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# Choice, Trust and Risk - The Policy Context and Mammography Screening

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## 1. Introduction

Mammography screening is now a well-established measure aimed at reducing mortality from breast cancer. However, while it is well established it is not without contention. Mammography screening has been the subject of fierce scientific debate about the evidence gathered using large scientific trials. There continues to be debate about the magnitude of benefit, issues of over-diagnosis, and the age at which screening should begin. These debates spill over into the policy arena where governments must decide which health measures to promote (and to fund). It is remarkable that policies about mammography screening differ between and within countries. This is particularly the case for policies establishing the age at which women should commence screening and the recommended interval between screening. Any policy decision about frequency of screening and lowering the age limit has resource implications and these must be weighed against the potential for benefit.

This chapter presents an international overview of the differing policy contexts in countries with mammography screening programs. It then explores the intersections between scientific knowledge, policy making and individual decision making with particular reference to the age at which screening should begin. Using research conducted with women in three different policy settings (two in Australian states and one in a Swedish county), it explores the differing ideas that form a crucial part of women's decisions to participate in screening. While most research focuses on women who don't participate in screening (there is a vast literature about the 'underutilisation' of mammography screening), we can learn much about health behaviour by talking with women who have chosen to be screened. This is particularly the case where screening is contentious.

The research at each of the sites comprised qualitative interviews with women aged 40-49 years who had participated in screening. Interestingly, the risk of breast cancer is not the main reason that women choose to be screened. For women in rural Uppsala, Sweden, trust in authorities was the dominant discourse; for women in rural Victoria, discourses of rights and choice predominated; and for women in rural Tasmania, trust in technology was a key reason for participating in screening. Women in rural areas also utilise services that are delivered in their local area because they highly value regional health services. These ideas are necessarily bound up in sociological concepts of choice, trust and risk. An

understanding of these differing ways that women in different policy settings view the 'invitation to be screened' is an essential part of exploring what information women should receive about screening, and how they will respond to the provision of screening services.

## 2. The intersections between scientific and policy knowledge

In western developed countries, policies to reduce the mortality (and morbidity) from cancer have become a national health priority. Breast cancer is a major cause of mortality for women in many such countries, and the quest to reduce breast cancer mortality has seen early detection emerge as the leading policy strategy. The scientific evidence supporting early detection in the form of mammography screening is viewed as being strong – however, it is also contentious. The translation of scientific knowledge into public health policy is never a simple process, but this is all the more difficult when there is general agreement around the principle of early detection, but disagreement about factors such as the age at which screening should commence and screening intervals. The 'story' of the evidence surrounding mammography screening is quite well known. However, as is illustrated in the following re-cap of this story, scientific evidence alone doesn't provide all the required knowledge for successful policy implementation.

Randomised controlled trials are studies where the efficacy of an intervention is judged following random allocation of study participants into a study group that receives the intervention and a control group that does not receive the intervention. At the end of a specified period of time the results are compared. Evidence from such trials is regarded as 'the most scientifically rigorous method of hypothesis testing available in epidemiology' (Last, 1995: 140). Eight randomised controlled trials of mammography screening were conducted in the United States, the United Kingdom, Sweden, and Canada. The earliest of the trials was the Health Insurance Plan (HIP) of New York which was conducted in the 1960s (Shapiro et al., 1982). This was followed by Swedish trials commencing in the late 1970s and early 1980s: Malmö (Andersson et al., 1988), Two County (Tabár et al., 1985) and Stockholm (Frisell et al., 1991). At approximately the same time, a randomised controlled trial arm of the broader United Kingdom screening research commenced in Edinburgh (Roberts et al., 1990). Trials have been also been conducted in Canada (Miller et al., 1992a; 1992b), and Gothenberg in Sweden (Bjurstam et al., 1997). A trial in the United Kingdom from 1991 to 1997 aimed to identify the evidence of benefit for women below the age of 50 found a reduction of 17%, but this was not statistically significant (Baines, 2011). Proponents of screening mammography cite evidence from these trials that mass mammography screening as a population-based strategy reduces mortality from breast cancer by approximately 30% for women aged 50–74 years.

These findings have formed the scientific justification for breast cancer screening programs. The Australian policy setting can be used to illustrate the use of scientific policy and the broader political concerns that contribute to government decisions to establish a screening program. In the lead up to the introduction of the Australian screening program, the Screening Evaluation Coordination Unit (SECU) at the Australian Institute of Health conducted a review of the overseas evidence and reported to the Australian government on the feasibility of establishing a national breast cancer screening program (Australian Health Ministers' Advisory Council, Breast Cancer Screening Evaluation Screening Committee, 1990). In examining the scientific evidence, the SECU unit focused on the HIP and the Two

County trials as providing evidence of benefit. It also took into account other non-randomised trials that also showed a benefit from screening and included a discussion of the Malmö and United Kingdom (Edinburgh) trials which had not achieved statistical significance but had reported the potential for benefit from mass screening. Based on all the evidence considered, the SECU predicted that with a 70% participation rate in the targeted age group, the reduction in mortality from breast cancer would be around 16% (noting that this figure included non-participants and those outside the targeted age group) (Australian Health Ministers' Advisory Council, Breast Cancer Screening Evaluation Screening Committee, 1990: 26). The Australian policy documents reflect this claim by stating that an organised national screening program will result in a *significant* reduction in breast cancer mortality (National Advisory Committee for the Early Detection of Breast Cancer, 1992).

This review of scientific evidence was accompanied by feasibility research aimed at understanding issues associated with policy implementation. Feasibility studies, often in the form of pilot screening programs, were conducted in the five most populous Australian States. These pilot programs were aimed at applying the Australian context to the application of the selected scientific knowledge. Issues examined included strategies for encouraging women to participate in screening, psycho-social issues in implementation, analysis of the costs of screening, and technical aspects of service delivery.

Within the broader policy context in Australia, funding concerns also contributed to the need for a nationally organised program. The national universal health insurance program, Medicare, covered payments for diagnostic mammography for the relatively small number of symptomatic women (women with breast lumps or other potential signs of breast disease). However there was the perception that, increasingly, asymptomatic women were seeking to have mammograms. This blurring of the distinction between diagnostic and screening mammography (a population-wide program for well women) had the potential for a 'blow-out' of costs due to increased *de facto* screening mammography. Duckett (a former senior health bureaucrat and, from 1994 to 1996, secretary of the then Australian Department of Human Services and Health) points to the two aims of the mammography program: 'In addition to the health enhancement objective of promoting early detection of cancer and thus reducing breast cancer mortality, this program had the objective of moderating the previous rapid growth in expenditure on mammography' (1999: 81). Therefore, the decision to implement the screening policy seemed to bring together advocates arguing for the efficacy of reducing mortality from breast cancer, those establishing the feasibility of the programmatic aspects, as well as health bureaucrats concerned with expenditure.

Population based screening, however, is not without its critics. Since the incidence of the disease is much lower than in a diagnostic population, such screening programs require large numbers of well people to participate, in order to demonstrate effectiveness. For most people who participate in the mammography screening program, there will be no benefit, in terms of reduced morbidity or mortality. In a radio interview, one health bureaucrat encapsulated this aspect of screening programs by stating: 'It is a community action rather than an individual action and we can never, ever say to women that as individuals they individually will benefit' (Australian Broadcasting Corporation, 1998). In fact, at an individual level, for some women the outcome will be worse. The possibility of having a 'false negative' test result may mean that women are falsely reassured about the absence of breast cancer, a 'false positive' test

result may subject women to a series of further tests, and the uncertainty resulting from indicators of benign breast disease may mean that treatment which is unwarranted will be recommended. Foster points out that, as a secondary prevention program, 'breast cancer screening cannot prevent breast cancer, nor can it promise a cure; it is rather an attempt to gain better control over the disease' (Foster, 1995: 116).

In addition to the criticism of the potential harm of screening as a population based strategy, there has been criticism calling into question the epidemiological evidence of benefit (for example, Schmidt, 1990). From the commencement of the promising reports about the possibilities of mammography, Dr Petr Skrabanek, a senior lecturer in community medicine at Trinity College in Ireland, maintained that the reduction in mortality was a substantial overestimate of the evidence (Skrabanek, 1985). Dr Maureen Roberts (1989), who established the Edinburgh mammography program, argued that screening had not delivered the promised benefits in an article in the *British Medical Journal* published shortly after her death from breast cancer. More recently, following the Canadian study results, critics have focused on the lack of mortality benefit, the potential harm for women from the program in terms of over-diagnosis, and issues associated with screening asymptomatic, well women who have no breast problems. They claim that 'although politically attractive, the benefits of mass population screening, even in older women, are too small and the harm and cost generated too great to justify widespread implementation of screening mammography as a publicly funded health measure' (Wright & Mueller, 1995: 31). Further, in 1999, there was extensive media coverage in Sweden raising questions about the evidence from the trials, together with claims that the programs that have been implemented have not delivered the promised mortality benefits (Atterstam, 1999; Sjönell & Ståhle, 1999a; Gøtsche & Olsen, 2000). These critical voices, however, are not part of a vigorous and public debate about the efficacy of screening programs, rather emerging publicly only occasionally and generally dismissed by the central proponents of screening as 'ill informed', even endangering women's lives. As noted by Atterstam, the space for a critical point of view is minimal (1999: 1).

Ongoing debate has existed about the scientific evidence for screening women aged between 40 and 49 years. More recently, studies have attempted to ascertain the magnitude of benefit, but these results are contested. Commentary, dispute and refutation of claims from the Canadian trials that, in 1992, resulted in a questioning of benefit of population-based mammography screening continues ferociously almost 20 years later (Baines, 2011). The level of dispute also reveals the entrenched positions that various experts and commentators occupy in their reading of the scientific results from the trials. A recent review by Fletcher (2011) problematizes the changed landscape of screening, arguing that while it had its place as a secondary prevention measure, it is an 'imperfect tool' and that with progress in primary prevention and treatment, the need for screening should decrease. Such a message may be difficult to reconcile with the 'early detection is your best protection' message that forms part of the dominant discourse about breast cancer screening. That policies rest on dominant beliefs and often imperfect and uncertain science is evident when policies for breast cancer screening are explored.

### **3. Policy implementation and policy settings – an international overview**

In arguing that policy is an ongoing process, rather than a finite event, Considine says, 'policy is the continuing work done by groups of policy actors who use available public

institutions to articulate and express the things they value' (1994: 4). Understanding policy choices relating to mammography screening involves more than identifying who benefits and who loses. It is about understanding the dominant ways of thinking about an issue, the cultural dimensions of the issue, and whether policy players have their voices heard, or are excluded from the debate. Health policy is a broad area. In intervening in health at a policy level, governments are called on to undertake a variety of tasks relating to health financing for medical and hospital systems, as well as undertaking measures to redress health inequalities. Increasingly, governments are required to ensure provision for expensive high technologies in health and put in place programs to protect health. Texts analysing the politics of health and health policy portray the health system as complex, resource intensive and a site of much political contestation in the formal political arena (see, for example, Palmer & Short, 2010).

Palmer and Short claim that health policy is distinctive in three significant ways: first, the role of the dominant profession – the medical profession – in shaping policy direction is unprecedented in comparison to other policy areas; second, consumers are confronted with a complex arena of services where it is difficult to distinguish between 'good' and bad' services; and, third, the nature of health care means that decision making is often associated with life and death issues and, therefore, is psychologically stressful. This leads 'the community to see health care and its providers as being "different" (2010: 25). Accompanying this latter perception is the implicit assumption that consumers can trust health care providers, that governments will provide effective and efficient health care and that health care policies and innovations will have a sound basis in scientific research. This is particularly the case with policies involving technologies. However, the relationship between health care provision and research evidence is not clear cut (Davis & Howden-Chapman, 1996).

As can be seen from the outline of evidence in the previous section, consensus about the evidence is widespread but not universal. Leaving aside the question of whether screening should be implemented at all, the lack of universal consensus is particularly important when governments and health authorities are deciding who they should be screening (i.e., the age at which screening should begin) and what the screening interval should be. These decisions are made combining a range of factors: resource implications and who should pay (it is more costly to extend the target group and to screen at shorter intervals); political implications (whether professional or consumer groups are demanding availability and access to services; where decision making fits within an election cycle); implementation implications including the structure of governance for health services and health workforce availability; geographical considerations; and how to access the target population groups – in particular whether active strategies for recruitment can be used or whether women are encouraged to self select into the screening program.

In addition to the issues identified above governance of a population based health program will affect the claims that can be made about its effectiveness in meeting targets. In many jurisdictions in western countries, two tiers of government are involved in policy direction and implementation. The roles that different levels of governments play in screening programs are diverse, with many devolving responsibility from a national government to state or county governments (BreastScreen Australia Evaluation, 2009). Thus, while the screening policy is decided at the national level, operational responsibility for the programs

is devolved to levels of government such as states, territories, provinces or counties. This is particularly important to note in countries like Australia and Sweden where populations in various jurisdictions are low and may be dispersed. With different operational procedures, guidelines and recruitment strategies existing within countries, there is a risk of variation in population coverage, thus diminishing the capacity of the program to demonstrate overall population level benefits. In some countries, private providers coexist alongside the state services that are provided. Again, this has implications for determining policy parameters (such as eligibility and recruitment) as well as the determination of effectiveness.

In order to explore the differences in policy settings a desk top search was undertaken. It draws on two main sources – the international review of selected policy settings carried out by Australian policy makers (BreastScreen Australia Evaluation, 2009) (based primarily on stakeholder interviews) and the information provided by participating countries to the International Cancer Screening Network (2010) where English was available. In addition to the information provided, reports or publications of specific network members were downloaded, and further searching was undertaken where information was unclear (either by corresponding with member countries, further searching on participating country health websites, or through the academic literature). What emerges is a picture of considerable complexity. While generally established as government public health initiatives, there is a combination of public and private providers. The private sector plays a role in screening in a number of countries, with sole responsibility for parts of countries such as England and New Zealand. Objectives for participation are generally set at a national level (generally 70% of the total population, but 80% in England) with regions or specific services having operational responsibility. This brief description of the selected policy settings, with particular emphasis on the age at which screening is recommended or available, and where the information is available, the strategies for recruitment, highlights the differences in approach that exist both within and between different countries

### **Australia**

Australia has a national government that determines policy but operational responsibility for service delivery is devolved to State/Territory governments. Screening is free of charge for women attending through the national program. In most (but not all) States/Territories, women aged 50-69 years are invited to attend screening at 2 year intervals. Invitations are based on the electoral roll (elections are compulsory in Australia); where access to the electoral roll is not possible, women are encouraged to attend for screening through advertising. In 2004-05, the participation rate for women in the 50-69 years target group was 56.2% (with variation between Australian states) (Australian Institute of Health and Welfare, 2008). Women aged 40-49 years can attend for screening, but whether, having attended, they will be invited back at 2 year intervals varies between individual states.

### **Canada**

The Public Health Agency oversees the Canadian Breast Cancer Screening Initiative (Public Health Agency of Canada, 2008), but has less of a leadership role than other countries where national governments establish programs and devolve operational responsibility. Responsibility for mammography programs is devolved to the 12 Provinces/Territories, all of whom provide screening for women aged 50-69 years every two years. It is estimated that approximately 60% of women aged 50-69 years age group have had at least one

mammogram (Hanson et al., 2009). All but three Provinces/Territories allow women to access the program from age 40 years. All programs allow women aged over 70 years to be screened. A range of strategies are used to invite women to participate – letters of invitation, media campaigns and referral from medical doctors. Policy documents indicate a reliance on doctors referring those women outside of the eligible age groups. In five of the Provinces/Territories, women aged 40-49 years are reinvited for screening on an annual basis; the remainder do not reinvite women in this age group.

### **England**

England has a nationally coordinated screening program, but screening services are devolved to individual screening units in National Health Service (NHS) regions. Women aged 50-70 years are invited to attend and in 2004-05 overall 75% of women invited to screening attended (NHS, 2006). The invitations are based on general practice registers. Women are screened at three year intervals. Women aged over 70 years are able to continue to participate in the program if they wish to do so. From 2012, following the 'Age Trial' (Moss et al., 2006), that investigated the age at which screening should commence, women will be invited to attend screening from age 47 years.

### **Finland**

Finland has a unitary government that provides an organised screening program based on a national population register. The target age group is 50-69 years and women are invited to attend screening when they turn age 50 years of age. In Finland there has been debate about the age range for mammography screening. Initially women aged 50-59 years received regular invitations to screening, and women aged 60-69 received 'irregular' invitations (depending on the municipality); from 2007 all women aged 50-69 have been invited to the free screening program. Participation in screening by the target population is very high, with 87.9% of women invited to screening in the past three years having participated (Palencia et al, 2010).

### **Ireland**

In Northern Ireland women aged 50-70 years are invited to attend the screening program every three years. In the Republic of Ireland, women aged 50-69 years are invited every two years. Both programs are free. The register of eligible women is compiled using government and private health sources in addition to individual women registering. There is approximately a 73-75% acceptance of screening invitations in both Northern Ireland and the Republic of Ireland (Kinneary et al, 2010). Screening is provided via mobile and fixed site services.

### **Italy**

With guidelines set at the national level, Italian mammography programs invite women aged 50-69 years to screening. The mammography programs are devolved to the 21 geographical regions and there are a total of 130 screening programs – 64 in the North, 39 in the Centre and 27 in the South and Islands. Some programs include women aged over 70 years. Since the commencement of screening programs some facilities include women aged 45-49 years as the national government has provided free biennial mammography for women in this age group. There are large differences in population participation between the regions, partially attributed to the fact that some programs in the Central and Southern regions have only recently been established, and due to dispersed populations some regions

struggle to provide a biennial service to all women in the target age groups (Georgi et al., 2009).

### **Netherlands**

Mammography is provided for all women aged 50-75 years of age. Women outside this age group may still access mammography, but the out-of-pocket expenses to do so will depend on their health insurance arrangements (all citizens are required to have health insurance). Approximately 84% of women invited to screening attend (Palencia et al, 2010).

### **New Zealand**

Women aged 45-69 years are eligible to participate in screening in New Zealand, although the publicity materials emphasise that the greatest benefit is for women aged 50-69 years. For the two years up to December 2006, 60% of women aged 50-64 years had participated in screening, below the target of 70% and with high variation in participation between population groups (Thomson, Crengle & Lawrenson, 2009). Service delivery is devolved to eight regionally based lead providers, with funding responsibility the role of the central government. The private sector plays a key role in providing services. Women register for screening by phone or online. In some areas women are identified through general practice registers and are invited to screening.

### **Norway**

Women aged 50-69 years are invited to be screened every two years. There are 26 stationary and 4 mobile screening units. The Central Population Registry of Norway is used to identify eligible women. Invitations are mailed to each eligible woman, suggesting a time for an appointment. Approximately 77% of all women invited participate do so (Kalager, et al, 2010).

### **Sweden**

Sweden's central government has established mammography screening with delivery of mammography programs devolved to the 20 counties. While the two year screening interval is consistently applied, counties vary in whether women aged 40-49 years can access the program. The majority of counties invite women aged between 40-74 years to screening; six provinces invite women aged 50-69 years, and in a few cases the age range is slightly different again. Eligibility is based on the national population register. Screening is low cost, with women making a small co-payment for the service. The participation rate for women invited to screening is approximately 80% (Palencia et al, 2010).

### **United States of America**

Guidelines for mammography screening in the United States of America emphasise the importance of clinical breast examination as well as mammography screening. While the Food and Drug Administration sets standards for mammography facilities, arrangements for screening are indicative of the health system more generally – where insurance coverage dictates recruitment and participation, and there is no organised national program beyond the setting of quality standards and guidelines for women. The United States Preventive TaskForce (2009) recommends mammography screening for women each two years commencing at age 50 years. Like the Australian policy context, the Taskforce emphasises that the decision to be screened between ages 40-49 years is an individual woman's decision

and should be made taking account of personal beliefs about the benefits and harms. Various other stakeholders disagree with this advice and recommend screening from age 40 years. Women participate in screening through their health maintenance or health insurance organisations (although most states mandate that insurance companies reimburse all or part of the cost of mammography for their members). Uninsured and low income women aged over 40 years who qualify for Medicare health insurance are able to access a screening mammogram each year (with eligibility for a baseline mammogram between 35-39 years) (National Cancer Institute, 2010).

The selected international cases highlight the differences in policy in different health care settings. What is surprising is the level of scientific contention around the evidence particularly in relation to the magnitude of benefit for aged under 50 years. This plays out in differences within policy settings about women's participation in mammography screening. This is illustrated more clearly in the following section which reports on interview studies with women in three different policy settings who chose to participate in mammography screening.

#### **4. Women's choice to be screened – different policy settings, different choices?**

As previously stated, the age at which screening begins is a key site of policy difference, with the links between scientific evidence and policy knowledge unclear. The rest of this chapter focuses on this issue and explores the perspective of those women in different policy settings who have participated in screening programs while aged between 40-49 years. The aim is to highlight how embedded the policy context is in shaping what appears to be individual behaviour. Three policy settings have been chosen because their policy context differs for women aged 40-49 years. These three settings are two states in Australia and one county in Sweden. The first site is Tasmania. This island state is geographically isolated from the rest of Australia. It is a decentralised state. Of a total population of approximately 476,000 people, approximately 60% live outside the capital city of Hobart. The second site is the state of Victoria. Less decentralised than Tasmania, it has a population of 5.1 million people with 3.7 million people living in the capital city of Melbourne, but an extensive regional and rural hinterland that comprises 1.4 million people. The third site is Uppsala, Sweden. With a total population of approximately 336,000 people, Uppsala is also quite decentralised, with 40% of the population residing outside its major municipality.

The key difference between policy settings in Australia is whether they re-invite women in the 40-49 year age group once women have chosen to attend. As stated earlier, the Australian policy on screening targets women aged 50-69 years but allows women aged 40-49 years to make an individual decision about whether to participate in screening. Tasmania has a policy of reinviting women once they have attended once. In the more populous state of Victoria, women are not reinvited – rather they must make the decision themselves as to whether they continue to participate in screening while they are in the 40-49 year age group. Another key difference between these two states, relates to jurisdictional issues. Health providers in Tasmania are unable to access the electoral roll to call women to screening once they turn 50 years of age, relying on public information campaigns to encourage women to participate, whereas Victoria recruits women using the electoral roll. In both Tasmania and Victoria, mammogram facilities are provided both at fixed sites and through mobile services

to rural areas. By contrast, the Swedish county of Uppsala actively invites women to screening at age 40 years, with a recruitment letter giving an appointment date and time for individual women to attend.

Of particular interest in this study was the decision making that rural women participated in when they decided to have a mammogram when aged 40-49 years. Rurality has been linked with poorer health outcomes and a key concern to policy makers in decentralised countries is how to best serve small populations in rural areas (Palmer and Short, 2010: 274). In each of the three policy settings examined, an emphasis has been placed on encouraging rural women's access either through mobile services (Tasmania and Victoria) or by locating mammography at smaller regional centres (Uppsala). Exploratory research in Tasmania found that screening rates in the 40-49 year age group were substantially above those estimated by BreastScreen Australia and in the Victorian setting were significantly lower. This indicates that perhaps some other factors related to rurality and the provision of services might be important in understanding women's decisions about mammography.

In order to examine women's decision making about mammography screening in these three different contexts, a qualitative study was designed. Using an interpretive methodological approach and a purposive sampling strategy, semi-structured interviews were conducted with women who had participated in mammography screening between the ages of 40-49 years. The interview schedule was in four sections. First, demographic information was obtained. Women were then asked about their ideas about health generally – the importance of health, and whether they took steps to maintain health. They were then asked about their screening history, their reasons for choosing to be screened, their ideas about mammography screening and their knowledge of contemporary debates about the age at which screening should commence. Finally, they were presented with some statements about mammography screening and asked whether they agreed or disagreed with them. These Likert questions were derived from the exploratory study originally carried out with women in the Tasmanian site (Willis and Baxter, 2003). While all questions (apart from the Likert scale questions) were open-ended enabling participants to reveal as much or as little as they wished, the schedule was designed to elicit responses from the broad ideas about health to specific information about their screening experiences. Where answers were unclear, additional probing questions were asked.

The interviews were audiotaped and transcribed verbatim. Analysis commenced with transcription of the first interview, ensuring that interviews were flexible enough to capture the important issues at each site. This was particularly important for those interviews carried out in Uppsala (see below). In both the Australian settings, the Chief Investigator interviewed all participants. In the Swedish study, the process differed a little because of the reliance on a Swedish interviewer (five interviews were conducted in English) and translation into English. This required attention to the ways that words and phrases are given meaning in the Swedish cultural context and how they could be best understood in English.

Interviews were analysed using a thematic analytical approach that incorporated both inductive and deductive elements. As the interview schedule had specific questions (outlined above), themes relating to reasons for attending were initially deductively derived from the data, but the contextual information presented by participants then allowed inductive exploration of these themes. Following transcription, each transcript was read, re-

read and sections coded. Transcripts were then compared to find similarities and differences between responses. This then enabled the sorting of responses into categories. Further immersion in the data enabled the identification of themes relating to social and cultural ideas about knowledge and trust.

Ethics approval for the study was obtained from the Human Research Ethics Committee, University of Tasmania for the Tasmanian and Victorian cohorts and the Research Ethics Committee, Uppsala University for the Swedish cohort.

### **Study Site 1: Tasmania, Australia**

This research was informed by findings from a pilot study of 14 women in small rural sites on the east coast of Tasmania (Willis and Baxter, 2003). The Tasmanian cohort comprised 22 women located at four small rural sites on the north west coast of Tasmania - a geographically isolated area of Tasmania. These small geographic locations are serviced each two years by a mobile breast screening service. Women were recruited to the study through advertising in local newspapers and posters at local health centres. Characteristics of the women who chose to participate in this study have been reported elsewhere (Willis, 2004). Women were aged between 43 and 52 years at the time of the interview. All had participated in screening prior to turning 50 years of age. All but four had been re-screened at least once. Of the four who had not been re-screened, two had decided against screening at least until they were age 50, one was not due to be re-screened, and one was currently unable to access the program as she was receiving treatment for breast cancer (detected through the screening program).

In exploring the key reasons for deciding to be screened, participants were categorised into two groups, each with equal numbers. Women in the first group were characterised as 'high risk/high fear'. They perceived they were at elevated risk of breast cancer and this was a key factor in choosing to participate in mammography screening. Five participants believed this was the case because they had 'cancer in the family', five other participants had a previous history of benign breast conditions and saw themselves as higher risk of breast cancer, and one participant was included in this group because she was 'just terrified of getting breast cancer'.

The second group were those participants characterised as 'low risk/low fear'. This group of women saw themselves as having low or no risk of breast cancer but believed it was important to take advantage of the screening service anyway. They were most likely to see the service as providing an important health opportunity and it was their responsibility to take advantage of it. The opportunistic decision can be encapsulated in this quote:

*Well, its a free test and I might as well use it. I'll do anything if its concerned with health ... I thought I might as well get in early.*

Participants in this 'low risk/low fear' group did not see themselves as at high risk of getting cancer. In fact many of them stated that they didn't think they would ever get cancer. However, they argued that it was important to take any precaution that was available to them. For some, screening was a way of 'exercising control' over their health.

Across both groups two key themes were important. These were the high level of 'trust in technology' and the notion of 'individual responsibility'. Inherent in this latter theme was

the importance of having 'good health habits' with mammography being seen as something that should become a health habit in taking responsibility for health and wellbeing.

In indicating a high level of trust in technology, some women drew on their lack of confidence in their capacity to perform breast self examination, and this was a factor in deciding to participate in screening. Having a test and using technology were presented as unproblematic and, generally, certain ways of defining one's health status. The view of technology and testing that is portrayed through these interviews is of a benign test with the main benefit of confirming one's healthy state. Only three of the participants discussed whether the technology could be fallible. Participants indicated that they had a high level of trust in the technology as a means by which they could obtain reassurance and confirmation of their good health. As one participant said:

*The good thing about having the mammogram is that its reassuring. It tells us of any change, if its fine, you know its fine... I never think of it as having a down-side because the results are too important*

Even where participants reflected on the possibility of having additional testing due to a false positive mammography result, the prevailing view was that such testing was essential in the process of confirming one's healthy state.

Participants also saw themselves as taking responsibility for their health. They saw the choice to be screened as part of their 'good health practices' that were important indicators that they were taking care of themselves. Mammography co-existed with a range of practices they engaged in, from their annual check up with their general practitioner, to ensuring that they got sufficient exercise and had a healthy diet, to low levels of 'risk behaviours' such as smoking or excessive alcohol consumption. They thus saw themselves as engaging in a 'good health habit' and that it was important to get into this habit before the age of 50. Participants believed that they were more in tune with their bodies at a younger age, and that it would be more difficult to 'get into the habit' once they were older. If it was a routine aspect of their health care that was entrenched in their health practices, this was seen as beneficial. For example:

*I thought, I'll get started now and it won't be so scary when I am 50... Yes, getting myself into the habit so that once I was 50 at least I was already in that habit, it wasn't something that I had to consciously take that other decision and another step to go along.*

*It's good to get into a routine ... Because it means it becomes a part of your life, rather than just something you remember maybe three years later ... it becomes a routine, it becomes part of your life. It's a safety net, I suppose.*

In discussing why they had chosen to be screened even though the target group was from age 50-69 years, participants discussed their belief that there was an increased number of younger women getting cancer, and that the age limit should be lowered. Indeed, what they perceived as the arbitrary nature of the age limit also meant that they should be able to exercise choice. Participants emphasised the importance of 'making up their own minds' about participation.

*It depends whose opinion you listen to ... I'll just follow my own thoughts... Its a service thats there for me every two years and I am not interested in different opinions and different flavours of the day because of the changes on a weekly basis... I suppose the chance of women over 50 getting cancer [is*

*higher] ... I don't know what they base their figures on. Women younger than that are getting breast cancer. So I don't know whether they should have an age. I think they should make it free for all if you want to have the screening done. That's the service there for you irrespective of your age and it should be free.*

### **Study Site 2: Victoria, Australia**

The notion of choice in the decision to be screened has a different dimension for women in the state of Victoria. Because they are not re-invited once they have participated, women aged 40-49 years at this policy site must 're-make' the decision to be screened each two years until they turn 50 years of age. The Victorian participants in this study comprised 28 women located at two regional sites in rural Victoria. The average participation rate for women in this age group choosing to attend for screening is low in comparison with the Tasmanian study sites (at the time of this study between 10% and 13%). Two regional sites where there were sufficient numbers of women to gain a diverse sample aged between 40-49 years who had participated in screening were identified. These regional centres were located approximately 100 kilometres from the capital city. Local media and health services were enlisted to advertise the project and women contacted the researcher directly if they wished to participate in the interview study.

While most of the Tasmanian cohort emphasised choice and were opportunistic in their reasons for attending screening, differences in the Victorian cohort were readily apparent. With a much lower percentage of women in this age group attending for screening than the population centres in Tasmania, what emerged are clear reasons for concern about breast cancer and the need to exercise their right to be screened. That this was a political decision was evident in one participant's account of seeing a poster advertising the mobile service for women aged 50 years and above and someone had crossed out 50 and replaced it with '40', thus alerting her to the possibility that she could also attend.

The two categories of risk perception and decision making found in the Tasmanian cohort did not adequately capture this more complex decision making in this policy context. Thus, in terms of primary reason for attending mammography screening there were four categories that encapsulate this initial decision.

1. Opportunistic - similar to the low risk/low fear group in the Tasmanian cohort, six women described initially attending because the service was available and so they believed they should use it. Of these participants, 1 also participated because she was 'close in age to 50 years' and one also discussed having a family member who had experienced a benign growth removed from her breast. While they had attended the screening service because it was available, these two participants also discussed these factors as contributing to their decision.
2. Family history and fear of cancer - For seven women the fact that they had a 'family history' of cancer (not necessarily breast cancer) was the primary reason that they decided to attend for screening. This was the only group that perceived themselves as 'high risk' of cancer themselves, and thus were similar to the 'high risk/high fear group' in the Tasmanian cohort.
3. Having indirect experience of cancer through knowing a close friend who had experienced breast cancer prompted three women to attend for screening when it was available. They did not believe that they were at high risk of getting breast cancer, but

knowing someone who had experienced the disease heightened their awareness of the importance of screening tests such as mammography.

4. The largest group were those who had previously had mammograms for diagnostic reasons. Twelve women had either had a prior history of benign breast conditions or they had other symptoms that had required a mammogram, and when the screening service was available in their region after these events, they took the opportunity to be screened while still in their 40s. Many women in this group had also participated in 'well women's checks' run by a private screening service at the capital city, and this had included mammography, so they had a high awareness of being screened for breast cancer. Most interestingly and in contrast to the Tasmanian participants, this group also did not perceive that they were at high risk of breast cancer, despite their having had previous breast problems.

As with the Tasmanian participants, in this group there were also strong views about the power of technology. Mammography was viewed as preferable to breast self examination or a clinical examination by a medical professional. For example:

*I think the visual thing is more comforting and reassuring than someone doing a breast examination on you and saying you're fine. That's their opinion, but if its in an x-ray, you can actually see it and somebody's looked at it, and if you're give the all clear, well you think, that's peace of mind.*

*Just peace of mind, I suppose. It's something that you can do quickly and cheaply and it lets you off the hook. You think, oh well, I'm OK, I've had that test done. I don't need to bother doing the arm up behind my head [breast self examination].*

Reassurance and peace of mind were the key advantages of mammography discussed by participants. Almost all participants used these words to describe how they felt about mammography.

With regard to policy differences (and the fact that the policy in Victoria required women to take responsibility each two years to participate in screening), participants generally believed that women should take responsibility for their health, but also added and 'it would be nice to be notified' when they were due for rescreening. With regard to women's responsibility, illustrative statements include:

*Women should be interested enough in their own bodies to want to remember.*

*I would imagine that women who are concerned about their health would at least make some sort of note of when they'd be due again and do it themselves without having to be reminded*

The complexity of a policy focused on age as defining eligibility was problematised by women. When asked if they knew why the screening program targeted women aged 50 years and over, about half the group had some awareness of the links between cancer and age. Many, however, believed that cancer and age were not necessarily related, but that women of any age could get breast cancer. Moreover of those women who mentioned the links between cancer and age, some expressed some uncertainty about this link as it contradicted their experiential knowledge gained through local communities and the media. There was some discussion of media coverage of young celebrities who had breast cancer, contributing to the belief that breast cancer is also a young women's disease. The ideas about age and risk were encapsulated in statements such as:

*There is no firm statistic to say it is always over 50 years that you get breast cancer. I mean there are women in their 20s getting it. And age holds no barrier on this.*

*It doesn't have to be any particular age, it can be any age that you can get breast cancer. You can be in your 20s, 30s or 50s whatever... Breast cancer is something that can happen any time.*

*But I still think it should be encouraged for women who are under 40 because I think that some of those ones...could have a problem picked up earlier. It might be too late by the time they're 50.*

### **Study Site 3: Uppsala, Sweden**

The Swedish cohort comprised 32 women attending for screening at two rural sites in Uppsala. All women aged between 40-49 years who were scheduled to attend mammography screening at two decentralised centres in Uppsala county in a one week period in August 2003 were invited to participate in the study. Women were advised about the study with an additional insert in their recruitment to screening letter. Participants ranged in age from 40 to 50 years.

Most women had attended mammography screening three or more times, some having attended prior turning 40 years of age (for diagnostic reasons). Four participants from one of the two sites were attending for the first time, having turned 40 years of age during the past year. Participants were asked their reason for attending. The key initial finding that relates to the policy context was that, unlike the two other settings, participants did not and could not discuss participation in mammography screening as a matter of choice. Hence the title of the main findings paper from this part of the study 'I come because I was called' (Willis, 2008). This was, in essence, the reason why they had participated – the health authorities had called them to attend and they did so. Twenty-seven of the 32 participants included this reason in their response to the question about why they first attended. They described this in terms of a 'good offer'. The way participants felt about being called can be summarised by the response of one participant:

*I got called and then, in my opinion, there was nothing to decide about. It was just to go there. This is the sort of thing, make sure to go when you get such a chance. That's how I think. There's nothing to discuss really.*

As this response started to emerge as a consistent trend, participants were asked: 'if you were not called, would you attend?' Most women replied that they would not attend unless they thought they had a symptom that should be investigated, for example, a lump in the breast. Those participants who answered that they would attend without being called drew on reason such as family history of or being 'that kind of personality that likes to take control'. These responses illustrate how an organised and targeted program for women works in a policy setting where there is a high degree of trust in medical authorities. In a climate of trust, people are happier for those in authority to make decisions. Some women described themselves, and the Swedish culture, as being obeying. So if the call to be screened came, women did not have to think about the decision. Even the fact that they did not have to make the appointment time themselves was important.

Again women's risk perception did not really affect their decision to attend. All but four believed that they were at low risk of having breast cancer, although, unlike the other cohorts, they were more likely to acknowledge the uncertainty of risk assessment. For example, participants made comments such as:

*I think I am at low, risk, but you never know.*

*I don't think I am [at risk], but you never know. My mother hasn't got it. But of course, I could get it anyway'.*

Family history was perceived as being the most common indicator of high risk, so responses to questions about risk tended to be discussed in this way. For example, when talking about the links between being at low risk and family history, participants made comments such as:

*I don't know, but not on my parents, or grandmother, nobody has breast cancer.*

*No, no, in our family, we have more cervical cancer.*

When asked about the best thing about having a mammogram, participants in this cohort also differed slightly from the two Australian cohorts where the key response was 'peace of mind that there was no breast cancer'. While the theme of 'peace of mind' (expressed as reassurance, or safety/security in this group) was identified as important, women in this cohort were more likely to identify that the best thing about mammography was the possibility of having breast cancer detected earlier, and therefore there was greater potential for treatment and cure'. As the following participants said:

*You get to know if you have breast cancer.*

*If something has happened you get to know it at an early stage.*

Women were asked about their awareness of the policy differences between different counties. The interviewer presented this difference as follows: 'Uppsala calls women when they are aged 40, but Stockholm calls women when they are aged 50 – do you know why this might be the case?'. Sixteen participants were not aware of the debates about age and were quite shocked, didn't believe that such a difference existed or were appreciative of the policy as enacted in their own community. Indicative responses are as follows:

*I think its crazy that they don't have the same focus on women under 50, the earlier the better.*

*I knew that everyone is called when you get 40, its all of Sweden I think.*

*Oh, I didn't know that. Then we're really spoiled here.*

Ten participants discussed being aware that there had been some debates in the media about the age debate with four of these discussing that this may be because the risk of breast cancer increases with age, but even then comments were made such as:

*Probably you are at higher risk when you are older. I guess that's a fact, but it can't hurt to start earlier.*

This discussion was reiterated by 12 other participants who argued that the age should be lower, primarily because they had known someone under 50 years with breast cancer with some participants arguing that breast cancer was 'spreading down in age'. Others mentioned that the decision must be purely based on economic reasons (9 participants) and were concerned that women in this age group weren't being screened.

## **5. Discussion - key ideas and policy discourses**

Sociological ideas about choice, risk and trust can shed light on the participation decisions that women make about attending for mammography screening. The notion of 'choice' is

particularly relevant in the Australian context, because the policy for women aged 40-49 years is predicated on individual women making the choice about whether to participate in screening. Here the emphasis is on women being well informed and having the capacity to make choice, in contrast to women aged 50-69 years where the state takes more of a role in facilitating their participation in screening. It is interesting to reflect on this policy emphasis on choice, as the state takes more of a passive role because of the much higher level of uncertainty about evidence of benefit, handing the decision back to individuals.

These ideas are particularly relevant in considering the scientific and public uncertainty about screening in this age group, the popular discourse that the incidence of breast cancer is rising in this age group, and media coverage of young women's battles with breast cancer (in Australia, Kylie Minogue, a celebrity figure was diagnosed with breast cancer in her 30s; similarly, actress Belinda Emmett died from the illness, and Jane McGrath, the wife of popular cricketer, Glenn McGrath, died from the illness, but has remained in the public eye through media coverage of her husband's commitment to raising funds for better care of women with breast cancer).

While the key themes of trust, risk and choice emerge across all three cohorts in this study they are differently emphasised according to the policy settings. Perceptions of risk alone cannot explain why different factors emerge in differing policy sectors. Alongside 'system trust' which was important in the Swedish example, there is also the emergence of uncertainty about age and breast cancer. This is important in the two Australian sites, but particularly in relation to the Victorian case. Here in the context of uncertainty women need to draw on a rights-based discourse in order to protect their entitlement to be screened. The ideas around choice and community action are particularly important in the Tasmanian context - they are re-invited each two years once they have decided to attend, so their entitlement to the service is less fragile than their Victorian counterparts, but they are aware of the social consequences for choosing or not choosing to use the service. The importance of the local service emerged as a theme across each of the settings.

The presence of the breast screening mobile service is highly visible and the service is well advertised through local networks and local media, suggesting that there becomes a strong social encouragement among the community networks to attend while it is there. This was evident in both the Tasmanian and Victorian cohorts. Women were asked about what advice they would give to a friend and the strength of their answers was surprising with all but four participants in the Tasmanian cohort stating that they would actively encourage their friends to attend. For example, women in the Tasmania cohort said:

*Essential. As soon as someone turns 40 I tell them to go.*

*Since I've been going for screening, I've been jumping on people to do that as well.*

*Yes, I'd say, "Come on, we'll go together and we'll do lunch". I'd encourage them.*

Location in a rural setting was linked to participation for women across all three cohorts. In this way, participation was screening was identified as a community action. People in rural centres are acutely aware that when services are provided they must use them, otherwise they risk losing them. As one Victorian participant stated when asked if it was important to use services like the mobile screening van:

*Definitely because they'll keep coming. We're pretty disadvantaged with lots of things and it's great to see something come and basically the idiom is if you don't use it, you lose it, so yes, I think it's important.*

While the perceptions of individual risk remained low, women in the study identified the importance of using the service provided because it may help other women. This is powerfully encapsulated by one of the women from the Tasmanian cohort who points to the fact that she decided to participate in breast cancer screening primarily for community reasons, not because she believed that it would benefit her personally:

*At the time the bus was very new. It was the first time it had ever come [here], and it advertised for women over 50. You could go as a choice thing and I thought I had absolutely no person in my family with breast cancer at all. But I thought if I didn't go, and all the people didn't go, the bus wouldn't come back again. So I went really to make sure the bus would come back again. Because it mightn't be me it helps, but it could be someone else. Because it costs nothing and its only a few minutes of inconvenience and paid... I'm positive that I will never have breast cancer.*

In Victoria, the mobile service served as a reminder for women to attend the service, in the absence of formal reminder letters. This was also one way that the screening staff encouraged women to re-attend. For example, one woman said she was told by staff that she wouldn't be re-invited until she turned 50, but that the service was well advertised in the local area and so she would know that she was due to be rescreened because the service would come back in two years. So all she had to do was to phone and make an appointment.

Additionally, in the Swedish cohort, the use of a local service was also seen as a political action – that of reminding decision makers that 'we are many women here as well', and that services should not be centralised. It was in this setting that women were more likely to state that they would not use the service if they had to travel further distances. This perhaps indicates that trust in authorities is easily broken - as these women had not actively made the choice to participate in screening, their commitment to it was dependent on the provision of adequate arrangements for screening by health service authorities.

The provision of information to this age group is problematic. The scientific disagreement about the efficacy for women younger than 50 years, combined with the difficulty of translating epidemiological knowledge to the decision making processes at the clinical or individual level, means that clear information provision to assist informed choice is difficult to achieve. Across the three cohorts, there was some knowledge that the risk of breast cancer increases with age, but there was also uncertainty about this and confusion about whether this was the case. Many women talked of younger women who had been diagnosed with breast cancer and this subjective knowledge was sufficient to argue that the age at which screening should commence should be lower. In this way, screening was presented as a largely unproblematic solution to the problem of breast cancer. Only a few women mentioned that it may not be entirely accurate.

It has been suggested that modelling the outcomes of screening mammography can provide women with the information they need when deciding whether to be screened. Barrett et al (2005) argue that a clear statement of the risks and the benefits of screening can be modelled and thus provide more balanced information to women. Hersch et al (2011) problematise the mismatch between women's beliefs and values and the need to ensure informed consent in the context of 'widely held positive attitudes and often uncritical support for

mammography and screening generally'. In a study of Canadian women, Vahabi and Gastaldo (2003: 253) note that women 'are basing their decision on incomplete information'. It is also claimed that 'the messages that women are receiving about mammography are skewed in favor of screening' (Silverman, et al. 2001: 239) in part because population based programs such as mammography require large numbers of women to participate in order to show efficacy. However, while the push for balanced information is important, information provision in itself is, I argue, insufficient as the sole source of knowledge that should be taken into account in the decision to be screened. Social ideas and values are likely to influence the way that apparently neutral information is received and acted on. This is where ideas about trust may be useful. With close attention to the role of trust in health care encounters, there must also be attention to how trust occurs in situations where the information is inadequate. While some theorists argue that what is required is a 'leap of faith' in such situations, others argue that trust emerges from taking account of available information (see, Meyer et al., 2008) - thus, those women who draw on experiential knowledge, knowledge of living in a rural community, and on dominant discourses about cancer may have incomplete epidemiological knowledge but draw the evidence that is available to them. It is not surprising that such evidence results in a high level of trust in the technological response to cancer, through mammography, and in the health authorities who provide the service. This notion of trust is very different to that envisaged by some policy makers who may prefer to believe in the objective and rational consumer carefully considering how the scientific evidence will play out in an individual risk assessment. The policy setting cannot be divorced from such considerations.

## 6. Conclusion and policy implications

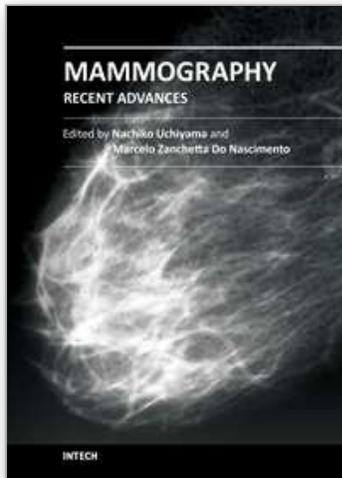
The research reported in this chapter goes some way to understanding how policy impacts on women's decision to participate in breast cancer screening. This research can be contrasted with dominant understandings of women's behaviour in two key ways. First, most research in this area focuses on why women don't participate and aims to understand how best to reach 'non-compliant' or under-served populations. Second, research tends to draw on individualised models of behaviour to understand women's decision making. This research aims to connect the policy context with the decisions that women make about participation in breast cancer screening. What is evident from the brief international review of selected countries is that there isn't a clear message for women aged 40-49 years to draw on in their decision making. The policy advice that this should be an individual risk assessment decision by women themselves is at odds with all of the scientific evidence which is aimed at a population based approach. As clinicians well know, population based evidence is difficult, or impossible, to translate into a message about individual benefit. For women at the three policy sites investigated for the qualitative study, the different policy settings did affect how they understood the decision to be screened, and identified a range of factors that cannot be individualised - decisions about health care are made within a social context where dominant ideas about cancer meet health service provision. This is particularly relevant when considering how the impact of the social affects rural women's decisions to be screened. As Pasick and Burke (2008: 358) argue, we need an understanding of mammography use "that is not abstracted from daily life and all its variations, our theory must reflect a more complex and nuanced approach to the socio-cultural and behavioural mechanisms involved".

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## **Mammography - Recent Advances**

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In this volume, the topics are constructed from a variety of contents: the bases of mammography systems, optimization of screening mammography with reference to evidence-based research, new technologies of image acquisition and its surrounding systems, and case reports with reference to up-to-date multimodality images of breast cancer. Mammography has been lagged in the transition to digital imaging systems because of the necessity of high resolution for diagnosis. However, in the past ten years, technical improvement has resolved the difficulties and boosted new diagnostic systems. We hope that the reader will learn the essentials of mammography and will be forward-looking for the new technologies. We want to express our sincere gratitude and appreciation to all the co-authors who have contributed their work to this volume.

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