

Summary

Purpose of this report

Over the last five years or so, various forms of (commercial) screening have become available, such as health checks and total body scans. In addition, an increasing number of self-test products have come onto the market, which consumers can use to test themselves (or have themselves tested) for diseases or disease risk factors. The expectation is that the availability of screening products and services will continue to increase in the years ahead, as scientific and technological developments make it possible to service the latent demand.

Media reports on the subject have generally been positive, but doctors are more critical about the safety, consequences, quality and value of (commercial) screening. It is not without reason that the Netherlands has the Population Screening Act (WBO) to protect the public.

Against this background, the Ministry of Health, Welfare and Sport (VWS) asked the Council for Public Health and Health Care (RVZ) and the Health Council (GR) to prepare an advisory report on the topic. In particular, the minister wished to know what role the government should play in relation to the growing availability of (commercial) screening.

Scope and terminology

Before embarking on any discussion of this subject, it is very important to clarify what is meant by ‘screening’ and exactly what type of screening is referred to. RVZ therefore begins its report by defining its terminology and classifying the various forms of screening.

Screening: testing one or more people for a medical condition, the precursors of a condition and/or risk factors for a condition, where no symptoms of the condition are manifest and the subject does not feel unwell.	
Population screening	The systematic provision of screening to a precisely defined population group.
High-risk screening	The systematic provision of screening to people at elevated risk of developing the condition screened for, e.g. diabetes mellitus.
Case-finding/opportunistic screening	Screening people who belong to a defined at-risk group or people who visit their doctors in connection with other, unrelated matters.
Health check	Screening that may involve anything from the completion of a questionnaire to thorough physical examination and/or laboratory tests.
Total body scan	An MRI or CT scan, possibly supplemented by physical examination and/or laboratory tests.
Self-test	A test carried out by the subject, using a consumer product, without the involvement of a (medical) professional.
Home-collect test	A consumer test that involves the subject obtaining a sample of his/her own body tissue or similar and sending it for testing at a laboratory; the laboratory subsequently sends the results straight to the consumer.
Street-corner test	A consumer test made available and performed in a public place, such as a shopping centre.

Developments

‘Policy makers don’t know half of what is coming our way,’ said a doctor during a debate on commercial screening. The report accordingly begins with a brief summary of key developments in the field of screening.

Supply and demand are growing

Growth in the supply of genetic (self-)tests is particularly striking. In the USA, there are already known to be seventeen companies offering predictive genetic tests. At the same time, consumer demand is growing. A recent study suggested that 9.6 per cent of the Dutch population made use of diagnostic self-tests, and that a wide variety of care providers and care institutions were involved in the provision of the other forms of (commercial) screening. Also of note are the many forms of screening available and the fierce competition on screening amongst care institutions and insurers. By international standards, the Netherlands appears to be pursuing a conservative policy.

Screening brings both potential health benefits and potential hazards

The increasing availability of (commercial) screening products and services brings both potential health benefits and potential hazards. Screening has the potential to contribute to improved public health, by

enabling treatable diseases to be detected early. Screening can also increase awareness of the health risks associated with certain forms of behaviour, and thus promote healthier lifestyles.

It is not without drawbacks, however. ‘We will soon be living in a hypochondriac society, in which we are obsessed with our physical wellbeing,’ said a contributor to one of the debates. In other words, screening may contribute to a situation where many people are unduly preoccupied with their bodies and their health. It is also conceivable that some people will have difficulties obtaining life insurance, or other forms of insurance, as a consequence of an adverse genetic or other test result, or their refusal to undergo screening. Furthermore, any form of screening is bound to generate a certain percentage of erroneous positive or negative results.

Estimation of health benefits and costs

Not enough is yet known about the health benefits and costs of (commercial) screening to draw any definitive conclusions about its value. However, it seems unlikely that, for example, self-testing will lead to substantial additional pressure on the mainstream care system as a result of people being prompted by the results to seek professional help. The data currently available suggests that it is just as likely that more self-testing will reduce expenditure within the health service, since some self-test users will decide that they do not need to see a doctor.

Does screening make sense?

The increasing availability of (commercial) screening products and services is problematic in various respects. The supply is not sufficiently transparent, for example, and there is a lack of good information concerning the need for and value of the various tests. The information that is available is difficult to understand. Opinion differs as to whether screening makes sense. Ordinary members of the public and scientists disagree about the value of total body scans, for example, and about the best age to test women for cervical cancer. However, RVZ believes that the most urgent social and ethical problem is that the public is not properly protected against the misuse of predictive (genetic) medical data. Such misuse could lead to people being excluded from employment or denied insurance. The present legislation is inadequate in this regard. WBO is also lacking in certain respects: no allowance is made, for example, for screening at the subject’s request.

RVZ’s view

RVZ makes the point that most people seek expert advice – usually from their GPs – if they believe that they may have a health problem or if they want health-related information. Screening needs to be assessed in a global context: the internet and open borders mean that the availability of information, products and services is not confined by national boundaries. Furthermore, the Council believes that ready access to an ‘evidence-based’ supply of screening through primary care providers is likely to provide more health benefit than professional reticence towards screening, or the prohibition of self-tests or total body scans within the Netherlands.

The Council believes that the government’s role should be to protect the public, while respecting the individual’s freedom of action. Hence, the government should lay down regulations that ensure that people are not harmed or disadvantaged by screening. At the same time, it is necessary to allow suppliers and service providers to meet the public demand for screening. Such an approach would be consistent with the government’s commitment to a regulated market economy.

Recommendations

RVZ makes a number of recommendations. Priority should be given to research into and the promotion of ‘health literacy’: consumers need to be able to understand information about forms of screening in order to make rational decisions. RVZ advises the minister to develop or commission the development of a programme aimed at promoting health literacy.

The increasing availability of genetic and other (self-)tests raises certain ethical questions. The Council would like to see debate concerning the ethicality of parents subjecting healthy children to genetic screening.

RVZ believes that the government should at the earliest opportunity look again at the possibility of protecting the public against the misuse of genetic and other data. The minister is accordingly advised to work within the knowledge and consultative system to set up a committee that would consider whether the Medical Examinations Act could be amended to provide appropriate protection or whether other/new legislation could be introduced, similar to the Genetic Information Discrimination Act in the USA.

Generally speaking, however, RVZ believes that self-regulation has more potential than the imposition of still more rules on screening. A great deal can be achieved in the context of the existing regulatory regime. Nevertheless, RVZ recommends a number of changes to the existing rules: genetic self-tests and cancer self-

tests should be treated as high-risk forms of screening, thus ensuring that they have to be carried out by experts; the advertising of high-risk screening products should be prohibited and the European Commission should be encouraged to investigate misleading advertising for screening products and services on the Internet. If the outcome of a review of legislation in this field were to lead to the conclusion that the Population Screening Act should remain in force, the Act should be modified to allow more scope for screening at the subject's request. Thus, healthy consumers in the Netherlands, like their counterparts in many other countries, could obtain scans on demand and at their own expense.