

Key outcomes for studies on breast cancer screening: what is missing?

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What has not been researched?

Not researched, not possible

Not researched, not necessary

Not researched, not in focus

Not researched, no methods



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Screening is difficult to understand

- Study about knowledge of GPs and other MDs on screening (NNS, expected effects,...)
- Study comparing the knowledge of citizen and health professionals (i.e. radiologists)
- Populations based screening is a “complex system” or has characteristics of a “wicked problem”

Complex systems

- Incomplete understanding of all factors and rules involved
- Follow non-linear dynamics
- difficulties with their formal modelling and simulation
- Are RCTs valid research methods for the investigation of complex systems?

G. Bateson, F.Hayek, K.Popper,...

Wicked problems

- standard examples of wicked problems come from the areas of public planning and policy
- Solutions to wicked problems are not right or wrong.
- Every wicked problem is essentially novel and unique.
- Every solution to a wicked problem is a 'one shot operation.'

Rittel and Webber, 1973

What has changed?

- Public awareness
- Mammographic screening
- Multi-disciplinary team meetings
- Specialisation across the pathway
- Attention to margins
- Systemic adjuvant therapy

What has been tested in RCTs?

- Public awareness
- Mammographic screening
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Ideal for Estimating Overdiagnosis

- Compare group of women invited to screening for 20 years aged 50-70 with an exactly comparable (age, risk CA breast etc.) uninvited group
- Follow to death
- Any excess of breast cancers in the invited group would represent overdiagnosis
- **Such a study does not exist**

Overdiagnosis – estimate from RCT's

- Need to follow up beyond screening – allow for compensatory drop/lead time (latter difficult to estimate) – minimum 5-10 years follow up after end of screening
- No Screening of the control group at the end of the trial as otherwise all patients screened, just some more than others!

Overdiagnosis – estimate from RCT's

- Agreement on definition of overdiagnosis – the numerator
- No agreement on the denominator – if a % what is it a % of?
- At least 10 different ways of estimating it.
- Marmot review Panel focussed on 4.

Conclusion

- Have we stopped breast conservation because the trials are “old” ?
- Have we stopped treating hypertension because
 - It overdiagnoses
 - The trials vs no treatment are old?
- There is NO trial of removing population mammographic breast cancer screening

What will women do instead?

- Genetic testing?
- Self examination?
- See other people outside the health care professional's sector
- Will women read the figures of all the studies?
- Opportunistic screening?

Individual perspective

- Misnomer: positive test – negative test
- Benign diseases of the breast
- What other harmful interventions do women take free of their will
- “overdiagnosed” lesions that need treatment
- How does “overdiagnosis” influence individual decisions?

Anxiety level comparison

- Anxiety is short-term and does not affect women's overall health and well-being*
- Waiting for a mammogram result versus:
- A common health problem that women in their 50ies may have experienced already
- Baseline?
- Relief from induced fear ? Where does the fear come from?

*JAMA, Apr21, 2014:Consequences of false positive...

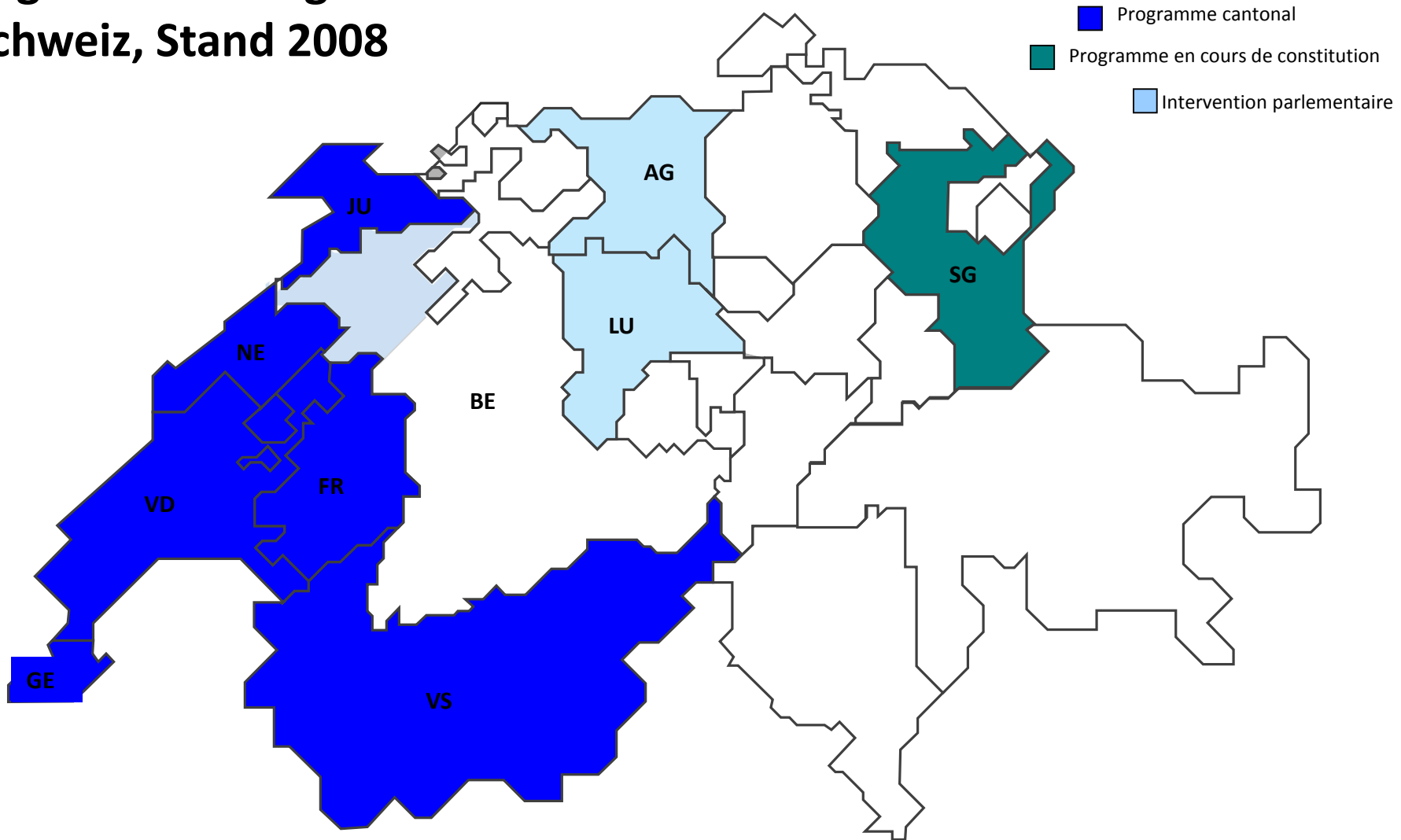
Comparison

- Womens perception – knowledge versus
- Health professionals knowledge - perception

Cross-country, cross cultural

- Different health care systems (NHS- private)
usage of opportunistic screening will be high
- “Cultural” embodied attitudes to public health
measures in general; example Switzerland
ongoing introduction of mammography
screening
- Urban – rural gradient: does it matter?
- Issue: not comparable studies

Organisierte Programme Schweiz, Stand 2008



Gender aspect in health literacy

Health literacy of men and boys:

- less knowledgeable than women and girls about health in general, specific diseases and their risk factors (Courtenay 2000)
- less able or likely to access, interpret and apply information to maintain and improve health (Galdas et al, 2005, AIHW 2008)
- exhibit low levels of health literacy even about male-specific health issues (Singleton 2008)

Screening in place since longtime

- **Cancer incidence** in absence of screening needed as comparison : cervical: historical data
- **Interval cancers** diagnosed due to new opportunistic further screening

Most indicators related to effectiveness

- Are valid when you start a new screening in a population
- Low and Middle Income Countries
- Valid when starting a new screening method vs an old one

Monitoring pre-cancers

- And shifting from cytology to HPV in cervical cancer
- HPV: EU guidelines allow for different approaches
- Monitoring can be used for understanding better screening mechanisms and dynamics

- Robust background theory
- New area to be explored
- Practical problems
- Monitoring is an opportunity

Future directions

- Screening changes the treatment
- You can research: lifestyles and screening

EBM and complex systems

- Dunning-Kruger effect