INFORMED CHOICE IN SCREENING

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I) Background considerations on the impact of "information factor" on demand of medical services

A) For health economists demand analysis seeks to identify which factors are most influential in determining how much care people are willing to purchase. That knowledge can be used to forecast demand more accurately and to predict changes in utilisation. The classical determinants of demand are incidence of illness and a set of cultural-demographic and economics factors.

The assumption of consumer choice is implicit in research on demand, however the validity of this assumption in health care has been questioned. Many authors insist that physicians have the ability to manipulate and induce patient demand. In its most radical version, this "supply induced demand" theory claims that in the classical doctor-patient encounter the patient does not decide, he selects a physician who then makes these choices [1, 2]. Alternatively, the physician may provide the patient with appropriate technical information on the options under consideration, and let him or her make the final "informed" choice.

Very little research is available in economic literature on the impact of the "information factor" on demand. Most work in this area has examined what kind of information consumers need in order to choose a physician or a hospital but not a medical diagnostic or therapeutic procedure [3].

The question we want to discuss here is what amount and quality of information is needed in order to allow people feeling in good health to make "ex-ante" an evidence-based choice [4] that expresses their preferences to undergo or not a screening procedure.

Unfortunately no study in this particular area seems to be available in health economic literature [3]. Probably the "perfect" agency theory (physician acting on the patient's behalf) has prevented health economists from investigating further in this area. Health is not a good like carrots or cameras and attitudes, expectations and risks and benefits perception could be considered, under some conditions, as powerful incentives as economic ones may be.

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For screening it is also important to point out that payment schemes usually reward physicians for the number of people they persuade to undergo a screening, rather than for the quality of information provided to eligible subjects [5]. To reach economic efficiency a high participation rate is needed for public screening programs. This later often collides with the provision of an evidence-based information on benefits and harms to eligible people.

B) For public health professionals there has been an increasing consensus in considering health care consumer preferences as a value "per se". The precondition is providing to patients knowledge about "evidences" and "uncertainties" on effectiveness, adequacy, risks, adverse events and possible alternatives (evidence-based information) with the aim to allow him or her to enhance the integration of "technical" information with individual expectations and values in order to reach a really informed patient choice [4, 6].

Without an adequate level of relevant information the consumer tends to accept every service proposed not only in the hope of maximising benefits but also to minimise "regret" [7].

This latter could be a rational choice under uncertainty due to lack of information relevant for decision-making.

II) Screening and informed patient choice

A) The rationale for acting

Screening seems to represent the best area to involve health care consumers to express their preferences. In fact the subject of these procedures is not the individual in the classical doctor-patient encounter (often drenched with anguish and hopes) but more often the general public or selected groups of population, usually feeling in good health, encouraged to undergo a particular diagnostic procedure with the aim to detect a disease in its presymptomatic stage. The obvious assumption is that earlier the disease will be detected more effective will be the treatment and/or the outcomes.

Thus, all the best conditions seem combined in screening practices to start involving routinely eligible subjects to express ex-ante their informed preferences to undergo or not this kind of preventive "health lottery" if exposed to an adequate amount of information about benefits (mortality, morbidity, disability, etc, avoided), harms and uncertainties (anticipation of diagnosis without benefits, false positive results, unnecessary treatments for inconsequential diseases, false reassurances, anxiety, inconveniences and costs, etc) on the yield of the screening practice proposed. Thus,
for screenings a compulsory ethical duty to give "ex-ante" an evidence-based information to every subject eligible can not be disregarded [8, 9].

The rationale underlying the promotion of a true informed consent in this area is also supported by the impressive development and increase of diagnostic and screening procedures (compared to treatments) and by the expected further dramatic increase in the near future of such practices based on genetic tests [10, 11, 12] and, as a consequence, the problem of related direct and indirect costs for society.

B) The threats

The main threats to an informed patient choice in this area are represented by the lay press and by the "educational" materials produced by professionals.

In fact media have plunged the civil society in an overly optimistic and "mythical" view of the effectiveness of medicine in general and screening practices in particular by spreading to the community messages that (i) emphasise benefits of medical services (even if only potential), (ii) gloss over uncertainties, adverse events and side effects and (iii) ignore legitimate scientific controversies [13]. The same is true for most leaflets and materials developed by professionals and agencies to inform and educate patients [13, 14]. This "magnification of the power of modern medicine", perceivable in almost every mediatic health input to the civil society, not only suits the interests of the health care providers, but also those of the public itself, which undoubtedly prefers to receive reassuring and benefit-emphasising messages, rather than more complex ones likely to induce anxiety and distress [15]. This results in a growing gap between expectations and reality [16], in an increasing demand of health goods for a potentially unlimited well-being and in a deeply established perception by the public that all prescriptions are necessary, effective and adequate. Not surprisingly between 70 % to 80 % of the general population of UK, Germany, Italy, France and Switzerland believe that medicine has to be considered as an "exact (or almost exact) science" [17].

As a consequence of those societal perceptions, it is important to realise that for medical profession and health agencies, providing to the civil society or to eligible subjects evidence-based information on benefits, risks, harms and uncertainties of screening practices [18] implies a collision with (i) the existing "external" official professional consensus and (ii) the favourable and uncritical public general attitude toward any kind of screening practice in agreement with the accepted wisdom that "prevention is better than cure" and that "medicine is almost an exact science".
It is also important to consider that if the information is really honest and evidence-based the participation rates for number of screenings will probably collapse.

III) Some empirical evidences

A) Willingness to undergo a screening test according to information provided to eligible subjects.

At least two studies have shown that people can understand and make choices taking expectations and individual values into account when they are honestly informed. These studies have shown that people's willingness to accept screenings (for prostate and for pancreatic cancers) would dramatically decrease (between 70 % and 80 %) if citizens were given proper information about benefits, risks and adverse events [19, 20].

Figure 1 shows that 60 % of the population was willing to submit themselves to a screening of questionable value for pancreatic cancer (tumour marker ca-19.9). The stated willingness was reduced to 13.5 % when information was provided about the limited sensibility of the test (70 % false positives), annual incidence of the disease (11 cases every 100.000 inhabitants), and survival (3 % at 5 years). Wolf obtained similar results for the PSA prostate cancer screening, strongly promoted nowadays [19].

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<th>Figure 1 WILLINGNESS TO UNDERGO A SCREENING TEST (*) FOR PANCREATIC CANCER</th>
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<td><strong>Group receiving &quot;Basic&quot; (*) information (N=401)</strong></td>
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<td><strong>Accept</strong></td>
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* see reference [20]
B) Public perception of effectiveness of mammography screening.

It is not the goal of this paper to discuss the effectiveness of mammography screening programmes even if various reasons of concern seem emerging [21, 22, 23]. One fact is however undeniable: women's expectations about the benefits of mammography screening, in terms of breast cancer avoided (!) and breast cancer deaths prevented, exceed any reasonable evidence based on the accepted general consensus [24] that mammographic screening significantly reduces breast cancer mortality in women aged 50 to 69 (according to the swiss breast cancer epidemiological figure the absolute reduction is estimated in 3 breast cancer deaths avoided among 1000 women aged 50 and over screened for 10 years).

We present here, for the first time, some results concerning Switzerland derived from a survey carried out in various countries (Switzerland, Italy, UK and USA). The results refer to two questions asked to a representative sample of the Swiss female general population (N=1028) about the benefits of mammography breast cancer screening.

A first shocking result (see Figure 2) shows that 65 percent of the adult Swiss female population believes that regular mammography prevents the risk of contracting breast cancer (similar results were found for UK [69 %], USA [57 %] and Italy [81 %]).

![Figure 2](image-url)

**Figure 2** Mammography is an X-ray examination of the breasts. Which of the following statements concerning mammography reflects your opinion? Regular mammography every 2 years in women who are well:

- Prevents the risk of contracting breast cancer
- Reduces the risk of contracting breast cancer
- Does not have any influence on the risk of contracting breast cancer
- Don't know

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<th>Switzerland (N=1028)</th>
<th>Morges (informed population) (N=460)</th>
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<td>Prevents risk</td>
<td>10</td>
<td>21</td>
</tr>
<tr>
<td>Reduces risk</td>
<td>55</td>
<td>59</td>
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<tr>
<td>Influence</td>
<td>27</td>
<td>18</td>
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<tr>
<td>Don't know</td>
<td>8</td>
<td>2</td>
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Another result (Figure 3) shows that only 4% of the Swiss sample has correctly estimated the magnitude of the benefit expressed in terms of number of breast cancer deaths prevented among 1000 women aged 50 and over screened for 10 years. Similar results were found for UK, Italy and USA.

As expected women exposed to the informative leaflets provided by the official mammography screening programme carried out since 5 years in the Swiss district of Morges, emphasise significantly more all kinds of benefits (see Figures 2 and 3).

Although worrying, these results are not surprising, since beside the enthusiastic messages on benefits given by the lay press also those provided by professionals and public agencies in booklets and pamphlets systematically avoid to provide figures about real benefits, adverse events and uncertainties [13, 14].

Furthermore the familiar and misleading "one in eight, or nine" statistics is generally quoted in most "educational" and "informative" leaflets giving probably in this way the most powerful and fearful incentive to undergo mammography screening [25].

All this prevents people to make "ex-ante" with serenity an evidence-based choice.
Misunderstanding on the duty to give complete information about positive and negative outcomes of mammography screening may also arise according to which perspective the issue is approached with. Even, if, from a public health standpoint, preventing 3 breast cancer deaths (equivalent to a relative mortality reduction of 25% according to the Swiss breast cancer epidemiological figure) every 1000 women aged 50 and over screened every two years for 10 years can be considered a positive result, we should admit that from an individual perspective the opinion can be different. In fact, if a woman is not one of those 3 women who may have a substantial benefit, she may experience mainly inconveniences and negative effects. The most negative consequence of breast cancer screening for the large majority of women diagnosed with cancer may be having the diagnosis 3 to 4 years earlier without any bearing on their recovery. This extra-time spent with the knowledge of having breast cancer without benefits seems to be the real harm caused by screening. The problem is that no one might know this in advance.

IV) Conclusions

Empirical evidences show that the quality and the extend of the information could change the willingness of people to undergo a screening test [19, 20]. Furthermore the evidences provided here for mammography screening confirm that expectations exceed any reasonable evidence about benefits.

Consequently, allow every eligible subject to make "ex-ante" a fully informed individual choice about the decision to undergo or not a screening is an ethical compulsory duty that can not be disregarded even if the screening is clearly effective without or with negligible harms (as for phenylketonuria).

To do so society and eligible subjects must be "ex-ante" fully and honestly informed about benefits, risks, harms and uncertainties [18] in the aim to allow people to integrate personal expectations and values in the decision to attend or not the screening programme.

Furthermore, informed subjects who decide to undergo the screening must be offered accredited high quality screening and follow-up services.

In the meantime the content of the currently produced leaflets, pamphlets and supports aimed at promoting screening practices should be carefully reviewed and critically assessed on the basis of the available evidence and presented in a comprehensible and useful form [13].
To facilitate comprehension and give a more realistic estimates, benefits and harms must be presented in **absolute terms** (and not in relative ones) or as a number of "cases" related to 100, 1000, ..100000 subjects, population, services etc [18].

Economic incentives to the medical profession and agencies should not be targeted to increase screening participation rates but to promote an "ex-ante" informed choice by every eligible subject.

An informative community intervention campaign on benefits, risks, harms and uncertainties of more performed screenings, aimed at empowering the public, could also keep the medical profession under an "healthy pressure" that could lead to more adequate attitudes and practices [26].

Unrealistic expectations about benefits and lack of information about harms and uncertainties could also represent increasing reasons for medical litigation [27].

As Maureen Roberts, clinical director of the Edinburgh Breast Screening Project who died of breast cancer on 9 June 1989, said: "The decision must be theirs, and a truthful account of the facts must be available to the public and the individual patient" [28].
REFERENCES


**Bellinzona: Sezione sanitaria, 2001**