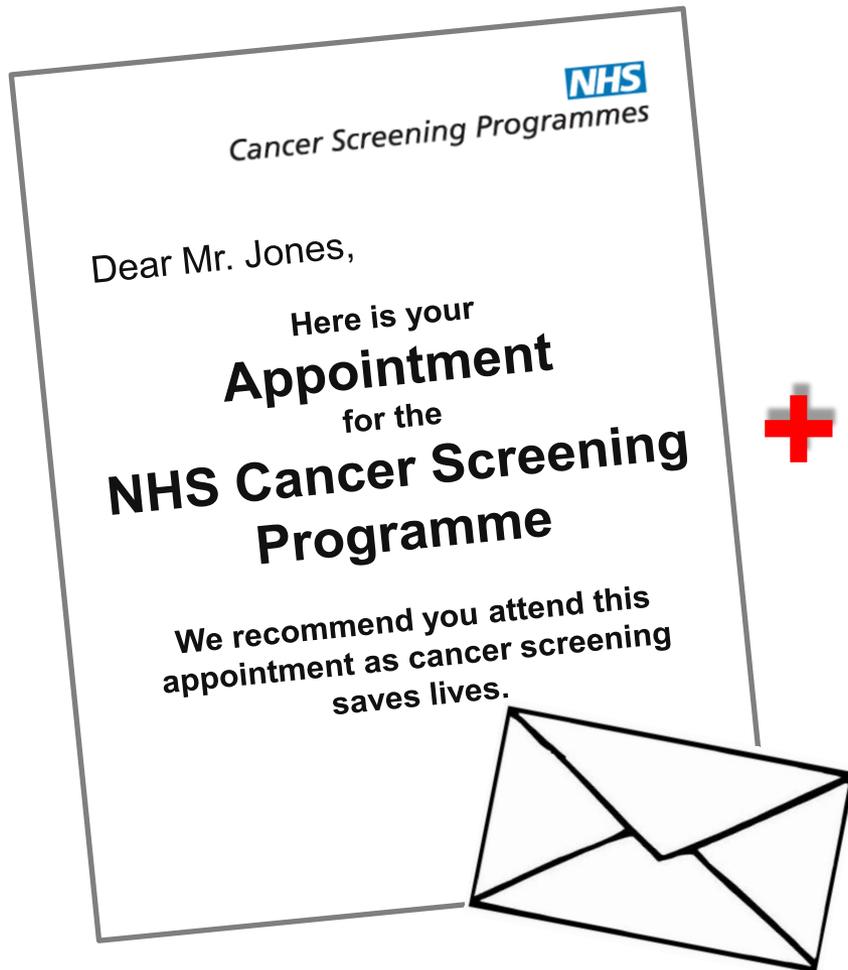
Be Screened



Analyse and Choose



A third way.....Consider an offer?



Choice

What do the public want?

- » UK survey of 2067 adults aged 50-80 years
 - 44% preferred a strong recommendation
 - 36% a statement that the NHS recommends, but it is up to you
 - 15% wanted information with no recommendation
 - 4% don't know

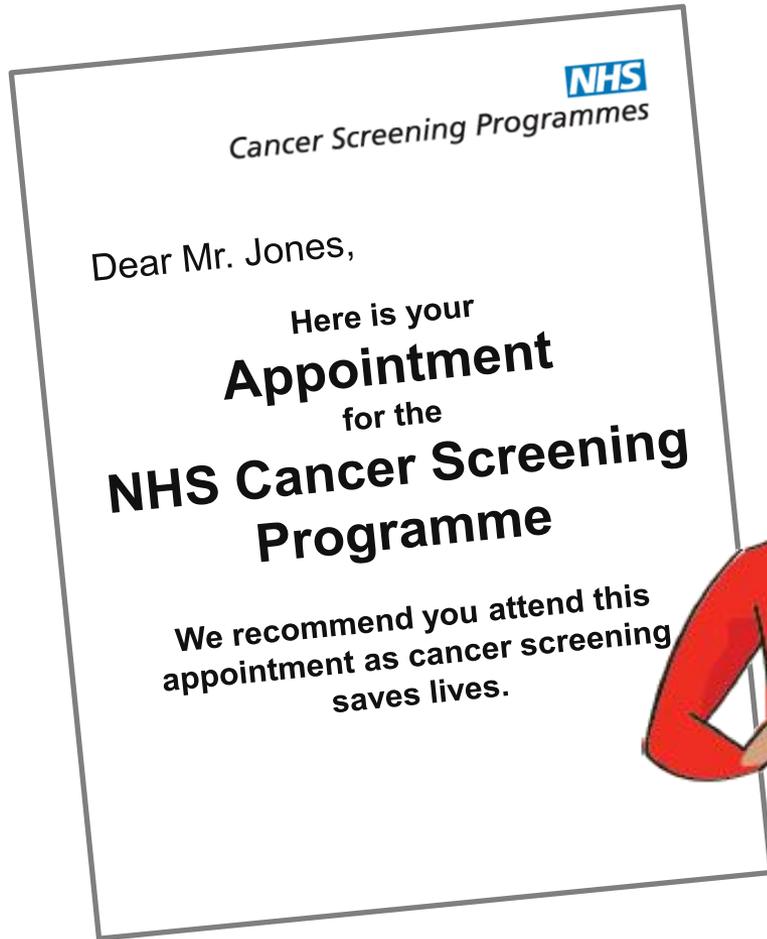
Campbell et al (unpublished data)

What do the public want?

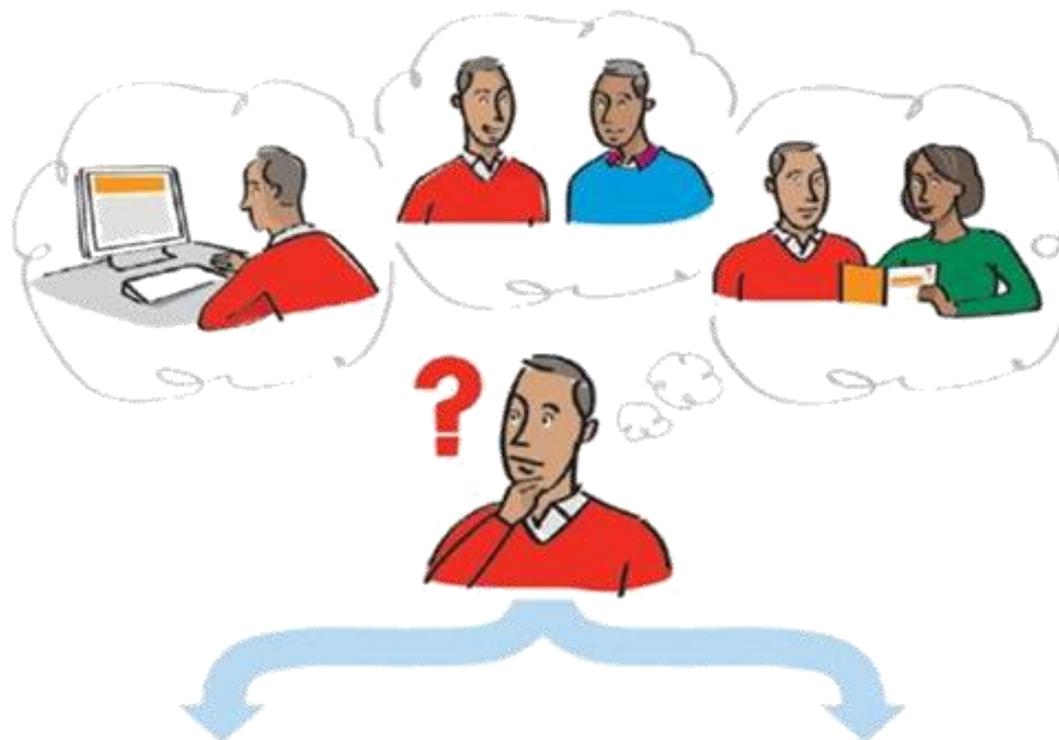
- » UK survey of 2067 adults aged 50-80 years
 - 79% trusted NHS to decide if a screening test was worthwhile
 - Universal preference to receive all information on benefits & harms
 - 87% said it was unethical not to inform about all possible risks of screening
 - 29% did not need to know risks if research shows screening saves lives

Campbell et al (unpublished data)

A way forward?



Deciding whether or not to have screening



**Choose to have
Screening**

**Choose not to have
Screening**

Aimed at wide readership with scientific accuracy

THE LANCET

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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 ^a, Julio Frenk MD ^b, Dr Felicia M Knaul PhD ^c, Lawrence N Shulman MD ^d, ...

Ar ... podarowicz

MD ...

HR ...

Se ...

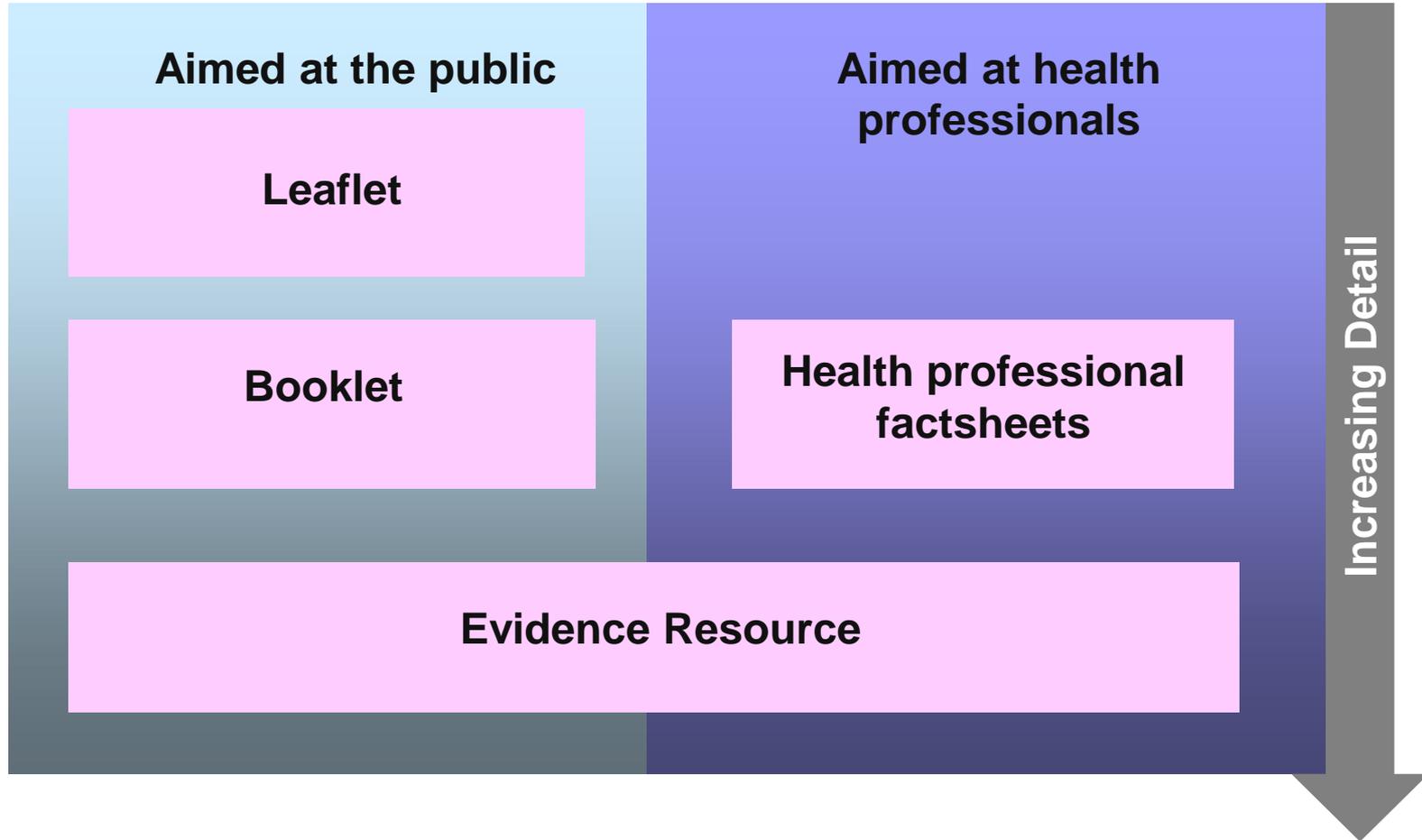
Su ...

Scientific accuracy

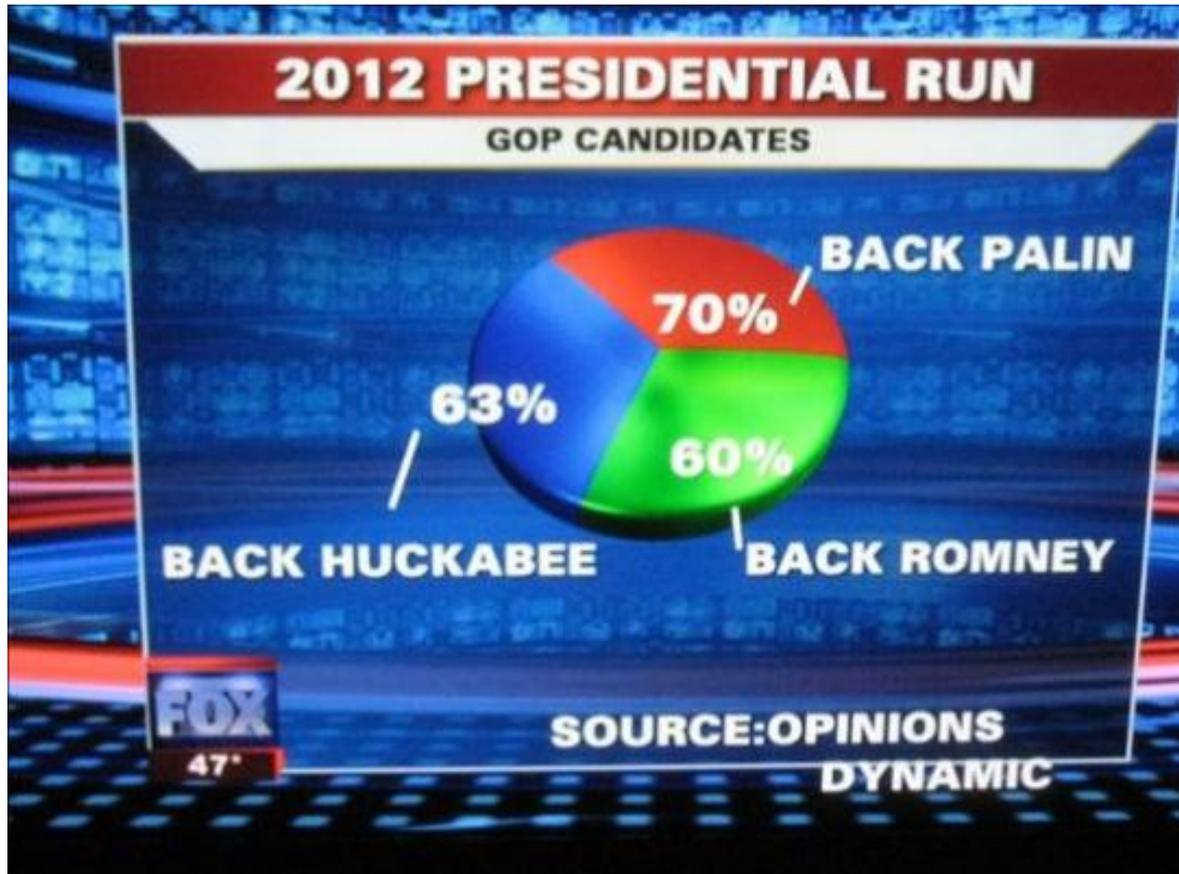


Readership

Levels of Information

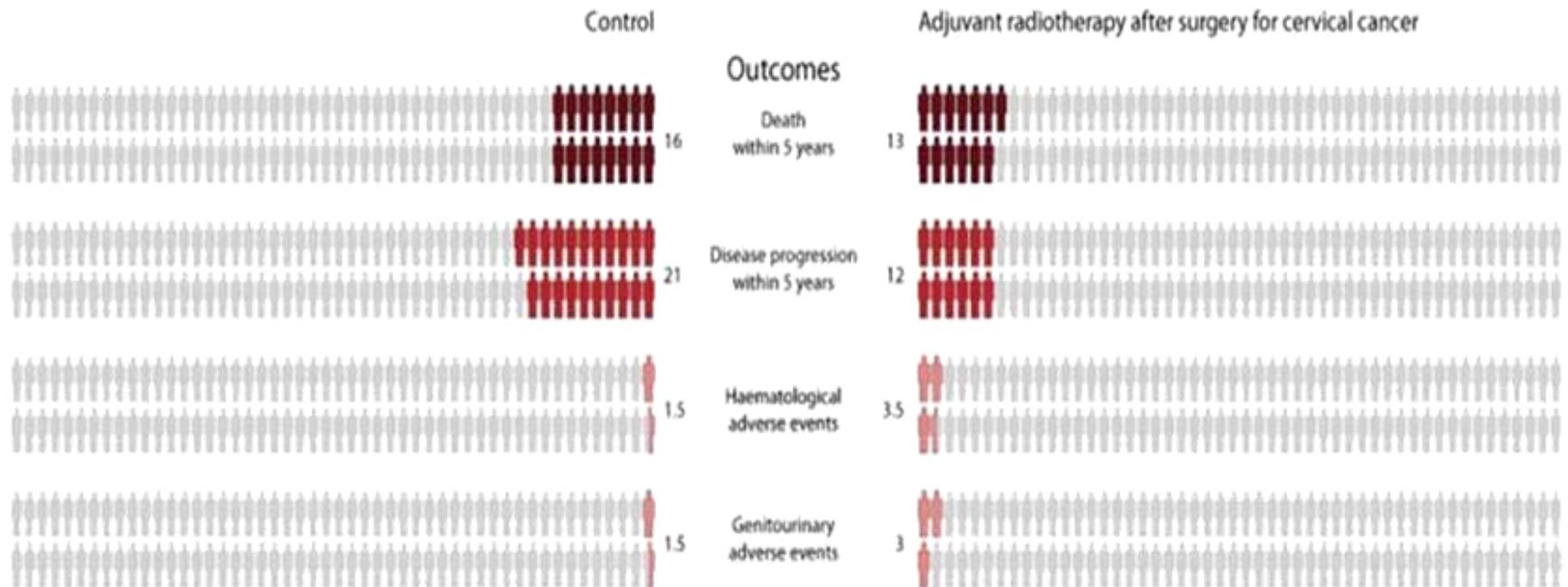


Visualizing data



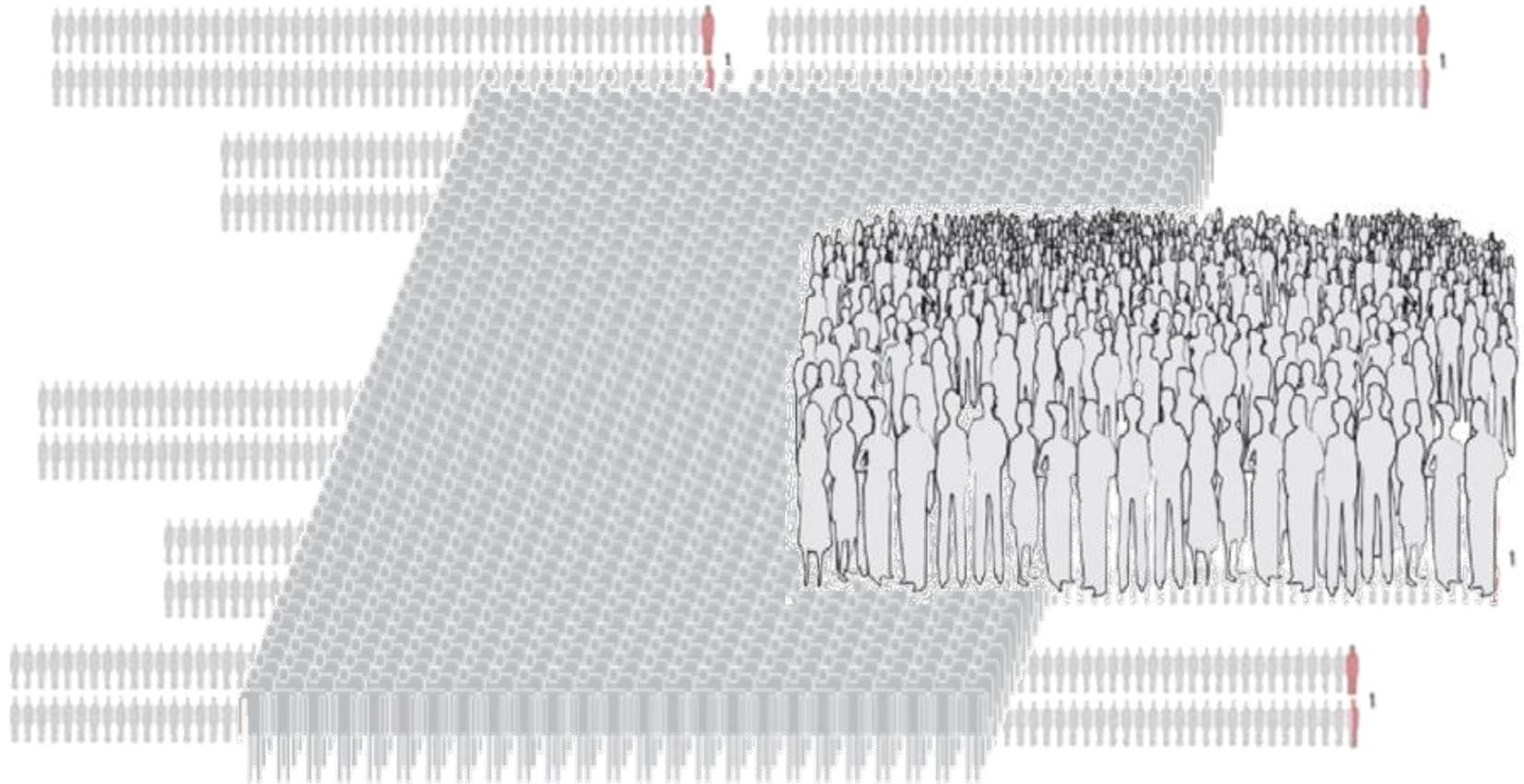
Communicating benefits & harms

Benefits & harms of radiotherapy in management of cervical cancer

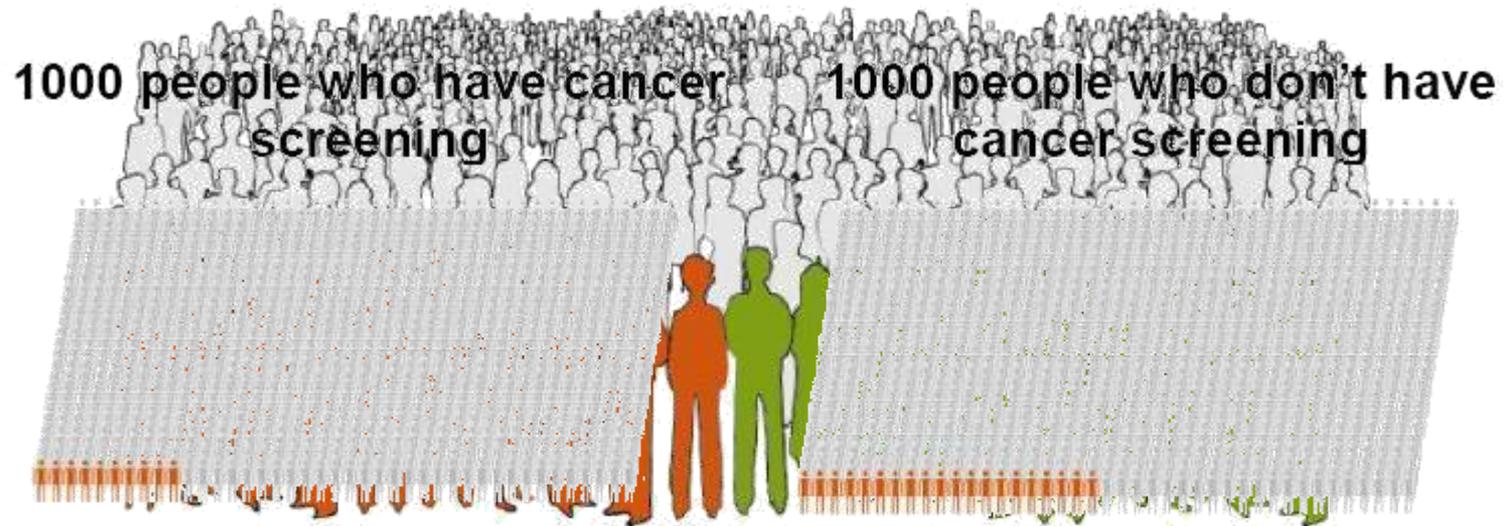


Spiegelhalter D et al, Science, 2011

Representing the Denominator

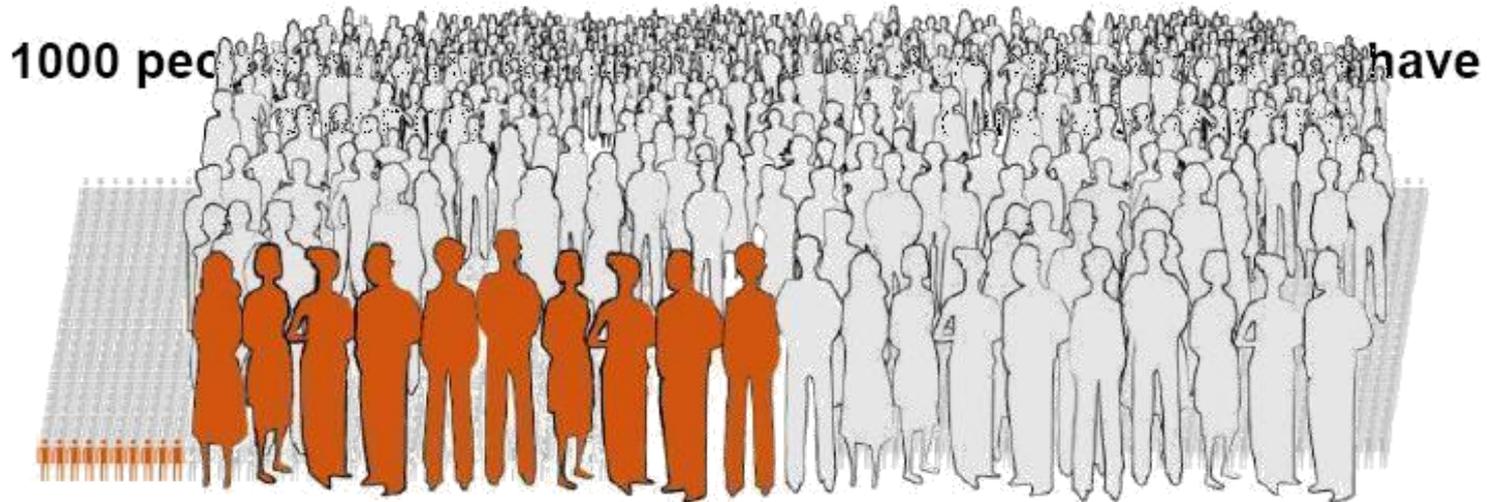


Communicating benefits



All these 1000 people had cancer screening. The orange people will die of the cancer. The green people are those who avoided dying of the cancer because they had screening.

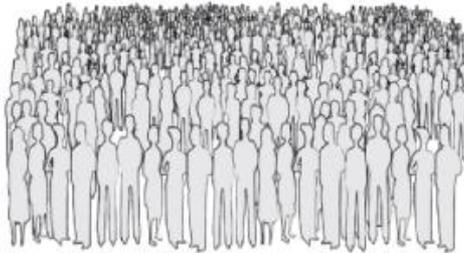
Communicating harms



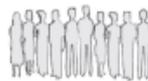
All these 1000 people had cancer screening. People in orange are those who will receive treatment for a slow growing cancer that may never cause any symptoms or shorten your life. This treatment could include surgery, chemotherapy and/or radiotherapy.

Communicating benefits

This is a crowd of 1000 people.

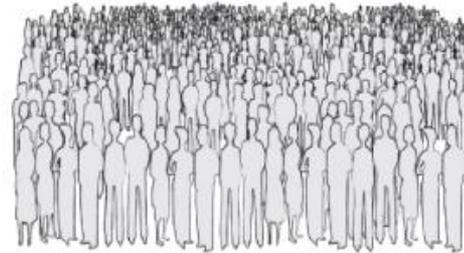


If everyone in this crowd
decided to go for cancer
screening...



...10 will die of cancer.

This is a crowd of 1000 people.



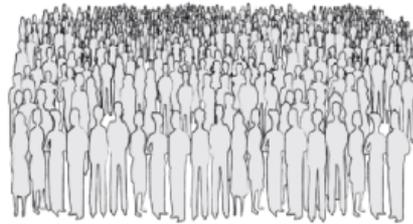
If everyone in this crowd
decided not to go for cancer
screening...



...20 will die of cancer.

Communicating harms

This is a crowd of 1000 people.



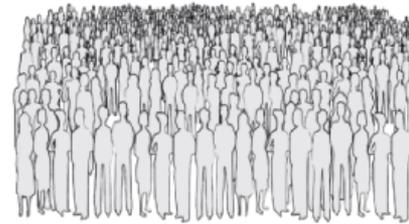
If everyone from this crowd
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screening...



... 10 will receive treatment for a slow
growing cancer that may never cause
any symptoms or shorten your life.

This treatment could include surgery,
chemotherapy and/or radiotherapy.

This is a crowd of 1000 people.



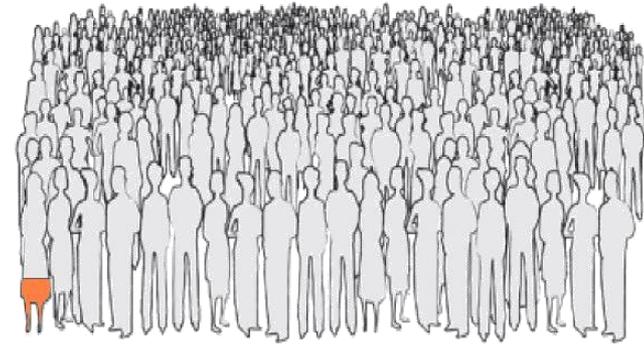
If everyone from this crowd
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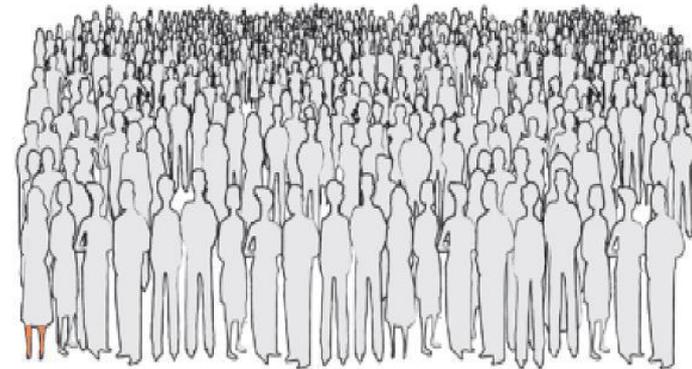
...no one would receive such
treatment.

How do we show very rare events?

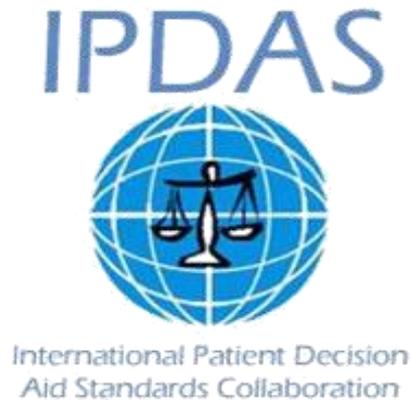
For every 1000 people who are screened for bowel cancer with flexible sigmoidoscopy, 0.3 will have bleeding needing hospital treatment.



For every 1000 people who are screened for bowel cancer with flexible sigmoidoscopy, 0.03 will have their bowel torn.



Commitment to quality



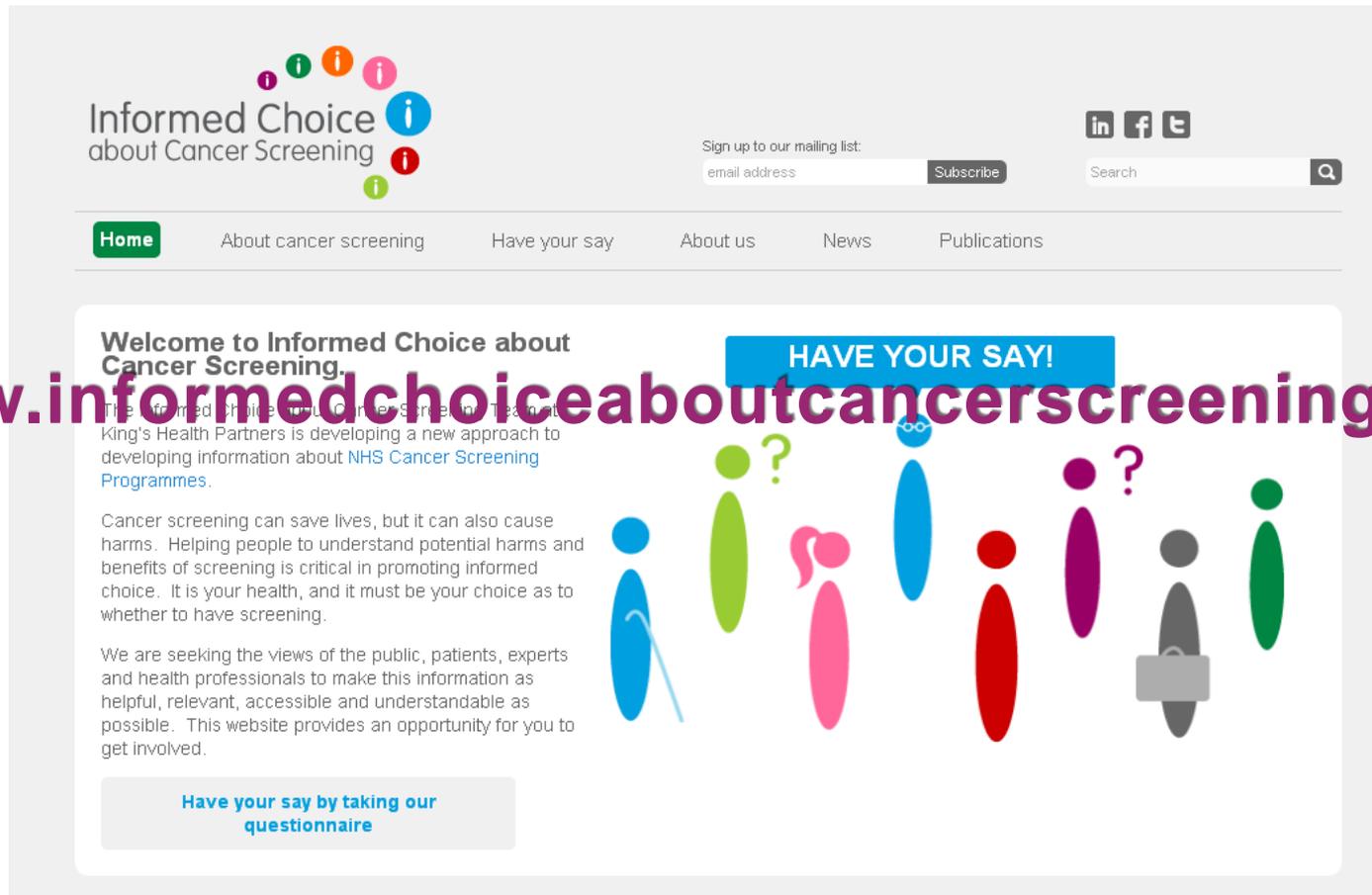
Supported & shared decision-making



Most important...

- » Citizens will be involved in developing and testing
- » Rigorous evaluation

Consulting on Informed Choice about Cancer Screening



The screenshot shows the homepage of the website. At the top left is the logo with the text "Informed Choice about Cancer Screening". To the right are social media icons for LinkedIn, Facebook, and Twitter, and a search bar. Below the header is a navigation menu with links: Home, About cancer screening, Have your say, About us, News, and Publications. The main content area features a large blue button that says "HAVE YOUR SAY!". Below this button is an illustration of seven stylized human figures in various colors (blue, green, pink, red, purple, grey, green), with question marks above some of them. To the left of the illustration is a text block that reads: "Welcome to Informed Choice about Cancer Screening. The Informed Choice about Cancer Screening Team at King's Health Partners is developing a new approach to developing information about NHS Cancer Screening Programmes. Cancer screening can save lives, but it can also cause harms. Helping people to understand potential harms and benefits of screening is critical in promoting informed choice. It is your health, and it must be your choice as to whether to have screening. We are seeking the views of the public, patients, experts and health professionals to make this information as helpful, relevant, accessible and understandable as possible. This website provides an opportunity for you to get involved." At the bottom of this text block is a button that says "Have your say by taking our questionnaire".

www.informedchoiceaboutcancerscreening.org

Acknowledgements

The Informed Choice about Cancer Screening Team

Professor Amanda J Ramirez, Director

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Mary Ohene, Administrator

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



Process

- » Setting up an expert group
- » Assembling the evidence
- » Developing the leaflets
- » Testing the leaflets
- » Developing the booklets
- » Developing & testing the fact sheets
- » Obtaining agreement from a DH Screening Information Advisory Committees
- » Evaluating the information

Information alongside a recommendation: evidence for potency



Communicating deeper uncertainties