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► To cite this version:

Marie Ménoret, Didier Torny. 'Don't think, just Pink': Knowledge and Ignorance in Public Health Policies. European Consortium for Political Research General Conference , European Consortium for Political Research (ECPR), Aug 2015, Montréal, Canada. halshs-01249214

HAL Id: halshs-01249214

<https://shs.hal.science/halshs-01249214>

Submitted on 30 Dec 2015

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'Don't think, just Pink':
Knowledge and Ignorance in Public Health Policies

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Communication presented at ECPR, Montreal, 26th-29th August 2015

Breast cancer is the most frequent cancer in human populations, particularly in industrialized countries¹. Touching a woman out of twelve, its importance drove to the establishment of many public policies for its prevention, its detection and treatment. Based on the accumulation of knowledge in clinical and epidemiological areas, these public policies, are often presented as canonical examples of the Evidence-based public health policies (EBPH), although they have been largely built before the formation of the concept, derived from that of Evidence-Based Medicine (EBM)².

Based on scientific literature and on the recommendations for mammogram screening in many countries, this paper analyzes the ways in which the systematic mammographic monitoring of women, established in the 1980s and 1990s from previous knowledge, address new knowledge, whether produced by clinical trials, observational studies or knowledge of patients. It shows how certain knowledge are deliberately ignored or minimized, leading to very minor changes in these policies monitoring, despite growing criticism of their effectiveness or their drawbacks. Finally, we conclude by asking the question of the historicity of this type of public health policy design and the scientific knowledge they carry.

¹ Jemal, Ahmedin, et al. "Global cancer statistics." *CA: a cancer journal for clinicians* 61.2 (2011): 69-90.

² The concept was not really coined by a single paper, but rather discussed in many public health or epidemiology journals from around 1997 on. See for example Jenicek, Milos. "Epidemiology, evidenced-based medicine, and evidence-based public health." *Journal of epidemiology* 7.4 (1997): 187-197 and Brownson, Ross C., James G. Gurney, and Garland H. Land. "Evidence-based decision making in public health." *Journal of Public Health Management and Practice* 5.5 (1999): 86-97.

1/ Systematic mammography: an evidence-based public policy

The issue of monitoring of breasts for cancer detection purposes has been discussed for a century, framing and being framed by battle against cancer as a fight against delays³. In the interwar period, different activists promoted self-examination techniques to detect tumors at the earliest, for the purpose of medical examination and intervention, including mastectomy⁴. Despite the lack of evidence of their effectiveness, these self-examination techniques were recommended from the post-war by many learned societies and became the subject of public policies, mostly in terms of health education. In the 1970s, monthly self-breast examination - like clinical examination by a doctor - were widely considered as practices to promote, in order to reduce mortality from breast cancer. From the 1980s on, criticisms have been arising: its proponents responded by saying practices had to be overseen, women trained, right protocols adopted⁵.

Clinical trials were launched worldwide, sometimes very large, like the one shaped by the USSR and the WHO⁶ or the one sponsored by the US National Cancer Institute in Shanghai⁷. Indeed, the techniques were considered relatively simple and mostly inexpensive, therefore likely to be adopted by a large part of the world population. Trials did not respond to the preventive hopes widely supported by WHO. That gradually led to recommendations not to promote self-examination from the early 2000s, particularly because of the significant number of consecutive biopsies of "detections" by patients, even as mortality was not affected by the self-examination.⁸

Conversely, the use of mammography in the prevention of breast cancer mortality has very early been the object of investigations intended to prove its efficacy. Truly developed from the 1940s based on X-rays technology, it gradually brought out a medical segment with its own specialists and equipment, developed by private industries in the mid 1960s. This segment was very active in the production of scientific evidence, especially in two large randomized controlled trials (RCTs): one began in 1967 in New York⁹ and one in two Swedish counties in 1977¹⁰, and both showed a 30% reduction in mortality. This led many public authorities to promote mammography monitoring and to pay for its implementation management from the

³ Aronowitz, Robert A. "Do not delay: breast cancer and time, 1900–1970." *The Milbank Quarterly* 79.3 (2001): 355.

⁴ H. Lerner. *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America*. Oxford University Press, 2001.

⁵ See for example Kegeles, S. Stephen. "Education for breast self-examination: Why, who, what, and how?" *Preventive medicine* 14.6 (1985): 702-720 et Janz, N. K., et al. "Interventions to enhance breast self-examination practice: a review." *Public health reviews* 17.2-3 (1988): 89-163.

⁶ Semiglazov, V. F., et al. "The role of breast self-examination in early breast cancer detection (results of the 5-years USSR/WHO randomized study in Leningrad)." *European journal of epidemiology* 8.4 (1992): 498-502

⁷ Thomas, David B., et al. "Randomized trial of breast self-examination in Shanghai: methodology and preliminary results." *Journal of the National Cancer Institute* 89.5 (1997): 355-365.

⁸ That didn't prevent clinical breast examination to be performed by specialized or general health care professionals.

⁹ Shapiro, Sam, Philip Strax, and Louis Venet. "Periodic breast cancer screening in reducing mortality from breast cancer." *Jama* 215.11 (1971): 1777-1785.

¹⁰ Tabar, Lazio, et al. "Reduction in mortality from breast cancer after mass screening with mammography: randomised trial from the Breast Cancer Screening Working Group of the Swedish National Board of Health and Welfare." *The Lancet* 325.8433 (1985): 829-832.

mid-1980s on. This political agenda has been supported by the results of RCTs in the 1990s, showing once again the importance of reducing of mortality¹¹.

While some critics of this political enthusiasm appeared very early¹², they had no efficacy in opposing to the implementation of screening programs in Europe. By the late 1980s, systematic screenings policies were launched in the Netherlands, Finland and Great Britain, soon followed by most Spanish regions, Sweden, Denmark and France. Meanwhile, in the United States, very active social movements led to the extension of local programs and public funding¹³, while Canada developed its national program. In the early 2000s, all highly industrialized countries - including Korea and Japan - had their mammography surveillance program: while the age groups involved vary (from 40 to 50 years - 64 years to death), in every case it is the whole female population that is targeted through time, regardless of their individual or group risk factors¹⁴.

Obviously, the implementation of such policies is not solely due to a knowledge transfer process from scientific arenas to policy makers who would then apply a rational evidence-based policy¹⁵. The construction of a public policy remains a political process in each country, alliances between medical specialists, screening companies and sometimes women's movements have produced slogans, campaigns, funding. Moreover, national or local institutions in charge of these policies are allied in the International Breast Cancer Screening Network, which published comparative studies and lobbied for screening. But at the heart of this public policy, there is always a reference to the decline in mortality, proven by controlled trials to introduce the screening as a true knowledge-based policy, made to save lives.

2) Forbidden knowledge, ignored knowledge and minimized knowledge in an EBPP

Disagreeing with these policies, many scholar critics voiced out in the early 2000s, being widely published in biomedical literature; promoters of screening policies partly addressed them in commentaries, answers and new articles. The development of this controversy, which has been lasting for fifteen years, shows that the knowledge-based policy does not take into account certain knowledge, by various mechanisms, which analysis would feed the literature on the social production of ignorance. We will not discuss here all the criticisms of mammography programs based on the absences¹⁶ they produce as they fulfill the whole public space of "cancer prevention", for example in the US the movement focused on

¹¹ Nyström, L., et al. "Breast cancer screening with mammography: overview of Swedish randomised trials." *The Lancet* 341.8851 (1993): 973-978.

¹² See for example Skrabanek, Petr. "False premises and false promises of breast cancer screening." *The Lancet* 326.8450 (1985): 316-320.

¹³ Kolker, Emily S. "Framing as a cultural resource in health social movements: funding activism and the breast cancer movement in the US 1990–1993." *Sociology of Health & Illness* 26.6 (2004): 820-844.

¹⁴ Klabunde, Carrie N., Rachel Ballard-Barbash, and International Breast Cancer Screening Network. "Evaluating population-based screening mammography programs internationally." *Seminars in breast disease*. Vol. 10. No. 2. WB Saunders, 2007.

¹⁵ For a discussion on this point, see for example Marston, Greg, and Rob Watts. "Tampering with the evidence: A critical appraisal of evidence-based policy-making." *The drawing board: An Australian review of public affairs* 3.3 (2003): 143-163.

¹⁶ Croissant, Jennifer L. "Agnostology: Ignorance and Absence or Towards a Sociology of Things That Aren't There." *Social Epistemology* 28.1 (2014): 4-2

environmental causes of cancer¹⁷ or the gradual commercialization of a the social movement against breast cancer¹⁸. In this communication, we are not focusing on the contrasting aspects of the different national implementations, but rather on the common and invariant characteristics that homogenize the treatment of ignorance in these screening policies.

a/ The ethical forbidding: the establishment of a consensus on the basis of clinical trials prevented the repetition of RCTs with new screening machines on behalf of the loss of opportunity for patients that would not have access to mammography. So here we have to deal with an assumed ignorance which produces undone science¹⁹, not because certain fractions of the public or patients asked for a certain science, but in the name of the health of these populations.

b/ Minimization of risks: certain "tumors" identified by mammogram devices, more and more sophisticated and « specific », would never become morbid and even less deadly, as their natural history would be longer than the life expectancy of tested women. So, for its critics, the "benefit" of detection corresponds in fact to a "therapeutic risk" given the severity of the therapeutic measures (biopsy, surgery, chemotherapy) or their induced pathological effects. The issue of overdiagnosis, common to all cancer screening programs has been little publicized and understood by patients until the early 2000s²⁰. Then it became more public and discussed in some screening programs, it is always discussed in relation to the decline in mortality proven by clinical trials, thus allowing developers to describe a positive benefits/risk ratio²¹ in favor in the scientific literature and insist more on profits than on the risks in their public discourse²².

c/ The endogenisation of uncertainties: the reading of mammograms is a complex process that requires significant expertise. If semi-automated devices have been developed to cope with the influx of clichés produced by screening programs, they have little decreased the variability of interpretations produced by radiologists, particularly in the USA²³. Most public programs have adopted a double reading system, publicly touted as additional security for tested women but that poses new problems in the many cases of discrepancy²⁴.

¹⁷ McCormick, Sabrina, Phil Brown, and Stephen Zavestoski. "The personal is scientific, the scientific is political: the public paradigm of the environmental breast cancer movement." *Sociological Forum*. Vol. 18. No. 4. Kluwer Academic Publishers-Plenum Publishers, 2003.

¹⁸ King, Samantha. "Pink Ribbons Inc: breast cancer activism and the politics of philanthropy." *International Journal of Qualitative Studies in Education* 17.4 (2004): 473-492.

¹⁹ Frickel, Scott, et al. "Undone science: charting social movement and civil society challenges to research agenda setting." *Science, Technology & Human Values* (2009).

²⁰ Black, William C. "Overdiagnosis: an underrecognized cause of confusion and harm in cancer screening." *Journal of the National Cancer Institute* 92.16 (2000): 1280-1282.

²¹ Puliti, Donella, et al. "Overdiagnosis in mammographic screening for breast cancer in Europe: a literature review." *Journal of medical screening* 19.suppl 1 (2012): 42-56. Hendrick, R. Edward, and Mark A. Helvie. "United States preventive services task force screening mammography recommendations: science ignored." *American Journal of Roentgenology* 196.2 (2011): W112-W116.

²² Chen, Jian Ying, Helen Eborall, and Natalie Armstrong. "Stakeholders' positions in the breast screening debate, and media coverage of the debate: a qualitative study." *Critical Public Health* 24.1 (2014): 62-72.

²³ Beam, Craig A., Peter M. Layde, and Daniel C. Sullivan. "Variability in the interpretation of screening mammograms by US radiologists: findings from a national sample." *Archives of internal medicine* 156.2 (1996): 209-213

²⁴ Duijm, Lucien EM, et al. "Independent Double Reading of Screening Mammograms in the Netherlands: Effect of Arbitration Following Reader Disagreements 1." *Radiology* 231.2 (2004): 564-570.

d/ The theoretical hierarchy of knowledge: many contemporary observational studies have shown a slighter decrease of mortality for women screened, or even a lack of effect. Through comparative studies between countries having implemented or not screening policies, they have shown a lack of mortality difference. In every country, breast cancer mortality diminishes through time, this evolution being mainly attributed to progress in therapeutic management²⁵. These results are often not discussed or are minimized due to their level of evidence lower than controlled clinical trials in the dominant version of EBM²⁶.

e/ The lack of recognition of women's knowledge and experience subject to the public health imperative. Despite strong incentives to submit to screening programs, participation rates remain insufficient in the eyes of its proponents, with the notable exception of Scandinavian countries²⁷. This relative lack of membership is typically read as much resistance or cognitive biases. The literature produced by medical anthropology²⁸, medical sociology²⁹ or women's studies³⁰ on the subject is almost never cited in the biomedical world and therefore not taken into account.

3) Indirect effects of ignored knowledge

These criticisms have very limited effects on screening policies, as no country has decided to stop its program on behalf of these complimentary or alternative knowledge. Nevertheless, there are three types of consequences of the publication and dissemination of this knowledge that do not support routine mammogram, much less its expansion and, in certain cases, aims at stopping screening programs.

a / Official recommendations of screening reduction: the political work made by critics of screening mammography is crystallized by groups of experts, doing literature reviews, that decline from their previously more extensive policy recommendations. In 2009, in the case of the United States Preventive Services Task Force³¹, in 2011 the Canadian Task Force on Preventive Health Care³². In 2013, for the first time, such a committee, the Swiss medical

²⁵ Autier, Philippe, et al. "Breast cancer mortality in neighbouring European countries with different levels of screening but similar access to treatment: trend analysis of WHO mortality database." *Bmj* 343 (2011): d4411.

²⁶ Independent UK Panel on Breast Cancer Screening. "The benefits and harms of breast cancer screening: an independent review." *The Lancet* 380.9855 (2012): 1778-1786.

²⁷ Youlden, Danny R., et al. "The descriptive epidemiology of female breast cancer: an international comparison of screening, incidence, survival and mortality." *Cancer epidemiology* 36.3 (2012): 237-248.

²⁸ For example Wardlow, Holly, and Robert H. Curry. "'Sympathy for my body': Breast cancer and mammography at two Atlanta clinics." *Medical anthropology* 16.1-4 (1994): 319-340.

²⁹ Barker, Kristin K., and Tasha R. Galardi. "Dead by 50: Lay expertise and breast cancer screening." *Social science & medicine* 72.8 (2011): 1351-1358.

³⁰ Klawiter, Maren. "Breast cancer in two regimes: the impact of social movements on illness experience." *Sociology of Health & Illness* 26.6 (2004): 845-874.

³¹ Woolf, Steven H. "The 2009 breast cancer screening recommendations of the US Preventive Services Task Force." *Jama* 303.2 (2010): 162-163.

³² Canadian Task Force on Preventive Health Care. "Recommendations on screening for breast cancer in average-risk women aged 40–74 years." *Canadian Medical Association Journal* 183.17 (2011): 1991-2001.

board, recommend stopping screening program in Switzerland³³. However, these recommendations do not have direct normative effects, and they had a very limited effect on women's practices at least in the US³⁴.

b/ Marginal changes in public policies: two separate one can be observed, mainly in the USA and Canada, and at least partly in the UK. First, as we have just told, debates about overdiagnosis and reassessment of the benefits/risks led to postpone the recommendation of a screening for women aged 40-49 years, and even not to recommend monitoring. Second, in three countries there appears a much more centered on full disclosure of women and the principle of informed consent in program participation³⁵. It should be noted that other countries are not at all affected by these changes: thus in France, a mammogram out of two is still performed out of the surveillance program, primarily to women from 40 to 49 years old, without effect despite the fact that these mammograms are publicly funded³⁶.

c/ Debates on the limitations of screening programs reached non-academic areas, including broadcast media, women press, and electronic forums³⁷. This is especially true of the works of Peter Götzsche which besides its abundant scientific production and comments, published a book for doctors and a brochure for the general public from the Nordic Cochrane Center³⁸.

Conclusion: current state of science and public policies

Screening policies, including mammography discussed here, are clearly the result of Foucault's biopolitics, where the State defends the health of the governed. But they rely on composite social forces, combining doctors, manufacturers and patients, in order to be defined and implemented, and it is these same actors who later defended them. We have shown that many types of knowledge were excluded, ignored or even forbidden to produce, but the screening defenders apply a symmetrical treatment to their critics: they would produce bad science, would base their conclusion on incomplete studies or would be subject to bias interpretation³⁹.

³³ Biller-Andorno, Nikola, and Peter Jüni. "Abolishing mammography screening programs? A view from the Swiss Medical Board." *New England Journal of Medicine* 370.21 (2014): 1965-1967.

³⁴ No effect on 40 to 50 years-old women (Pace, Lydia E., Yulei He, and Nancy L. Keating. "Trends in mammography screening rates after publication of the 2009 US Preventive Services Task Force recommendations." *Cancer* 119.14 (2013) : 2518-2523.. Very limited effect on 75+ years women (Jiang, Miao, Danny R. Hughes, and Richard Duszak. "Screening Mammography Rates in the Medicare Population before and after the 2009 US Preventive Services Task Force Guideline Change: An Interrupted Time Series Analysis." *Women's Health Issues* 25.3 (2015): 239-245).

³⁵ Following a tradition that has been legally settled by US activists on breast surgery in the 1970s, see Klawiter, Maren. *The biopolitics of breast cancer: Changing cultures of disease and activism*. U of Minnesota Press, 2008.

³⁶ Rogel, A., D. Lastier, and E. Salines. "Évaluation du programme national de dépistage organisé du cancer du sein en France: période 2004–2009." *BEH* 35.37 (2012): 399-404.

³⁷ Barker, Kristin K., and Tasha R. Galardi. "Dead by 50: Lay expertise and breast cancer screening." *Social science & medicine* 72.8 (2011): 1351-1358.

³⁸ <http://www.cochrane.dk/screening/mammography-leaflet.pdf>

³⁹ Hendrick, R. Edward, and Mark A. Helvie. "United States preventive services task force screening mammography recommendations: science ignored." *American Journal of Roentgenology* 196.2 (2011): W112-W116.

What is at stake in this controversy is the opposition between two visions of EBM: the first is aimed at the purification of biomedical evidence, only produced in RCTs and, facing their limits, by the generalization of meta-studies⁴⁰; the second, which recognizes the need to embrace as much knowledge as possible, and that RCT should be criticized as much in their methodological foundations and their implementation than other devices of knowledge production⁴¹. In other words, the first fully assumes ignorance it co-produces, because it is the condition of the formation of good knowledge for EBPH in a linear model of diffusion from science to politics⁴²; the second, in a form that is similar to the defense of the many forms of "evidence" produced by the social sciences⁴³, defends a model of aggregation of different types of knowledge.

Faced with a growing crystallized controversy and their relative failure in changing screening policies, critics have recently produced an explanation that would account for the divergence of perspectives: clinical trials, so dear to the advocates of screening, would adequately represent breast cancers before 1990, while the observational data would be adequate to the current cancers⁴⁴. Patients consult more often and earlier, tumors would be better managed, and the most appropriate treatments with fewer side effects, all kinds of factors would make obsolete the decline in mortality. But accounting for this type of explanation is potentially devastating for EBPH: if the "all things being equal" can not be ascertained and biomedical and epidemiological conditions keeps on varying, how to base a policy on knowledge that is by nature outdated?

⁴⁰ On the dynamics that explain how failures within RCTs reinforced their role as gold standard in EBM see McGoey, Linsey. "Profitable failure: antidepressant drugs and the triumph of flawed experiments." *History of the human sciences* 23.1 (2010): 58-78.

⁴¹ See for example this call to go beyond RCTs Victora, Cesar G., Jean-Pierre Habicht, and Jennifer Bryce. "Evidence-based public health: moving beyond randomized trials." *American journal of public health* 94.3 (2004): 400-405.

⁴² Black, Nick. "Evidence based policy: proceed with care." *BMJ: British Medical Journal* 323.7307 (2001): 275.

⁴³ Head, Brian W. "Three lenses of Evidence-Based policy." *Australian Journal of Public Administration* 67.1 (2008): 1-11.

⁴⁴ See for example Welch, H. Gilbert. "Screening mammography—a long run for a short slide." *N Engl J Med* 363.13 (2010): 1276-1278 and Gøtzsche, Peter C., et al. "Why mammography screening has not lived up to expectations from the randomised trials." *Cancer Causes & Control* 23.1 (2012): 15-21.