The Centre for
Evidence and
Values in
Healthcare
Helping people make better decisions in healthcare

Report of the Second Edition of the Centre of Evidence and Values in Healthcare

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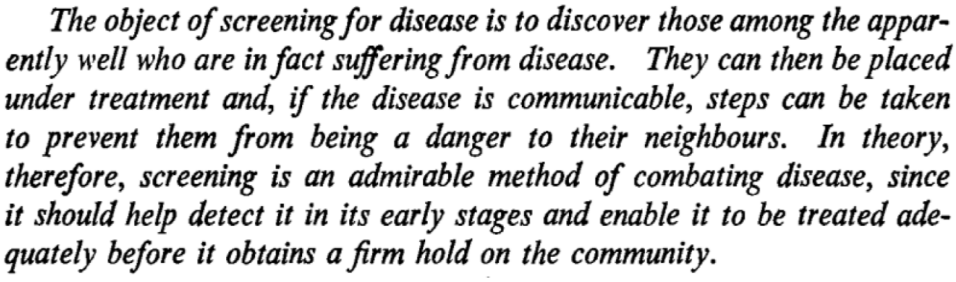
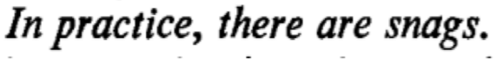
Screening - it's complicated. The science, evidence and practice of screening for disease

The second meeting of the Centre for Evidence and Values in healthcare (CEVH) was on the 5/2/26, in Parliament Hall, St Andrews. It may have been a miserably cold and damp day outside - but inside, the sold-out event was buzzing. Thank you for coming - the mixture of healthcare professionals from primary and secondary care, patients and lay people, academics, policymakers, students, philosophers, people working in the charity sector and government advisors made the event rich with perspectives, passion, knowledge and experiences. I introduced the day with thinking about what screening is and is not, by using a quote from the classic text from Wilson and Jungner : essentially, it is testing people who are well, or who believe themselves to be well. The idea is that this will improve peoples' health. This can be true - but it can also not be true. Good quality screening aims to ensure that the overall balance is beneficial.

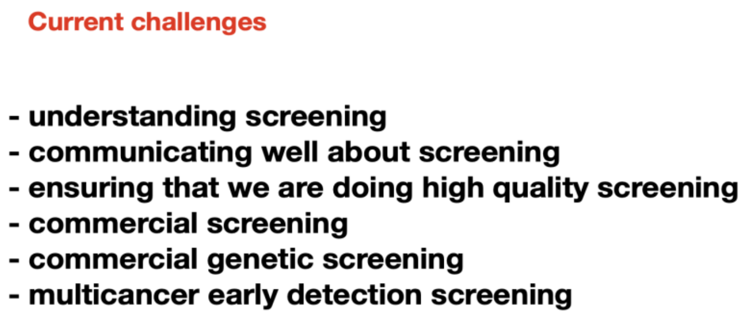


The object of screening for disease is to discover those among the apparently well who are in fact suffering from disease. They can then be placed under treatment and, if the disease is communicable, steps can be taken to prevent them from being a danger to their neighbours. In theory, therefore, screening is an admirable method of combating disease, since it should help detect it in its early stages and enable it to be treated adequately before it obtains a firm hold on the community.



In practice, there are snags.

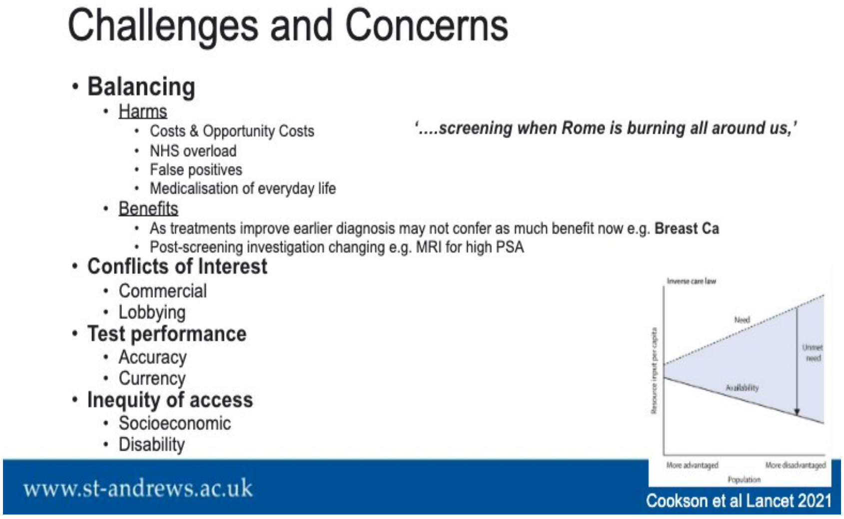
GPs, like me, are in the middle of a maelstrom. With the rise in the available direct to consumer testing, and pressure on citizens to speak to their GP about screening which isn't routinely offered on the NHS, I thought we had a lot to contend with. And of course, every consultation or test that is taken up by something that doesn't help people is an opportunity cost - it can't be used elsewhere for something that does help.



Current challenges

- understanding screening
- communicating well about screening
- ensuring that we are doing high quality screening
- commercial screening
- commercial genetic screening
- multicancer early detection screening

Before the meeting, we asked people what their biggest concerns were - which were wide, given the wide variety of people in the room, Professor Frank Sullivan summarised these, explaining how the balance and risks of screening over time may change - for example, as treatments for cancers get better, this could mean either that finding people before they developed symptoms could be more important (because earlier treatment would be beneficial) or less important (if treatment at a later stage is as good as earlier intervention). Evidence matters. And we were brought into a clear, real-world focus with a delegate asking us whether screening should even be a priority as the NHS is "burning all around us".



Challenges and Concerns

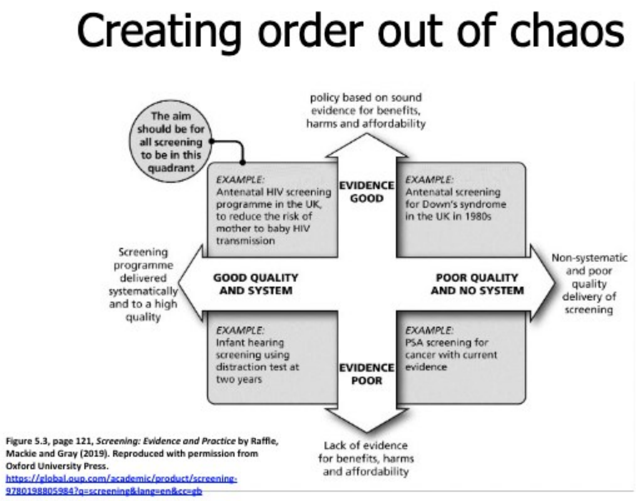
- **Balancing**
  - Harms
    - Costs & Opportunity Costs
    - NHS overload
    - False positives
    - Medicalisation of everyday life
  - Benefits
    - As treatments improve earlier diagnosis may not confer as much benefit now e.g. **Breast Ca**
    - Post-screening investigation changing e.g. MRI for high PSA
- **Conflicts of Interest**
  - Commercial
  - Lobbying
- **Test performance**
  - Accuracy
  - Currency
- **Inequity of access**
  - Socioeconomic
  - Disability

'....screening when Rome is burning all around us,'

Cookson et al Lancet 2021

www.st-andrews.ac.uk

This was followed by Dr Angela Raffle's keynote talk. She described her career and the "chaos" that screening for cervical cancer in the UK was in when she was a registrar in the 1980s. Different health boards were doing different things - testing women at variable intervals, with no quality assurance, and recall systems were ineffective and messy. She described how she worked with Sir Muir Gray to establish the UK National Screening Committee, and make cervical screening not just a test but a programme. This illustrated two major themes of the day: first, that an effective screening was not just about doing a test. Instead, good quality screening is about giving people good quality information, effective choice, high quality tests, delivery of results and actions as needed. In other words, it should be a programme, and one that is evidenced, organised and managed properly.



Creating order out of chaos

policy based on sound evidence for benefits, harms and affordability

The aim should be for all screening to be in this quadrant

EXAMPLE: Antenatal HIV screening programme in the UK, to reduce the risk of mother to baby HIV transmission

EVIDENCE GOOD

EXAMPLE: Antenatal screening for Down's syndrome in the UK in 1980s

Screening programme delivered systematically and to a high quality

GOOD QUALITY AND SYSTEM

POOR QUALITY AND NO SYSTEM

Non-systematic and poor quality delivery of screening

EXAMPLE: Infant hearing screening using distraction test at two years

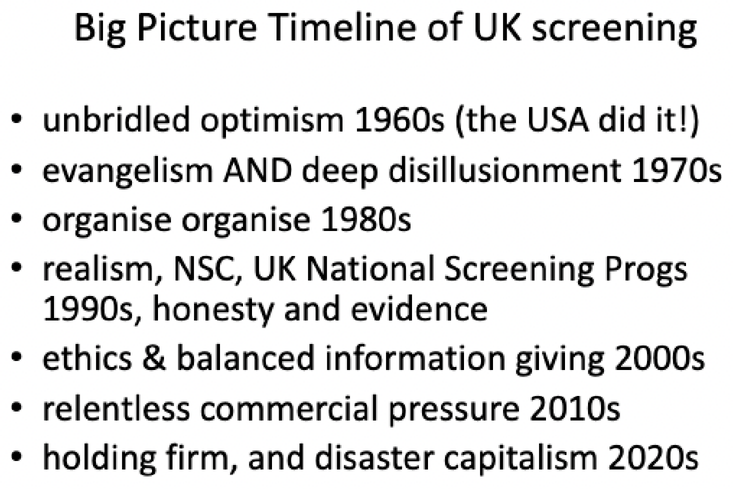
EVIDENCE POOR

EXAMPLE: PSA screening for cancer with current evidence

Lack of evidence for benefits, harms and affordability

Figure 5.3, page 121, *Screening: Evidence and Practice* by Raffle, Mackie and Gray (2019). Reproduced with permission from Oxford University Press.
https://global.oup.com/academic/product/screening-9780198805984?q=screening&lang=en&cc=gb

And second, the UK National Screening Committee is essential to effective and rational screening. It ensures that screening is underpinned by evidence and is capable of doing more harm than good. Throughout the day, the respect people had for the difficult work the Committee does was evident. Dr Raffle also explained, very clearly, how actors with conflicts of interest have repeatedly attempted to subvert decision making in screening - and how we need to 'hold the line' in ensuring that what we do is evidence based, even though we may come under a great deal of pressure not to do so.

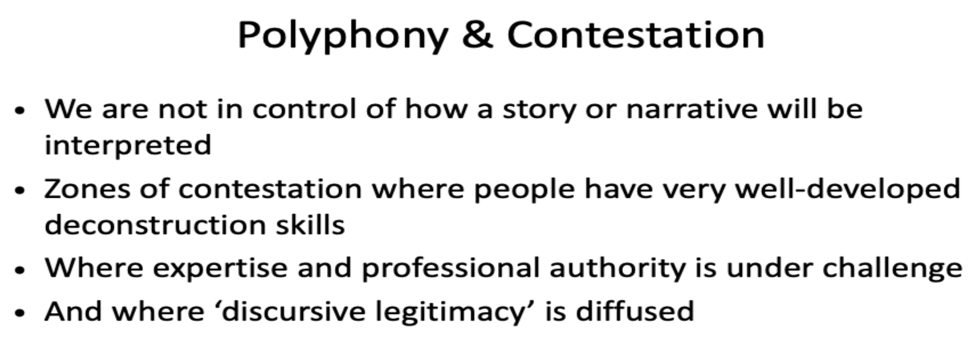


Big Picture Timeline of UK screening

- unbridled optimism 1960s (the USA did it!)
- evangelism AND deep disillusionment 1970s
- organise organise 1980s
- realism, NSC, UK National Screening Progs 1990s, honesty and evidence
- ethics & balanced information giving 2000s
- relentless commercial pressure 2010s
- holding firm, and disaster capitalism 2020s

After lunch, we heard from Professor Kevin Orr , one of the founders of the Centre. As Professor of Leadership and Governance, he talked about narratives of screening and how this is effectively a 'contested space' where scientific legitimacy is not always clear. For people trying to give evidence based arguments about what screening is and isn't useful, this illuminated why it can be so difficult;

public health expertise can be (despite best efforts) behind people who have a financial interest in bringing more screening to the public - and who are already in direct dialogue. He described the situation in California when the policy on legalising cannabis was being created, and the way that governance arrangements created channels for activism that meant that public health arguments didn't always break through. This was a brilliant insight into how we have to think of the best ways to helpfully inform people about the science of screening - story telling may be more effective.

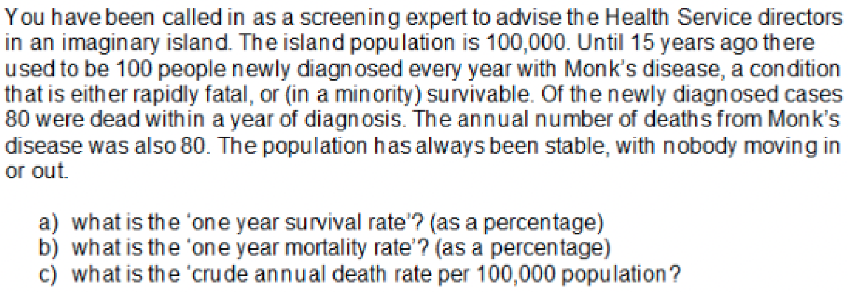


Polyphony & Contestation

- We are not in control of how a story or narrative will be interpreted
- Zones of contestation where people have very well-developed deconstruction skills
- Where expertise and professional authority is under challenge
- And where 'discursive legitimacy' is diffused

This was followed by a precis of all the statistics we needed to know: Robin Alexander, a medical statistician kindly came over from the School of Medicine, explaining perfectly the sometimes confusing terminology that many of us have been taught years ago (and have perhaps forgotten some/most of). This whistle-stop tour was a perfect update, reminder and explainer.

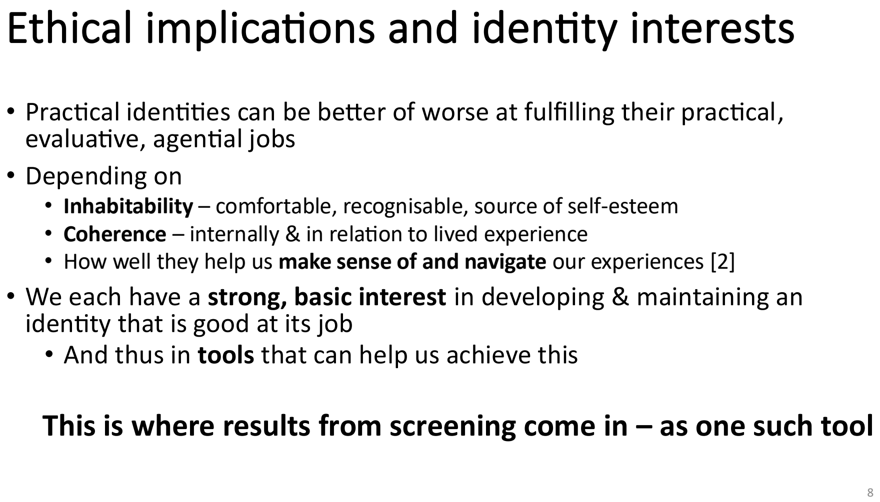
Next was a workshop hosted by Dr Raffle. We were put in the position of being public health officials, charged with making decisions about whether to introduce a new screening programme in our country. We were given data, questions to answer, and some help from Dr Raffle, as well as Drs Sam Warne, Emma Gale, and Katrin Metsis, resulting in a great debate at our tables, and feedback session.



You have been called in as a screening expert to advise the Health Service directors in an imaginary island. The island population is 100,000. Until 15 years ago there used to be 100 people newly diagnosed every year with Monk's disease, a condition that is either rapidly fatal, or (in a minority) survivable. Of the newly diagnosed cases 80 were dead within a year of diagnosis. The annual number of deaths from Monk's disease was also 80. The population has always been stable, with nobody moving in or out.

a) what is the 'one year survival rate'? (as a percentage)
b) what is the 'one year mortality rate'? (as a percentage)
c) what is the 'crude annual death rate per 100,000 population?

Dr Emily Postan, Reader and Chancellors' Fellow in Bioethics, University of Edinburgh then spoke. We were very grateful to her for coming to Fife and crossing the bridge! One of the most important things the Centre tries to do is consider multiple perspectives on topics - not just viewing challenging topics through a purely medical lens. With her philosophical background, this talk considered the different meanings that people can ascribe to test results - for may not just be about knowledge but also identity. It can mean that some people take tests for very different reasons than obtaining just a result - and we need to consider about this when we are understanding how to advise people, or interpret tests.



Ethical implications and identity interests

- Practical identities can be better of worse at fulfilling their practical, evaluative, agential jobs
- Depending on
  - **Inhabitability** – comfortable, recognisable, source of self-esteem
  - **Coherence** – internally & in relation to lived experience
  - How well they help us **make sense of and navigate** our experiences [2]
- We each have a **strong, basic interest** in developing & maintaining an identity that is good at its job
  - And thus in **tools** that can help us achieve this

This is where results from screening come in – as one such tool

Finally, we were joined by two people at the sharp end of policymaking. Dr Tasmin Somerfield, Consultant in Public Health Medicine and National Clinical Advisor for Screening in Scotland explained the way that policy is made in the UK and Scotland. This was a very helpful explanation of the checks and balances that go into the system in order to ensure that it moves with the evidence - and future changes that might result - for example, from the success of the HPV vaccination programme.

Richard Foggo, Co-Director of Population Health, reflected on the day and the opportunity for dialogue it offered. It was very helpful to hear how policy makers have to deal with the world as it is. Our hope is that the Centre for Evidence and Values in Healthcare can offer forums for people to discuss and debate challenging issues together, and indeed Richard acknowledged that this event was doing exactly that in the most helpful and informative manner. We all want the same thing - better healthcare- and there is much to learn from understanding different perspectives.

Some testimonials and feedback from attendees:

> *"Superb day. Talks both inspirational and informative. Really useful networking opportunities"*
>
> *"Very wide-ranging talks with absolute experts"*
>
> *"Greater understanding of the subject and the limits of it so will be more informed in my activity"*
>
> *"Empowerment to address these issues with friends, family, colleagues and policy makers"*

As an addendum:

At several points during the meeting there were reflections on the difficulty in accessing high quality information for men considering PSA testing. Two resources that might be useful:

The Prostate Cancer Risk Management Programme

Cancer Research UK - advice for professionals and for men thinking about having a screening test

We at the CEVH are going to consider ways we could usefully help with this type of decision making in primary care.

With thanks to everyone who attended this exceptionally full and busy day, and of course to The Della Fish Foundation for supporting the Centre for Evidence and Values in healthcare.

Margaret McCartney
7/2/26