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# ***THE MAGIC WORD?***

## **ETHICAL EXPERIENCE OF PRIORITIZING CANCER-RELATED HEALTH ACTION IN A SWEDISH CONTEXT**

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# Myself and the subject

- Focusing on bioethics since 1990, public health ethics since the early 2000's
- Specialist on the ethics of screening

Juth & Munthe 2012: *The Ethics of Screening in Healthcare and Medicine: Serving Society or Serving the Patient?* Dordrecht: Springer  
Nijsingh, Juth, Munthe 2017.

- Active work with priority setting and assessment of new pharmaceuticals for the county government of Västra Götaland, Sweden since 2013

Information (only in Swedish): <http://www.vgregion.se/halsa-och-varld/varldgivarwebben/utveckling--uppfoljning/kunskapsorganisation/ordnat-inforande/>

- Member of the delegation of medical ethics of the Swedish Society of Medicine since 2014

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# The Notion of "Cancer" as a "magic word"

- Cancer has an iconic cultural position in the public mind throughout the developed world that triggers basic motivational mechanisms:
  - **Deadly and horrible:** a death sentence, extremely dangerous, lots of pain, horrific side-effects of treatments,
  - **Out of control:** may strike anyone at any time, relentlessly haunting us even under good public health conditions.
  - **The notion of a "cure for cancer"** as a metaphor for the most significant medical advancement imaginable
- Result: an elevated willingness to accept suggested methods and treatments with regard to cancer, regardless of actual effect and evidence, and in spite of the fact that patients with cancer live longer and longer and fare better and better.
- At the same time: we who are privileged often unjustifiably discount the significance of cancer as a health problem in *low resource settings*!

# The Swedish context of health care governance and resource allocation

- **Public health services run and funded by county governments**, based on own tax-base and taxation privilege: regional differences common
- **Central attempts to direct:** laws (mostly very general) and agencies, guidelines (SoS), evidence assessment (SBU), cost-benefit assessment for subsidy (TLV)
- **Specific regulation:** Law requiring that health care has to be of "good and proven" quality, and that resource allocation follows general criteria: (individual) need of care, proven benefit to patients, cost-effectiveness.
- **Recently:** voluntary central NICE-like operation by the counties: price-negotiations, cost-benefit assessment, etc.: The "NT council".
- **BUT:** any county may chose to fund anything that is not strictly illegal: regional clinical sector committees (eg. oncology) powerful.
- **Some counties have set up their own NICE-like operations**, for instance, Västra Götaland, where I participate.

# History and present trends: screening 1

- Any county may start or not start a screening program
- **Since 2014, Socialstyrelsen (SoS) produces imperative national screening guidelines**
- **The national screening council** advises the SoS, includes ethics, public health and health economics expertise, county representatives, etc.

For info (only in Swedish): <http://www.socialstyrelsen.se/riktlinjer/nationellascreeningprogram>

- Programs have been started before this. These have proven very difficult to limit or roll back. Huge public, stakeholder and media outcries result at any suggestion of this sort.
- **Current recommended cancer programs** are:
  - Breast (mammography): females 40-74 yrs (ongoing in most counties since the 1980's)
  - Cervical (cytology & HPV): females 23-64 yrs
  - Colon & rectum (fecal blood test): all 60-74 yrs
- **No other disease category similarly dominates adult screening programs:** cancer indeed is a 'magic word'

# History and present trends: screening 2

- **Since 2014:** Requirements of mammography program to improve information, and to better document positive and negative outcomes systematically. **Participants were found to largely view the program as non-voluntary (!), and info to downplay overtreatment risks.**
- **2018:** PSA+ screening for prostate cancer was rejected.
- Very negative response in media from stakeholders and public. Aggressive and public lobbying by doctors with a (disclosed) financial interest in the proposed screening methods.
- **BUT:** At least now, a "no" is possible: the argument - formulated by Juth & Munthe (2012) – that difficulty to adjust approved screening programs is a strong reason against rolling them out has gained some recognition.
- **In parallel:** Pro-screening arguments shaped in terms of women's rights seem to become less forceful, as the notion of harm due to screening programs is more widely understood and accepted due to the PSA debate (!)

# History and present trends: drugs 1

- **Two national agencies** influence what drugs can be introduced:
  - **Läkemedelsverket, LMV** (Swedish EMA/FDA): market licensing
  - **Tandvårds- och läkemedelsverket, TLV**: decision on subsidy based on cost-effectiveness assessment
- **Counties can introduce any licensed drug**, even if it is not subsidised: it's their money! Companies make separate deals, playing counties against each other.
- **Clinical drug introduction historically unregulated** beyond regional sector committees and usually quite vague guidelines, giving lots of room for empirical treatment, off label, etc.
- **The "arsenal model" of treatment is commonplace**, requiring a large supply of many different drugs that needs continuous update.
- This model seems to be successful, but **for each drug**, it is often very difficult to ascertain clinical efficacy or cost effectiveness.
- **Also here, there is a "magic word" effect**: Saying "no" to cancer drugs typically result in public outcries, and is difficult to handle for politicians, as patients are often have very high need of care.

# History and present trends: drugs 2

## Recent developments:

- Drug development for the arsenal model has adapted to orphan disease funding and assessment models:
  - Partly effect of personalized/precision medicine strategy
  - **Much higher cost in both relative and absolute terms**
  - **Very variable and more uncertain clinical effect**
  - **Weaker evidence base due to smaller populations, patients in advanced stages, etc.**
  - Undermining solidaric orphan disease funding schemes, unless these are adjusted
- **Increasing volume and rate of new formulas, principles and indications**
- **More centralised system** for cost-effectiveness assessment, price negotiations, procurement, etc., but county autonomy still applies.
- Slowly **increasing awareness of a growing sustainability problem** of the old model, but unclear how industry will respond to changes.
- Increasing political calls for a more centralised national health service system, but difficult to describe how it may be realised.

# On our way out of the magic realm?

- Maybe, some factors seem to push things that way:
  - Increasingly aggressive price setting strategy of industry, necessitating societal response
  - Increased political cost awareness and wariness regarding public health systems
  - Clearer focus on evidence assessment and horizontal priority setting
  - More harmonised national systems for assessment, introduction, procurement and price negotiation
  - Recognition of the pragmatic difficulties of limiting started programs
- At the same time:
  - The focus on costs easily leads to public backlash
  - Similarly, may become ethically problematic for health professionals
  - The notion of "withholding a cancer treatment" is still a strong political lever
- Upsides of the magic:
  - Rhetorically powerful in the face of sell-out and cutback schemes
  - May help motivate important health policy interventions in low resource settings (?)

# The Ethics and Pragmatics of Prioritising New Cancer Interventions

- **Cancer related health interventions have probably been unduly prioritised** due to a "magic word" effect.
- **While awareness is growing, some magic lingers**, and may affect what is politically possible, as well as ethically important factors, such as public and professional trust.
- While irrational as such, **the "magic word" effect may act as a sound counterbalance to other irrational influences on healthcare service priority setting**, such as ideologically motivated sell-outs and undue economisation of the social value of healthcare. **A simplistic "anti-magic" movement may be "kidnapped" for such political purposes.**
- **Therefore: "normalisation" of cancer in health policy should be long-term**, building on systematically increased awareness of healthcare priority setting, industry price-setting policy and the importance of evidence assessment.
- **In addition:** If some of the "magic" could be passed on to the assessment of the importance of cancer care in low resource settings, this need not be a bad thing.