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**EDITORIAL**

# Informed participation in cancer screening: The facts are changing, and GPs are going to feel it

> Offer up your best defense
> But this is the end
> This is the end of the innocence (Don Henley, lyrics, *The End of the Innocence*, 1989)

Participation in cancer screening programmes is by many considered a "no-brainer" – take part, ask no questions. Recent evidence, however, indicates that the innocent and optimistic faith underlying medical slogans, such as "better safe than sorry" and "an ounce of prevention is worth a pound of cure", is not necessarily valid for cancer screening [1]. As so often in medicine, reality proves more complex than expected. Statistics now show that population screening for cancer delivers little in terms of increased survival, whilst causing clinically significant harm to a large number of participants [1]. Some of medicine's basic assumptions regarding cancer development and human biology are thus being challenged – and the result is disillusionment and controversy. Some screening advocates choose to ignore the unpleasant news. But GPs have to keep up with reality [2] and prepare for scenarios like this one: in the doorway, after a consultation, a 50-year-old woman asks, "While I remember … I got a mammography invitation the other day. I feel a bit confused by the information about benefits and harm. I should go, shouldn't I? Or what do you think…?"

What should an updated GP actually think about current cancer screening options? A general rule of thumb may be: *a decision to attend screening may be just as wise and* "*correct*" *as a decision not to attend* [3,4]. We will qualify this statement with a brief summary of recent evidence. But note – this is about cancer screening programmes in the general population. We are *not* questioning the pursuit of rapid and effective diagnosis of cancer among patients who present with symptoms in clinical practice [5].

- A general benefit of early detection and treatment of cancer has long been taken for granted. However, no cancer screening programme has so far shown a decrease in total cancer mortality, or in total mortality – what has been achieved is only decreased mortality in relation to the specific cancer screened for.
- Finding a malignant tumour in its early stages should ideally lead to less aggressive treatment: less mutilating surgery, milder chemotherapy, and less radiotherapy. A major problem, however, is that this gain has high costs: many people become cancer patients unnecessarily. This phenomenon is called *over-diagnosis.* Screening programmes primarily detect non-aggressive, slow-growing cancers that already have a good prognosis [6]. Some cancers regress spontaneously, others will not grow further and will never lead to troublesome symptoms in the person's lifetime. Once such a cancer is subjected to screening, however, it is likely to be captured. Diagnosis of cancer can, in other words, occur *too early*, as has clearly been demonstrated in relation to neuroblastoma in children [7]. It is well documented that in cervical cancer screening there is a high spontaneous regression rate of dysplasia. More than half of women screened repeatedly for cervical cancer will be "captured" in a phase of dysplasia, and more than 50 will have to undergo conization for every cervical cancer death prevented [8]. In relation to mammography screening, randomized controlled trials show that for every prevented death from breast cancer, 10 women are "unnecessarily" over-diagnosed and treated for cancer [9]. This number may be even more unfavourable in ordinary screening settings [10]. In relation to prostate cancer screening (PSA testing) statistics indicate that 47 men are over-diagnosed with and treated for prostate cancer for every man whose life is extended [11]. And no one is able to distinguish winners (the few whose cancer deaths are prevented by screening) from losers (the many who are diagnosed with and treated for inconsequential cancer).

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- *False-positive test results* represent another problem with screening. No cancer screening test is perfect; test sensitivity and specificity never reach 100%. Therefore, false-positive results are bound to occur. The affected individuals go through additional examinations that can sometimes be physically harmful and in rare cases even lethal, e.g. in cases with a perforated colon after colonoscopy, complications to a laparotomy on suspicion of ovarian cancer, or a perforated lung [12]. The diagnostic journey is stressful, and adverse psychosocial effects related to false-positive findings are well documented [12–14]. Negative psychosocial consequences may persist for months or even years after the person was declared free from cancer after a false-positive finding [12]. In mammography screening, 200 or more women will receive a false-positive result for every death from breast cancer prevented [9]. In colorectal cancer screening with faecal occult blood testing, approximately 125 persons will get a false-positive test for each death from colorectal cancer prevented [15].
- Aggressive cancers with a worse prognosis are more likely to appear between two screening rounds: these are the so-called "interval cancers". People diagnosed with cancer less than a year after an uneventful screening may lose confidence in the healthcare system [16]. False-negative routine screening results may cause diagnostic delay as both patient and GP may rely too much on a recent normal finding.
- Yet another harmful consequence of screening affects the many patients whose prognosis is not changed despite the fact that their cancer is detected early by screening. For these patients, earlier diagnosis does not mean a longer life. It simply means more time with a cancer diagnosis.

The above-mentioned "downsides" of screening cannot be withheld from the public, although the facts are disturbing and bound to cause unease. Balanced and quantifiable information regarding the benefits and harm of screening (physical and psychosocial) must be made readily accessible to everyone. What effect this might have on the healthcare systems is hard to foresee. A rational strategy might have been to put current population cancer screening programmes on hold until better methods eventually become available. But this is unlikely to happen, as both politicians and professionals want to do everything possible to combat cancer. What is more likely to happen – and this process has already begun – is a transfer of the responsibility for decision-making: Potential participants will be expected to make their own, informed choices in relation to screening. But it is very hard to know when the statistical benefits of screening are likely to outweigh the potential for harm. The conclusion will in most instances depend on value judgements and personal experiences. But one thing is certain: if you present the general population with personal medical choices that involve life, death, and statistics, it will increase the pressure on primary healthcare.

The idea that people should be allowed to take responsibility and make personal health choices has a strong appeal in contemporary society. In relation to cancer screening, we actually envisage that "respect for autonomy" can be used as a finalizing, rhetorical argument for screening, strongly upheld by faith and "the power of goodness" (fuelled by professional and commercial stakeholders, politicians, patients' organizations etc.) and to a lesser extent by solid, scientific evidence. Let us therefore think twice before primary healthcare workers take on the role of personal screening counsellors. Every minute spent on counselling "the worried well" must necessarily divert resources from other tasks and activities. This will either increase healthcare costs, or reduce the resources spent on those who need healthcare the most.

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