A good health check isn’t good enough

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A Good Health Check isn't Good Enough

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Introduction

Health checks test disease or risk factors for disease in people without specific symptoms or medical indication. They are offered through (online) advertisements, announcements or invitations, or in response to an individual expressing health related concerns in a physician-patient relationship. For example to a man who - now his neighbour has prostate cancer - asks his doctor for a Prostate Specific Antigene (PSA) test.

Health checks for adults that are not directed to infectious disease control – where this thesis focuses upon – may be offered by to populations through governmental screening programs, or to individuals.
In the Netherlands, the national screening program includes screening programs for breast- bowel- and cervix-cancer. In the United Kingdom, there is also screening for risk factors for cardiovascular disease (CVD). Typically, people in the target group (e.g. for the breast cancer screening program in the Netherlands: women aged 50-75) receive an invitation to participate. Most population screening programs are provided free of charge.
Increasingly, health checks are also offered to individuals. In the Netherlands, physiotherapists, pharmacies, General Practitioners (GPs), gyms, Non Governmental Organisations such as the Heart Foundation, specialized medical centres and companies offer checks on a wide variety of (risk factors for) disease, including cancer and CVD. Examples of these 'personal' health check offers include cholesterol tests at the train-station, all sorts of blood and urine tests that may be ordered online, electrocardiograms, lung function and prostate cancer tests at work, a variety of self-test that may be bought at pharmacists or drugstores, and total body (MRI)scans for which people have to travel to Germany because these checks are subject to licencing according to Dutch law and the companies offering them do not have a permit. Personal health checks differ from population screening programs in two respects: they are initiated by other actors than the government, and there is no predefined population to which the offer of testing is directed. (Juth & Munthe 2012)

Health checks may provide benefits in terms of health improvement or reassurance but can also result in damage to health, unnecessary worries or false reassurance. (Juth & Munthe 2012)

Especially when it comes to personal health checks, there is debate about their ethical evaluation and regulation. (Bijlsma et al 2014, Gezondheidsraad (GR) 2015, Human Genetics Commission (HGC) 2010) The on-going policy discussion in the Netherlands about the ethical evaluation and regulation of personal health checks (GR 2008, 2015, Raad voor de Volksgezondheid en Zorg (RVZ) 2008, Schippers 2015, 2016) prompted my research into the ethics of health checks.
What is a good health check and when is the offer of health checks ethically justifiable? With the research bundled in this thesis I aim to contribute to a substantiated answer to this question. It provides an overview of the different values at stake in health check offers, the effects health check offers have on these values, as well as how the expectations and capacities of (potential) users, the setting in which checks are offered, and the broader societal context may be taken into account in formulating measures to ensure an ethical offer of health checks. In the ethical framework for health checks based on this research (chapter 6), I indicate which conditions health checks offers and the societal context in which they are offered should meet to be ethically justifiable.

To give the reader an impression of the subject matter, this introduction starts with some examples of health check offers, their users, and accompanying ethical issues. Next, I will discuss existing Dutch laws and regulation on health checks and provide a short history of policy suggestions about ethical criteria for the regulation of health checks. After presenting research aims, -questions and -focus, I will conclude with the outline of this thesis.

From cholesterol to total body scan: benefits and harms

In this section, I will discuss four examples of health check offers in the Netherlands, and their users: the national cholesterol test, the screening program for breast cancer, a PSA test included in a medical examination at work, and the total body scan. My aim is to provide the reader with an overview of the variety of health checks, the way they are offered, and their potential benefits and harms.

The National Cholesterol test

The 'national cholesterol test' is an initiative of a pharmacy chain and is financed by the Dutch Heart Foundation, the Dutch Association of Dietitians and food company Unilever. In the national cholesterol test, the 'total' cholesterol is measured; the (bad) LDL and (good) HDL cholesterol together. In case of a total cholesterol level > 6,5, people are advised to see their general practitioner. A high level of LDL cholesterol or a skewed ratio between the level of LDL and HDL cholesterol is a risk factor for cardiovascular disease, just like high blood pressure, smoking, obesity, stress, diabetes, crill and a hereditary predisposition.

The (health) benefits of the national cholesterol test are questionable. If users with elevated total cholesterol levels would see their general practitioner and a high LDL cholesterol or skewed levels would be diagnosed, lifestyle changes and possibly medication may decrease risk on cardiovascular disease, especially when more risk factors are present. However, only 7% of the users with total cholesterol levels > 6.5 actually see their general practitioner. (Vermaat el al 2005) Moreover, many people do not succeed to permanently adjust their lifestyle (Centrum voor Ethiek en Gezondheid (CEG) 2005), which may result in feelings of guilt. (Gillespie et al 2012) On the other hand, users may be falsely reassured: single measurements are usually not considered reliable, the relationship between LDL and HDL cholesterol may also be skewed in total levels below 6.5, and people with a normal total cholesterol level may still be at high risk for developing cardiovascular disease.

The national cholesterol test is provided free of charge in pharmacies and in mobile units on for example stations, marketplaces, fairs and supermarkets. Potential participants are recruited by a banner stating: '*have your cholesterol tested here*'. It is not unusual to see queues before test locations. Information is provided through leaflets and the website: '*65% of the Dutch population has elevated cholesterol-levels*' and '*With only one drop of blood obtained from a finger prick, your cholesterol level can be determined. What are the risks of elevated cholesterol? (…) The LDL cholesterol easily binds to the walls of the blood vessels, causing the vessels to clog. This increases the risk of cardiovascular disease.*' (www.nationalecholtesteroltest.nl)

The way the national cholesterol test is offered does not encourage a careful weighing of potential benefits and harms before testing. Potential participants may experience social pressure from bystanders, the information provided does not seem sufficient to communicate the limitations of one total cholesterol test, and participation may be so easy, convenient and 'fun' that people test 'because the test is offered' and do not consider implications at all. (chapter 1)

During observations on the 'health fair' I met Marjan[1], 54 years old. To my question why she wanted to have her cholesterol checked she replied that the queue aroused some curiosity in her friends, they wanted to check out what was going on. And it can't hurt to know right? While waiting for results she was advised to stop smoking and make some dietary changes. She was pleased to hear her levels are normal and she had nothing to worry about. Marjans decision to participate didn't seem to be preceded by a weighing of potential benefits and harms. She experienced some reassurance, but the conclusion she had nothing to worry about is false: one measurement of total cholesterol is no reliable indicator for cardiovascular disease developing in the future. In any case she should stop smoking.

Breast cancer screening program

A mammography is an X-ray of the breast, which aims to detect breast-cancer. In many countries, mammographies are offered by the government through population screening programs to women between 50 and 75 (Rijksinstituut voor Volksgezondheid en Milieu (RIVM) 2018), often in mobile units ('the bus').

Breast cancer screening programs save lives on population level (Hewitson et al 2008, Independent UK panel on Breast Cancer Screening 2012). However, they also cause harm through over diagnosis (after false positive results) and overtreatment (treatment of conditions that would not have caused health problems during life). (Miller et al 2014, Olson & Gøtsche 2001) 70% of the women with a positive mammography do not have cancer. (Integraal Kankercentrum Nederland (IKNL) 2017, Verbeek et al 2013) And it is estimated that only 4 out of the 14 women treated for cancer benefit from that treatment. 7 of the remaining 10 would have been treated timely enough after revelation of symptoms, 1 would never have known that she had cancer and 1 dies despite the screening program. (van der Maas 2000, de Gelder 2012) Breast cancer screening programs may thus result in unnecessary worry, health care expenditures and health damage.

Potential participants are invited with a letter and leaflet in which benefits and harms of the screening program are discussed: '*The sooner breast cancer is detected, the greater the chance of a successful and less radical treatment. (…) If one of the X-rays shows an abnormality or if the photos do not provide enough information, you will be referred to the hospital. That does not necessarily mean that you have breast cancer. (…) Breast cancer is almost always treated, but in some women breast cancer grows so slowly that it will not cause any complaints during their lives. You may therefore be treated for cancer that you would not suffer from. (…) The screening detects seven out of ten cancers. If there is nothing to see on the X-rays, there is thus a small chance that you do have breast cancer. (…) Breast cancer may develop between two screenings. Please see your general practitioner if you detect anything unusual in your breasts*.' (RIVM 2018) Participation rate is high and the screening program is evaluated in positive terms (IKNL 2017), although many women experience the check as rather painful.

Since the start of my research, I've been talking to many people about their experiences with health checks. Frederique, 75 years old, always participated in the breast cancer screening program. She told me cancer was found, that she did not need extensive

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[1] The names of health check users are fictitious.

treatment, but 'keeps an eye on that breast'. Her daughter informs me that Frederique is referring to a false positive result she received a few years ago. Frederique is an educated woman and read the information brochure. This case shows how hard it may be to inform people about the (oftentimes limited) predictive value of health checks.

A PSA test offered at work

PSA tests check for Prostate Specific Antigen. During my research I met the director of a holding that performs the medical examinations for a variety of companies. The CEO of one of these companies requested him to include a PSA test in the medical examination offered, because of the popularity of this test. The director agreed for commercial reasons. (chapter 2)

It is questionable whether PSA tests may reduce mortality on population level. (Andriole et al 2009, Martin 2018, Schröder et al 2009) Elevated PSA levels may indicate prostate cancer but could also be caused by an inflammation of the prostate or a benign enlargement. As a result, the test has a low specificity and many results are false positive: only 2 of the 10 men with elevated PSA levels are diagnosed (through a puncture or MRI) with prostate cancer. The biggest concern is overtreatment: in approximately half of the diagnosed men, the prostate cancer will not result in any symptoms during life. (Nederlands Huisartsen Genootschap (NHG) 2014) Given that the treatment of prostate cancer often results in impotence (operation: 70%, radiation: 35-40%) or incontinence (operation: 9%, radiation: 2-6%) (IKNL 2014), it is questioned whether the benefits of PSA screening outweigh the harms. (Andriole et al 2009, Martin 2018, Schröder et al 2009) Like breast cancer screening, PSA tests may thus result in unnecessary worry, health care expenditures and health damage.

The employers of the CEO who requested PSA tests to be included in the medical examinations receive the standard invitation to participate stating: '*Why a medical examination? The fact that you have no symptoms does not mean that you are healthy! Preventive medical examinations may identify risks early on. You may then take measures to, in many cases, prevent disease, or to limit the severity of the condition. (…) In any case, the following tests will be performed: general physical examination (height, weight, blood pressure, pulse), eye test, heart and lungs, ECG, blood and urine tests and a bicycle effort test.*' (invitation form of a holding that performs medical examinations for > 50 companies in the Netherlands)

Physicians performing the medical examination state consults do not leave enough time to run through benefits and harms of tests. (personal communication) Employees, thus, are not aware of PSA being tested before they enter the test location and do not receive any information about benefits and risks of this test (nor that of other health checks included in the medical examination) before they sign the 'informed consent' form provided. Informed consent is meant to further and protect autonomous choice. (Beachamp & Childress 2012) This case shows this safeguard may be, literally, paper-thin.

Off to Germany for a total body scan

A total body scan usually consists of MRI scans of the skull/brain, skull, carotid arteries, upper and lower abdomen, pelvis, hips and lung, a variety of blood- and urine-tests (including a cholesterol and PSA test), an echo of the heart, ECG's, and a lung function examination. It may be expanded with a CT scans of the lungs or other tests. (e.g. prescan.nl) Total body scans are offered commercially and aim to detect cancer and (risk factors for) cardiovascular disease in an early stage such that treatment is timely.

Research showing any health benefits of the total body scan, so far, is absent. (GR 2015)
In the Netherlands, total body scans are highly contested. Critics point to high costs (around 1000 euro's), the chances of detecting untreatable disease such as aneurisms in the brain, the health risks of using contrast fluids and X-rays, and the chance of false positive results and detection of conditions that do not need treatment. These would result in unnecessary worry, health care expenditures and possibly health damage in follow up research. There is also a chance of false negative results; unwarranted reassurance may cause people to belittle symptoms that develop later with potentially negative consequences for health. (GR 2015)
Potential users may read about the different tests offered on the website. An intake in which the most suitable package of tests is discussed is performed in the Netherlands – for the actual total body scan, people have to travel to Germany because performance of this health check is currently forbidden in the Netherlands.
Sandra and Jan were up for their second total body scan when we met during fieldwork. Jan told me that their first visit was prompted by the illness and sudden cardiac death of his brother. He wanted to make sure they were okay. They were and that was such a relief that they decided to check every two years. When it was time for the intake with the radiologists, it turned out that Sandra and Jan forgot all about the informed consent papers. They read them quickly and signed. The radiologist asked Jan whether the spot that was found on the MRI of his lungs the last time they visited had been investigated further and if so, what the results of this research were. Jan didn't remember any spot; he was too relieved about his heart being okay. It is decided that a (more accurate) CT scan would be made to check whether the spot had grown. Jan didn't seem too worried and indeed; it hadn't. Sandra and Jan left; pleased and once again reassured. (observational research) This case shows the good of reassurance: Jan felt like a ticking time bomb before he found out his heart was okay after his first total body scan. In fact he was so relieved that he missed the spot in his lungs and did not consult his general practitioner about it. This turned out to be for the best because it saved him unnecessary worries, and society the costs of the CT that probably would have been made after referral. However, the spot could have been cancer that despite its early detection would have remained untreated. The CT scan exposes Jan to unnecessary radiation, which in itself may cause cancer. As in the cases described before, it is questionable whether Jan and Sandra carefully considered benefits and harms of total body scan before signing their informed consent.

Ethics and policy regarding health checks: an overview

Health checks may provide benefits and harms, to health and other values. Many countries have a constitutional duty to further and protect public health. (Grondwet artikel 22 lid 1, Nederlands Normalisatie Insituut (NEN) 2014) For this reason, health checks are offered through population screening programs and the offer of personal health checks may either be stimulated or restricted. To determine which health checks should be offered though population screening programs, a normative framework based on the Wilson and Jungner criteria (Wilson & Jungner 1968) is often used. As of yet, it is subject of discussion on which ethical criteria policy-decisions on personal health checks should be based. (Bijlsma et al 2014, HGC 2010, GR 2015)
In this section, I will discuss the normative framework based on Wilson and Jungner criteria to evaluate population screening programs and a variety of (Dutch) proposals concerning ethical criteria for the regulation of health checks in the Netherlands. This

will help the reader to understand and hopefully appreciate the focus of my research that will be set out next.

Ethical criteria for population screening programs and their offer

Internationally there is a broad consensus regarding the criteria to be met by responsible screening programs. That normative framework is based on the Wilson and Jungner criteria. (Wilson & Jungner 1968, Andermann et al 2008) A summary of these criteria by the Dutch Health Council reads as follows:

- The screening should concern an important health problem
- Benefits for participants should outweigh the disadvantages (utility)
- The test(s) should be reliable and valid
- Autonomy should be respected
- Screening should result in an efficient use of resources

The second criterion on utility is deemed most important. (GR 2008)

Governmental screening programs should thus meet the Wilson and Jungner criteria. The government should however not be expected to provide any and all types of screening that do. The government has a constitutional duty to further and protect public health. (Grondwet artikel 22 lid 1) Therefore, screening programs funded from public or collective resources are usually limited to those capable of generating actual health gains. Priority setting also includes disease burden and cost effectiveness. (GR 2008)

Debate about the ethical criteria for personal health checks and their regulation

There is debate in the Netherlands about whether and how personal health checks should be regulated. (GR 2008, 2015, RVZ 2008, Gezondheidsraad 2015, Ploem en Dute 2014, Schippers 2015, 2016) The just mentioned governmental duty to protect and further public health implies that the Dutch government should protect people from the risks inherent in unsound personal health check offers. (GR 2008, 2015, Ploem & Dute 2014) However, to what extent may or should the government interfere in the freedom of choice of individuals in order to protect their health?

In this section, a short history of the Dutch policy suggestions of the last decade will be provided.[2] Because any regulation of personal health checks is discussed in the context of existing laws, I will start with a brief review of the Dutch legal framework applicable to health checks.

Current laws applicable to personal health checks

The Dutch legal framework distinguishes between 'selftests' (carried out on one-self, and purchased in a drugstore, at the pharmacy or online, no professional service is required) and 'screening' (tests performed by a professional). I will focus on the rules and regulation on screening since this is also the focus of the research described in this thesis.

Physicians that offer health checks have to comply with the Medical Treatment Contracts Act[3], the Individual Healthcare Professions Act, the Act Exceptional Medical

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[2] Note the KNMG directive and the report of the Health Council of the Netherlands were drawn up (and in case of the KNMG directive: withdrawn) during the period in which the research bundled in this thesis took place.

[3] At the end of this introduction, a list of laws is provided including their English and Dutch names, and abbreviations.

Procedures and its accompanying decrees, and the Medical Examinations act; all of which guard the quality of medical care. One can think of provisions on informed consent, confidentiality, certain (risky) procedures may only be performed by medically trained personnel, and the criminalization of certain behaviours. (Ploem & Dute 2014) All health check providers, including physicians, are subject to the Healthcare Quality, Complaints and Disputes Act, the Personal Data Protection Act and most important: the Act on population screening. According to this law, screening involving the use of ionizing radiation, for cancer and for disorders for which no treatment or prevention is possible, is subject to authorization. Grounds to refuse a permit are: first, the screening test is scientifically unsound; second, the screening does not conform to professional medical standards; third, the expected benefit of the screening does not outweigh the risks for the participants. (Wet op het bevolkingsonderzoek (WBO) 1992)

The Health Council of the Netherlands (GR), the former Health Care Inspectorate (Inspectie voor de Gezondheidszorg (IGZ, now HYCI)) and a number of legal scholars state these laws, its monitoring and enforcement do not sufficiently protect potential health check users against the drawbacks and risks of health checks. (GR 2015, IGZ 2008, Ploem & Dute 2014) The scope of the de Act on population screening, the Decree in vitro diagnostics and the Special Medical Procedures Act is deemed too narrow such that a group of health checks is excluded from considerations regarding the need for safeguards. (Gezondheidsraad 2015, Ploem & Dute 2014) Research from the Health Care Inspectorate shows that enforcement of the de Act on population screening is problematic. (IGZ 2008)
The former Council for Public Health and Healthcare (RVZ now RVS) and the former minister of Health, Welfare and Sports Edith Schippers also criticise the scope of the de Act on population screening and its enforcement, but prefer other ways to protect citizens against potential harms and drawbacks of health checks over more or stringent enforcement of laws. (RVZ 2008, Schippers 2015, 2016)
In the following sections, I will review policy suggestions of these and other parties including revision of the Act on population screening.

2008: reports from the Health Council of the Netherlands and the Council for Public Health and Healthcare

About 10 years ago, the then minister of Health Welfare and Sports (Volksgezondheid, Welzijn en Sport (VWS)) asked the Health Council of the Netherlands and the Council for Public Health and Healthcare for advice regarding any updating of the policy concerning population screening programs and personal health checks. (Klink 2007)
According to the Council for Public Health and Healthcare, research into and the promotion of health literacy was deemed necessary because potential users should be able to understand information about health checks to make considered choices. Concerning policy, the Council for Public Health and Healthcare mainly called for self-regulation with an exception for genetic self-tests and self-tests on cancer that should only be offered by professionals. If the Act on population screening would be amended, it should leave more room for screening at request of citizens. Professional standards should be leading in the decision whether such a request can be honoured. (RVZ 2008)
The Health Council of the Netherlands argued for more government involvement when it comes to personal health checks. According to this Council, the core of the normative framework for responsible population screening programs discussed above; '*the principle that the provision of screening programs can only be justified if it has been*

established that the benefits to the participants outweigh the ever-present drawbacks, applies regardless of whether this is being provided through public or private channels'. (GR 2008 pp 23) The Council deemed the current level of protection against the risks of unsound screening inadequate, primarily because of the limited scope of laws (most health checks are hardly regulated) and advised a more active approach: a quality mark should be developed such that people would be enabled to sort the wheat from the chaff. If a close relationship between the quality mark and the professional standard could be established, this quality mark might also discourage the provision of unsound screening. Awaiting such developments, the Council did not consider it wise to make radical changes to the current scope of the WBO. Finally, the Council advised the instalment of a 'Standing Committee on Screening' that amongst others would '*Contribute to critical reflections on the normative framework itself, and on its further development; Control the information and quality mark system; Encourage the development of professional guidelines and standards*'. (GR 2008 pp 27).

The reports of the Council for Public Health and Healthcare and Health Council of the Netherlands thus differed in their conclusions about the desired action from the government. Perhaps as a result no direct consequences were affected on the basis of the reports.

2013: A guideline of the Royal Dutch Medical Association

The growing offer of health checks and doubts about the scope of existing laws and regulation led the Health Care Inspectorate and ZonMw (a funding organization of innovation and research in health care) to commission the former Quality Institute for Healthcare (Kwaliteitsinstituut voor de Gezondheidszorg (CBO)) to develop a guideline for health check offers. The Royal Dutch Medical Association (Koninklijke Nederlandse Maatschappij ter bevordering van de Geneeskunst (KNMG)) was asked to authorize, to coordinate the implementation and to evaluate this guideline. This was effectuated in October 2013 and from that moment; all doctors in the Netherlands were expected to act in accordance with the guideline when performing health checks.

The guideline consisted of recommendations about:

1. the purpose and effectiveness of the health check (e.g. providers should have knowledge of and documentation with data on impact, risks, sensitivity and specificity (1.2.3), evidence that benefits for the target group(s) outweigh any adverse effects or risks (1.2.4));
2. the process of offering and performing the health check (e.g. information before the test about the test procedure, advantages and disadvantages of the test, usefulness and risks of the test in general and specific to this person, costs. (2.1.1));
3. the management and improvement of the quality of the health check offer (e.g. agreements with chain partners for referrals from clients for follow-up actions with proven effectiveness (3.6)). (CBO 2013)

Providers must meet 55% of the recommendations in each cluster. (CBO 2013)

Note that providers having knowledge of risks, impact, sensitivity and specificity of a test and informing potential about these health check characteristics (recommendation 1.2.3 and 2.1.1) is not the same as minimum risk-, impact-, sensitivity- and specificity-standards. And that providers may meet this 55% limit without their health checks providing more benefits than harms (recommendation 1.2.4).

Physicians are first and foremost bound to the aforementioned laws. If these would contain stricter criteria, they supersede those of the guideline.

2015: A new report from the Health Council of the Netherlands

In response to a new request by the minister of Health, Welfare and Sports regarding criteria for health checks and risks citizens should be protected against by the government (Schippers 2012), the Health Council of the Netherlands published another report about the ethical evaluation of health checks and the role of the government in 2015. (GR 2015)

The Council reaffirmed that the criteria for responsible screening programs as derived from the Wilson and Jungner criteria are applicable to both population screenings programs and personal health checks. Health gains however are, according to the Council, not necessarily a precondition for personal health checks because to individuals, the results obtained may be of use purely as information or they may be valuable in terms of reassurance. Cost-effectiveness too is not considered a prime concern for the individual, although unnecessary healthcare burdens should be prevented as much as possible.

A summary of the Councils criteria for responsible personal health check offers reads as follows:

- Clearly defined target group
- Test must be clinically valid
- Participation must be voluntary and informed
- Facilities for follow-up research and care
- Confidential handling of data
- Continuous quality control of efficacy, efficiency and safety of the test procedure and any follow-up actions, and the information to users
- Advantages must outweigh disadvantages for users. For the purpose of this weighing the health check providers should provide information about:
    - Prevalence of the disease or disorder in the target group
    - Natural course and the variation in the severity of the disorder
    - The specificity, sensitivity and predictive value of the test method to be used and the impact of the test
    - The available options to users if a health problem would be demonstrated
    - Any favourable and unfavourable psychological, social and other consequences of the offer, participation or non-participation in the health check for the user, family members or groups in society
    - The chance of false-positive or –negative results, overdiagnosis and incidental findings, and the possible consequences thereof
    - The costs associated with the health checks (Gezondheidsraad 2015 pp 106, 107)

With regard to the role of the government, the Council considered the government to have a constitutional duty '*to ensure responsible provision and appropriate use of health checks (…) without interfering unnecessarily in the individual's freedom of choice*.' (Grondwet artikel 22 lid 1, GR 2015 pp 21) The government should ensure that health checks are provided and implemented responsibly, prevent the use of irresponsible health checks, help to ensure that people are provided with information that enables them to make an informed choice about participation, and monitor and enforce compliance with laws and regulation. As mentioned above, the Council deemed the current legal framework insufficient to guarantee a responsible provision of health checks. The Council considered the KNMG guideline a step in the right direction.

However, its scoring system and voluntary nature (there is no independent supervision as to whether providers comply to criteria) results in the situation that '*a pass mark is no guarantee that a given health check is actually responsible*'. (GR pp 23)

According to the Council, the necessity to protect people against the risks involved in health check offers is best described in general terms. Extra protection in the form of general (such as improvement of health literacy) or additional, restrictive measures (such as certified healthcare professionals) should be taken in the following seven conditions:

1. The health check is untargeted or broadly focused on a wide range of abnormalities, and there is a lack of knowledge for example about clinical sensitivity and specificity;
2. There is a complex follow-up process, involving (combinations of) follow-up diagnostics, therapy, aftercare and counselling;
3. There is a risk of a disproportionate invasion of privacy;
4. The target group also includes children and the legally incompetent;
5. The health check is insufficiently proportional to the health problem involved (e.g. too extensive or invasive) or there are clearly better or less harmful alternatives;
6. The health check may involve major societal effects, such as follow-up costs and/or displacement effects;
7. The health check is focused (directly or indirectly) on severe diseases or abnormalities for which no prevention or treatment exists. (GR 2015 pp 23)

To determine which protective measures would be needed, and when, and to stimulate the appropriate use of health checks, the Council again called for an independent national screening committee.

To protect people against the most risky health checks, mandatory permits would still be required. (GR 2015)

2016: Revision of the Act on Population Screening?

In response to the report of the Health Council of the Netherlands the then minister of Health, Welfare and Sports Edith Schippers proposed to amend the Act on Population Screening such that the category of health checks for which the permit requirement applies is reduced. She suggests dividing health checks in three categories with an increasing degree of quality assurance and supervision:

1. No restrictions on the offer of health checks without direct risks to physical or psychological health.
2. Professional standards and/or quality requirements (based on (existing) legislation and regulations) for health checks with medical risks. An important guarantee to for quality would be that the Healthcare Quality, Complaints and Disputes Act obliges all health check providers (including the non-medical professional) to comply to professional standards, such as the guideline of the Royal Dutch Medical Association (CBO 2013).
3. Permit requirement for health checks that focus on unpreventable untreatable diseases, for the population screening programs offered by the government and for health checks that target the same conditions as these population screening programs.

Next to this revision of the Population Screening Act, the minister calls for more supervision and enforcement from the Health Care Inspectorate (IGZ). Also, she wants health check providers to make mutual agreements about additional advertising rules that take into account the informed choice of citizens. Finally, she would welcome an information system for citizens with the pros, cons and quality of health check offers and is of the opinion that providers should properly inform potential users before the test about the risks, the uncertainties, the chances of a false result and the consequences of the health check. (Schippers 2015, 2016)

2017: Repeal of KNMG directive
In March 2017, the guideline of the Royal Dutch Medical Association KNMG was evaluated[4] and subsequently withdrawn. The evaluation report states that: '*The quality criteria are insufficient to protect citizens from health check related risks.*' (KNMG 2017 pp 8) Independent supervision as to whether providers keep to criteria proved unfeasible because certifying institutions lack specialist knowledge, potential users do not know whether health checks are performed in accordance with the directive and providers are not obliged to adhere to criteria. (KNMG 2017)

The ministers' classification of health checks in her proposal for a revision of the Population Screening Act, and idea that quality criteria are only necessary for health checks that may cause harm as direct result of the test (Schippers 2015, 2016) was controversial from the start – if only because it is very different from the advice of the Health Council of the Netherlands (GR 2015). But now the guideline of the Royal Dutch Medical Association no longer can function as guarantee for the quality of health checks in the second category of checks distinguished by the minister, everyone will agree that the policy question which ethical criteria, if any, should be used to regulate personal health checks, is back on the table.

Even more than I could have anticipated at the start of my research, a substantiated view on the ethics of health checks seems relevant indeed.

Research aim, questions and focus

The overall aim of this research project was to answer the question: What is a good health check and when may the offer of health checks be ethically justifiable?
The goal was to formulate a framework to evaluate health checks and determine whether it is ethically justifiable to offer them, and how they may be improved.

It was clear from the start of this research that health check offers affect more values than just 'health'. It was thus important to gain insight in which values may be influenced by the offer of health checks and to examine the effects of different aspects of health check offers and other relevant variables on the values at stake. This starting point led me to the following research questions:
Which values are influenced by health check offers?
Which aspects of health check offers mediate their effects on values, and in which way?
Are there any other relevant variables that may influence health check offers' effects on values? And how do they mediate health check offers effects on values?

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[4] I was interviewed for the purpose of this evaluation and then shared the critical notes mentioned in the section on this directive.

Furthermore, in the research conducted for the development of the ethical framework for health checks I paid special attention to three issues that seemed underexposed in the discussion around the ethical evaluation and regulation of personal health checks so far.

First, the proposals for the ethical evaluation and regulation of personal health checks thus far (Bijlsma et al 2014, HGC 2010, GR 2015) state that the benefits of health checks should outweigh the harms for users. However, it seems that health checks may affect non-users as well, for example because follow up care may drain on collective resources. Therefore, I also researched health check offers effects on non-users.

Second, opinion differs about to what extent and how citizens should be protected against the risks of health checks. Nevertheless, most proposals seem to assume that potential users act like rational decision makers: if provided with reliable and conclusive information, they will only participate in checks whose benefits outweigh harms. This assumption is at odds with longstanding (but not necessarily widely known, accepted or applied) insights from research in psychology. People are cognitive misers and usually do not carefully consider each aspect of a certain situation before taking action. More often, they act automatically, and are easily influenced by their (social) environment and emotions. (Baron 1998) I decided to pay special attention to the 'person' behind (potential) users in my research.

Finally, the idea that citizens should be protected against the risks of health checks stems from the constitutional duty to further and protect public health (Grondwet artikel 22 lid 1, e.g. Gezondheidsraad 2015) Health checks are thus seen as a (potential) public health problem. Yet, proposals thus far only indicate how *individua*l health checks may be ethically evaluated and regulated, while in public health policy, the effectiveness and desirability of a certain measure is usually discussed in relation to the effectiveness and desirability of other measures focussing on the same health problem. (Childress et al 2002, Grill & Dawson 2017, Kass 2001) In thinking about the ethics of health check offers, it seemed worthwhile to not only consider health checks in isolation from other health related measures.

Concerning sources of knowledge, next to literature, I decided to conduct research among (potential) users of health checks and health check providers. This because knowledge about their needs and perspective seemed limited while ethical criteria and regulation is drawn up in the interest of health check users. Health check providers determine – within the limits of the law – which checks are offered to whom in which way.

In the now following outline of my thesis I will indicate how each subsequent paper relates to these issues and how they contribute to answering the research questions.

Content

This thesis starts at the beginning: Why do people participate in cardiovascular health checks and what are their reasons not to? The most remarkable fining in this literature review, is that potential users do not always make considerate decisions. People may test just because 'the test was offered'. (chapter 1)

Subsequently I report on the empirical research among health check providers (chapter 2) and (potential) users (chapter 3). In interviews and focus groups we researched how they define 'good' health checks (i.e. checks that are likely to benefit users, respectively checks people want to participate in or that they would recommend to others) and what role, if any, they see for the government in the regulation of health checks. Amongst others, results shed an interesting light on the feasibility of informed consent and whether information provision is likely to withhold people from participating in health checks that are likely to result in harm to health or other values.

The following papers are primarily about the effects of health check offers on users and non-users. A Foucauldian analysis of the question whether health check offers empower or discipline people helped to reveal which aspects of health check offers and other relevant variables mediate their effects on values which way. (chapter 4) In the fifth chapter we discuss the effects of 'omnipresent' health checks because existing proposals for the ethical evaluation of health checks consider health checks on a case-by-case basis only.

In the final chapter, I present the ethical framework for health checks that may be used to evaluate and improve health check offers. It is based on an inventory of the values influenced by health check offers and insights in how the expectation and capacities of (potential) users, the setting in which health checks are offered as well as their 'omnipresence' may be taken into account in formulating conditions health check offers and the societal context should meet to be ethically justifiable. (chapter 6)

The thesis concludes with a Discussion in which research questions are answered, and my insights regarding the issues underexposed in proposals for the ethical evaluation and regulation of personal health checks thus far are discussed. Furthermore, I will suggest that the ethics of and policy regarding health checks may benefit from a broader ethical approach. A good health checks isn't good enough if other health related measures would result in a more favourable net effect on values.

Laws

Act Exceptional Medical Procedures: Wet op bijzondere medische verrichtingen (WBMV))
Act on population screening: Wet op het bevolkingsonderzoek art 2 lid 1, art 7 lid 1, art 4 lid 1 (WBO)
Decree in vitro diagnostics: Besluit in-vitro diagnostica (IVD)
Healthcare Quality, Complaints and Disputes Act: Wet kwaliteit, klachten en geschillen zorg (Wkkgz)
Individual Healthcare Professions Act: Wet op de Beroepen in de Individuele Gezondheidszorg (BIG)
Medical Examinations act: Wet op de Medische Keuringen (WMK))
Medical Treatment Contracts Act: Wet op de Geneeskundige Behandelings Overeenkomst art 7:453 BW (WGBO)
Personal Data Protection Act: Wet Bescherming Persoonsgegevens art 8 (WBP)
Special Medical Procedures Act: Wet bijzondere medische verrichtingen (WBMV)

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Chapter 1

Reasons to participate or not to participate in cardiovascular health checks

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Reasons to Participate or not to Participate in Cardiovascular Health Checks: A Review of the Literature

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Cardiovascular health checks test risk factors for cardiovascular disease (CVD). They are offered to improve health: in case of an increased risk, participants receive lifestyle advice and medication. With this review, we investigate what is known about the reasons why people do or do not test for CVD risk factors. To what extent do these reasons relate to health monitoring and/or improvement? And do reasons differ in different contexts in which health checks are offered? We conducted a literature search and included 22 papers in which we identified a broad range of motives. We conclude that (i) people have reasons to test related to health improvement *and* reasons other than health improvement, (ii) practical reasons related to the way health checks are offered (facilitators and barriers) play an important role and (iii) motives should be understood in the context of the situation in which health checks are offered. Our results are relevant for public health officials and providers of health checks: first, if people undergo testing for reasons unrelated to health, this could explain why participation in health checks does not necessarily lead to health improvement. Second, efforts to improve uptake not necessarily serve justice and may hamper informed consent.

Introduction

Cardiovascular health checks test risk factors for cardiovascular disease (CVD) such as cholesterol, sugar levels and blood pressure. They often include an assessment of risk factors related to lifestyle such as obesity, smoking and a sedentary lifestyle. In case of an increased risk, participants are advised to change their lifestyle. Alternatively or additionally, medicines such as statines or beta blockers are prescribed.

Cardiovascular health checks are offered since the 1970s in very different settings, community-wide (NHS, 2014) or targeted towards high-risk groups (Dekker *et al.*, 2010) in a variety of cultures, by a variety of providers ranging from general practitioners (GPs) to commercial companies.

Health checks are offered as a means to improve individual and population health. Knowledge of the presence of risk factors may stimulate people to take action, either through lifestyle changes or by taking medication. Thus the development of CVD may be prevented. Many providers assume that participants test in order to monitor and improve health.

With this review, we investigate what is known about the reasons to participate in or refuse a test for CVD risk factors. Additionally, we ask two subquestions. To what extent do these reasons relate to health monitoring and health improvement? Do reasons to test and to refuse a test differ in different contexts?

Previously, Dryden and colleagues (Dryden *et al.*, 2012) explored the socio-demographic, clinical and social cognitive characteristics of those who do and do not test for CVD, including health beliefs and reasons (not) to test. In contrast, we focus on *reasons* (not) to test and reflect on the meaning of our results for the practice of cardiovascular health checks. We developed a more comprehensive search strategy that resulted in 12 extra papers on motives (not) to test. We included qualitative as well as quantitative studies on reasons reported by participants, non-participants and potential

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participants on why they do and do not test for CVD risk factors. For ease of reading, in the following, 'motives' and 'reasons' will be used interchangeably.

We first report the various reasons to be tested, differentiating between reasons related to health improvement, reasons related only to health monitoring without consequences for health improvement, reasons other than health and practical reasons related to the way health checks are offered (facilitators and barriers). Next we will describe the reasons not to be tested, using the same categories. Thereafter we we will answer the two subquestions.

Methods

Selection of Papers

The following databases and electronic journal collections were searched, dating from the earliest time available up to December 2013: Embase, Medline (OvidSP), Web of Science, CINAHL, Psycinfo (OvidSP), Pubmed, Cochrane and Google Scholar. The comprehensive search strategy (Supplementary Appendix) was directed towards the combination of health checks and motives, using both thesaurus terms and title abstract words for terms such as health check, general medical, preventive screening and attitude, motivation and reason.

We conducted a broad and inclusive search for several reasons. We aimed to investigate into the state of knowledge with regard to motives to test and motives not to test for cardiovascular health; multiple disciplines are involved in research on this subject and all relevant literature regardless of study design had to be identified (Arksey and O'Malley, 2005). Unfortunately, 'health checks' are not indexed in a consistent manner in databases such as Embase, listed as e.g. 'check up', 'preventive screening' or 'routine health examination'. Similarly, 'cardiovascular' was sometimes indexed as 'lifestyle'. A comprehensive search strategy would inevitably pick up a large number of irrelevant studies.

After deduplication, we identified 4048 articles. As is common in various types of literature reviews, our first step in eliminating studies that did not adress our research question, was to screen titles and abstract screened for relevance using endnote X7 (Arksley and O'Malley, 2005). That process (conducted by Y.S.) resulted in 58 papers that qualified for further investigation. Using the selection criteria listed below, Y.S. carefully reviewed the full texts of these 58 papers, E.A. did the same with the abstracts.

Inclusion criteria were (papers had to meet all three criteria):

(1) papers on cardiovascular health checks;
(2) papers on motives of (non)participants or potential participants;
(3) papers that reported empirical research.

Exclusion criteria were:

(1) papers in other languages than English;
(2) papers that were not available online;
(3) conference papers, letters, editiorials and book chapters;
(4) studies on correlations between characteristics and living conditions of (non)participants and their participation rate (these are not reasons);
(5) studies on motives of (non)participants or potential participants reported by others (e.g. nurses, GPs);
(6) papers with an inadequate methodology (clarity of aims, appropriateness and rigour of design and analysis, including risk of bias, and relevance of results).

Any doubts about inclusion of a paper were discussed between Y.S. and E.A., on the basis of the full texts. In cases where doubts remained, M.S. was asked for her opinion.

To ensure complete coverage of the literature, reviewing is an iterative process (Arksley and O'Malley, 2005). When agreement was reached regarding the papers that were to be included, hand searches of references were performed until no further papers were identified. The additional abstracts were screened for relevance, and inclusion and exclusion criteria were applied to the full texts. Any queries were dicussed and agreed upon between the three authors. In total, 22 papers were included (Supplementary Appendix): 10 qualitative, 8 quantitative, 4 that reported both qualitative and quantitative data.

Analysis

Y.S. and E.A. independently identified reported motives for (non)participation in the full texts and grouped those motives according to content while preserving detail. For example: the motives 'fear of the test procedure' and 'fear of needles' were grouped together, 'being afraid to find out something was wrong' and 'do not want feeling of health to be disturbed by the offer of a health check' were not. The identification and

Table 1. This table summarizes the studies included, and describes the main methodology and the context. The numbers assigned will be used for referring to the included papers throughout the review for ease of reading

Number	Study	Number of participants (P); Non-participants (NP); or potential participants (PP)	Moment of study (before/after the check)	Methodology (quantitative/qualitative; main research method)	Context
1	O'Brien and Hodes, 1979	P: 296 & NP: 131	After	Quantitative/qualitative: questionaire with open question	NHS check GP UK
2	Connelly and Mushlin, 1986	P: 38 requesting a health check	Before	Qualitative: semi-structured interviews	GP UK
3	Tymstra and Bieleman, 1987	P: 210 & NP: 90	After	Quantitative/qualitative: questionaire with open question	GP Netherlands
4	Pill and Stott, 1988	NP: 259	After	Qualitative: semi-structured interview	NHS check GP UK
5	Norman and Fitter, 1989	PP: 178	Before	Quantitative: questionaire	NHS check GP UK
6	Norman and Fitter, 1991a	P: 11	After	Qualitative: semi-structured interview	NHS check GP UK
7	Norman and Fitter, 1991b	PP: 131 (questionaire) & P: 11 (interview)	Before (PP) & after (P)	Quantitative: questionaire / qualitative: semi-structured interview	NHS check GP UK
8	Jones *et al.*, 1993	NP: 98	After	Quantitative: questionaire	NHS check GP UK
9	Norman, 1993	P & NP: 150	Before	Quantitative: questionaire	NHS check GP UK
10	Norman and Connor, 1993	P & NP: 818	Before	Quantitative: questionaire	NHS check GP UK
11	Elnicki *et al.*, 1995	NP: 188	After	Quantitative/qualitative: questionnaire with an open ended 'other' category	Poor rural community USA
12	Strickland and Strickland, 1995	NP: 444 (281 households)	After	Qualitative: door-to-door-interviews	Poor rural community USA
13	Shiloh *et al.*, 1997	PP: 68	Before	Quantitative: questionaire	Neighbourhood clinic Israel
14	Nielsen *et al.*, 2004	NP: 18	After	Qualitative: interviews	GP Denmark

(continued)

Table 1. Continued

Number	Study	Number of participants (P); Non-participants (NP); or potential participants (PP)	Moment of study (before/after the check)	Methodology (quantitative/qualitative; main research method)	Context
15	Wall and Teeland, 2004	NP: 67	After	Quantitative: questionaire	Local preventio program Sweden
16	Engebretson *et al.*, 2005	P (5 groups) & NP: (1 group): 2–29 per group	After	Qualitative: focus groups	Various settings in a semi-rural area USA
17	Lomas and McLuskey, 2005	P: 14	After	Qualitative: semi-structured interviews	NHS check in the workplace UK
18	Deskins *et al.*, 2006	PP: 36	Before	Qualitative: semi-structured interviews and focusgroups	Poor rural community USA: cholestrerol screening program in schools
19	Murimi and Harpel, 2010	P (3 groups) & NP (3 groups): 38	After	Qualitative: focus groups	Health outreach project Poor rural community USA
20	Ng *et al.*, 2012	PP: 497	Before	Quantitative: face to face survey	Low SES groups Asia
21	Juwita *et al.*, 2013	PP: 66	Before	Qualitative: focus groups	Preventive health program Asia
22	Søgaard *et al.*, 2013	P: 1053 & NP: 436	After	Quantitative: survey	Free screening trial Denmark

classification of motives were compared, inter-rater agreement was analysed and further discussions were conducted to resolve any discrepancies. When agreement was reached, the groups of motives were, in consultation with M.S., given a representative name, e.g. ‘reassurance’. Using these names, or ‘codes’, Y.S. and E.A. then independently scored the papers: marking which paper reported on which codes (representing groups of motives) and what was mentioned about the motives. Results were compared whereby occasional differences in coding were easily agreed upon (Flick, 2013).

Differences between Included Papers

We included qualitative as well as quantitative papers that report on reasons (not) to test for CVD risk factors; these were studies in which potential participants, participants and/or non-participants were asked for reasons (not) to participate in a health check. In one study, participants who requested a health check were asked about their reasons. The other studies report about reasons to participate or not to participate in health checks that were offered to them. In some studies people were asked before a test was offered, others interviewed respondents after they did or did not participate in a health check. Moreover, health checks offered in different settings and to different populations were studied. All these papers provide data for our overview of what is known about reasons (not) to test. The way these data were obtained however has implications for their meaning and analysis. We refer to Table 1 for an overview of the methodological differences of included studies.

Intention to test is no perfect predictor to actual testing. Therefore, the reasons potential participants give when they answer the question why they would or would not participate in a health check, should be considered with caution.

Questioning people after they (did or did not) test runs the risk of collecting post hoc justifications. However, reasons obtained before a test is offered may not reflect the real motivating reasons of people to test; these reasons can only be correlated to participation.

In qualitative research, such as interviews or focus groups, respondents are asked open questions. Reasons obtained from qualitative studies are rich in detail but cannot be generalized because the response group is usually small. Quantitative research uses questionnaires or surveys with pre-determined answer options. Respondents are asked to indicate which of the presented reasons apply to their decision (not) to test, but cannot add reasons themselves. The quantitative studies did not consistently list the same reasons as options, and inclusion of reasons in questionnaires as such does not mean these are frequently used reasons. Some reasons that are included in almost all questionnaires, are indicated by only a very small (<5%) percentage of the respondents. More importantly, quantitative studies may miss important reasons. Qualitative papers report on many more motives than the quantititative papers included in their questionaires. Therefore, it is theoretically possible that more people would participatie in a health check for one of the reasons only mentioned in the qualitative studies than for reasons mentioned in the quantitative studies.

Finally, included studies report on health checks offered in very different settings, to different populations.

To take these differences between papers into account and to be able to answer our subquestion on the influence of context on reasons (not) to test, we adopted a narrative synthesis approach (Popay *et al.*, 2006). That means we do not make statements on the relative frequencies of reasons from the data obtained (as a quantitative review would), but confine ourselves to a description of the reasons, and we pay special attention to the relation between reasons and context.

Results

Our main goal is to establish what is known about the reasons why people do or do not test for CVD risk factors. We will first report various reasons to test, then on reasons not to test. We discuss quantitative and qualitative data together, but indicate which reasons are collected from which (type of) study. Reference numbers relate to the included papers listed in Table 1.

Next we will address our subquestions: First, to what extent do reasons to test relate to health monitoring and improvement? Second, to what extent do reasons differ in different contexts?

Overview of Reasons to Test

People take tests for very different reasons. These can be categorized in reasons related to health improvement, reasons related only to health monitoring which does not have consequences for health improvement, reasons other than health monitoring and/or improvement and practical reasons related to the way health checks are offered (facilitators). The results discussed below are mainly derived from qualitative studies since only 4 of the 12 studies containing quantitative data report (health related) reasons to test [1, 3, 10, 13].

Health improvement

Many studies mention that people test to prevent and control CVD [2, 3, 6, 7, 10, 13, 16, 17, 19]. They want to obtain information about their health status. They hope everything is fine, but would also want to know if it is not. ‘It’s no good looking the other way’ [6]. They stress the importance of early detection: ‘If they find anything wrong then it is usually at an early stage this age’ [3]. ‘What we can do is have a better quality of life if we know something is wrong with us, if we can do something to make it better’ [16].

A second reason why people test, which is often mentioned, is health concerns due to symptoms, individual lifestyle habits or family members with CVD [1–4, 13, 16, 17, 19, 21]. ‘I wanted to find out about my physical condition because I smoke and have put on a bit of weight’ [3].

Third, some people test after a doctor’s recommendation [6, 7]. ‘I respect dr G (. . .) he’s a good doctor, and if he asks, he’s not asking without a reason, so I thought well I’ll go’ [6].

A final reason related to health improvement is that health checks can prompt lifestyle changes or monitor their effect, thus providing focus for behavioural change and positive action [16, 17]. This is the only reason related to health improvement not mentioned in quantitative studies.

Health monitoring: reassurance

Both quantitative and qualitative papers report that participants do not aim to improve their health, are not interested in information about risk factors, but seek reassurance. They want to be sure they have no reason to worry about their health [1, 2, 4, 6, 13, 19]. ‘I didn’t think they were checking on me because there was something wrong with me. Well, it’s just nice to know you’re allright’ [6].

Reasons other than health monitoring and/or improvement: establishing contact with a physician; the influence of others and 'fun'

The following reasons to test were only mentioned in qualitative studies. The four quantitative studies on reasons to test did not include these motives in their questionnaires.

For some, the establishment of contact with a physician is the principal reason why they attend a health check [2, 17]. Lomas and McLuskey [17] state a cardiovasucular health check creates a forum to discuss other health issues with a professional. According to Connely and Mushlin [2] these 'other' problems are often psychosocial in nature.

A second reason to test other than health monitoring and/or improvement is the influence of others [2, 16, 17]. A positive screening experience of friends, family or colleagues functions as a motivating factor [16, 17]. Some people test to satisfy relatives [2, 16]. According to Engebretson and colleagues [16], often one family member, typically the wife, makes the decision to attend a screening for the whole family.

Finally, people test out of curiosity, for the 'fun' of it [16, 17]. Engebretson and colleagues [16] report on participants comparing their results as in a sporting competition.

Practical reasons/facilitators

The fourth category of 'reasons' is very practical. When asked why they test, many people come up with practical justifications: it was a good occasion to test [3, 6, 7, 16, 17, 19]. Convenient locations with wide opening times, services free of charge, free food, etc. encourage people to get tested. For example: 'It was a work-day, so we went' [16]; about a health check at the office, 'I got the invite, so I went' [17]; or 'because I was invited' [3]. Convenience is also mentioned in one of the quantitative studies on motives to test [6].

Overview of Reasons Not to Test

Reasons not to test vary widely as well. We categorized, as before, the practical reasons not to test related to the way health checks are offered and can be seen as barriers.

Health improvement

First, not everyone has questions about their health for different reasons. Some people feel healthy and fit, and therefore have no concerns about their health status. They consider their risk on cardiovacular disease to be low, for example, because they work out and do not smoke [4, 5, 7, 8, 10, 13–16, 19, 21]. Others have no questions about their health status because they already are in contact with medical services and therefore do not need a check [1, 3, 4, 7, 8, 15, 16, 19]. 'I see my doctor every year' [16]. Some of them are aware of their risk status, for example, because they just had a check up [1, 3, 4, 8, 14].

The second reason related to health improvement why people refrain from testing is that some people have no faith in screening. They do not think that screening is beneficial in reducing the threat of cardiovascular diseases [13, 14]. Some of them point to the limitations of screening: no risk factors today are no guarantee that disease will not start developing tomorrow. 'A health screening like that is a bit . . . sort of tricky. . . I mean, you get al false feeling of security in a way. There are things you can't check upon. One can go along to the health screening, but you have no guarantee that you won't get ill anyway . . .' [14].

A third reason not to test, is that people consider health care as only for those who feel ill. This reason is only reported upon in qualitative studies [4, 11, 14, 16, 18, 19, 21]. People do not seem to be used to seeing a doctor when they do not feel sick. Some of them are are uninformed about prevention [11, 18, 21]. 'They don't know that cholesterol and heart disease fit together' [18]. Others state that the doctor's time should be saved for those who really need it [14, 21]. The Malay women Juwita and colleagues interviewed, perceive it as 'inappropriate' to ask for screening if they are healthy. The majority of health personnel would be too busy handling ill patients [21]. Nielsen and colleagues' [14] respondents from Sweden state that individuals have their own responsibility for maintaining and restoring good health and that they should contact their GP if they had symptoms.

Finally, and also exclusively mentioned in the qualitative studies, some people put a low priority on health care and therefore do not attend health checks [12, 16, 18, 19]. It is noteworthy that these people come from poor, rural communities.

Health monitoring: concerns with the outcome of testing and the wish not to be informed

A reason not to test that is mentioned in a lot of studies is that people have concerns with the outcome of testing: they are afraid to find out something is wrong [3–5, 7, 8, 13, 14, 16, 18, 19, 21]. Interestingly, some studies report that people might be worried, but the worry is not their reason for non-attending [3, 4].

Some people do not even want to be informed about the possibility of a health check [14, 16, 22]. They do not want their subjective feeling of health to be disturbed.

The mere offer of a check could give them a guilty conscience and hence would influence their quality of life in a negative way, they state [14]. Another reason why people do not want to be informed about a health check is that some people believe that doctors should mind their own business; individuals have an incontestable right to determine their own lifestyle and to enjoy risky habits [14].

Other reasons than health monitoring and/or improvement

Some people explicitly state they just 'don't like doctors' and therefore do not attend screenings [1, 4, 11, 16]. As Engebretson *et al.* [16] point out, a lot of people do not attend screening for the same reason they do not like doctors. Doctors and sceening tests raise concerns about the screening appointment, for example, because people are afraid of needles [1, 4, 5, 8, 16, 18, 20]. Dislike of doctors may also refer to a resistence to new people and ideas. One of the respondents of Deskins and colleagues study in a poor rural community: 'This is a very inward focused community, and when you're coming in from the outside and people don't know who you are, it's hard... It has to be a member of the community, like an already establised doctor' [18].

Another reason that is mentioned in qualitative studies of poor communities is costs. Qualitative studies report that even if screening is free, further diagnostics might entail costs. Some people do not want to get tested because they are uninsured and therefore face not only the costs of the screening but also additional costs [3, 11, 12, 16, 18, 19]. 'I have no money, I feel fine. And why would I want to find out there is something wrong with me?' [16].

A further reason not to test that is unrelated to health monitoring and/or improvement, again only mentioned in qualitative studies, is concerns about privacy and confidentiality [16, 17]. 'Who is going to see it? What are they going to do with it?' [16]. People are afraid results may be disclosed to, for example, their place of employment. Related is 'embarrassment' as a reason not to undergo tests. People worry what the doctor or other people that may find out about their health status would think [4, 5, 7, 9, 10, 16].

A final reason not to test that is unrelated to health monitoring and/or improvement, is that people do not want to come to a health check alone, but do not have anyone to accompany them [19].

Practical reasons/barriers

A lack of time, no time, being busy, family and work responsibilities are frequently mentioned reasons not to get tested [1, 3–7, 9, 11, 12, 14–16, 18, 19, 22]. 'I work full time, so it's difficult to get time off. (...) It wasn't that I didn't want to come, it was just the circumstances and the timing that was a bit difficult.' [6].

A second practical reason not to get tested is a lack of knowledge or information about the possibility to check upon cardiovascualr riskfactors [4, 5, 7, 8, 11, 18, 19, 21]. People were not aware of the program or did not recall being invited. A lack of knowledge about the target-population (eg the perception that screening is 'only for the elderly') is also a reason not to participate [18, 19].

Accessibility is a third barrier [4, 5, 7, 11, 18, 20, 22]. Not all the screening facilities are easily accessible. Transportation problems and opening hours are barriers to participate in screening. Some people do not participate because they have no one to drop them off [20, 22].

Finally, qualitative studies report that some people did not get round to it, were too lazy or just forgot to attent to the health check [3, 4].

Subquestion 1: It is Not All About Health

Not all reasons to test or to refrain from testing are related to health. This is abundantly clear from the third and fourth categories of reasons: reasons unrelated to health monitoring and/or improvement and practical reasons.

It is noticable that only four quantitative studies researched upon reasons to test (instead of reasons not to test), and that the answer-options in these studies were exclusively health related: 'I test to prevent and control CVD', 'I test because of health concerns' or 'I test to reassure myself I'm healthy'. The qualitative studies showed people have have a wider variety of reasons to test. People also test for reasons unrelated to health monitoring and/or improvement: to establish contact with a physician, for the fun of it or for the interest of others. Participating in a health check because the timing or location is so 'convenient' could perhaps better be called a reaction to the way the test is offered than a considered choice.

Subquestion 2: The Context Dependency of Reasons

There is evidence to suggest that reasons are context-dependent.

When we compare the studies performed in the UK on NHS health checks offered via GPs [1, 4-10] with those performed in the USA in poor rural populations

[11, 12, 18, 19], it appears that one's concern about health and the associated interest in a health check is interdependent with knowledge and economic means to pay for insurance and/or treatment. Interviewees from poor, rural communities consistently mention 'costs' and or a lack of insurance as a reason not to participate in a health check [11, 12, 18, 19]. They also report limited knowledge on the goals and means of prevention [11, 18], and do not like doctors and/or inference from people outside their community [11, 18]. It seems that a lack of knowledge and economical means can result in a disinterest and a feeling that one does not 'need' a health check [11, 12, 18]. A parent from Appalachia: 'I'm 33 and I never had my cholesterol checked. I've no idea what it is, personally I don't care' [18]. Lower income African American respondents interviewed by Strickland and Strickland [12] in poor rural counties stated they 'did not need' a health check, while the program directors and service providers that were interviewed stated these people emphatically did.

These reasons not to test given by poor, uninsured Americans from rural counties were present in none of the other papers. In constrast, respondents from the studies performed in the UK on publicly funded NHS health checks offered via GPs mostly indicate practical barriers such as time and a lack of knowledge about the program [1, 4–10]. This contrast is a clear indication that motives (not) to test depend on the (economic and health care) context in which health checks are offered.

In addition, some findings point to another context dependency of motives. First, in the only study among people who requested a cardiovascular health check (in contrast being offered one), psychosocial problems were the primary reason for people to come to see their physician [2]. Psychosocial problems were mentioned in none of the other included studies. It could very well be that people that request a health check have different motives than people that take up the offer of a health check.

Second, the Malay women Juwita and colleagues interviewed, perceived it as 'inappropriate' to ask for screening if one is healthy [12]. This 'politeness' is not present in the other papers we included, which (except for [20]) report on Western studies. This could indicate that cultural differences influence motives (not) to test.

Discussion

We identified a broad range of motives (not) to test for CVD risk factors. People participate in cardiovascular health checks for a wide variety of reasons that certainly do not all relate to health improvement. It seems that the reasons differ in different contexts.

Limitations of the Study Approach

Despite our extensive search strategy, we may have missed one or more relevant papers. However, we identified 12 extra papers on reasons (not) to test that were not included in the review by Dryden *et al.* (2012).

Secondly, our conclusions are based on a classification of identified motives in categories decided upon by the authors, and are therefore somewhat subjective. However, this research strategy is common in qualitative research (Flick, 2013). Our categories and conclusions are firmly grounded in the data.

Thirdly, as explained before, we can not and do not make definite statements on the relative frequencies of reasons for the studies included differ in too many aspects: (i) in when they asked for reasons (not) to test, (ii) in whether they interviewed potential participants, participants and/or non-participants, (iii) in their methods used and (iv) in the context health checks were offered.

Change in Lifestyle Without a Health-Related Reason to Test?

Because cardiovascular health checks are offered to improve individual and population health, the assumption (of providers) is that the target population would test for the same reason: health improvement.

As we have shown, people also test to establish contact with a physician, for the fun of it, for the interest of others or because it was 'convenient'. The last group is very much influenced in their decision to participate by the manner in which health checks are offered. When the context facilitates testing, they test, when they perceive barriers, they opt not to.

Does it matter if people test for a reason or because it is convenient to do so? Does it matter whether this reason is related to health improvement or not? We believe it matters because it could partly explain why participation in health checks does not necessarily lead to improvement in cardiovascular health, as recent reviews show (Krogsboll, 2012; Si *et al.*, 2014). When people do not test in order to improve their health, why would they follow through with lifestyle changes or other interventions after receiving their test results?

As health checks appear to be offered to improve health, and there are many studies to attempt to improve the uptake of health checks. This is reflected in the questionnaires of the quantitative papers that focus on reasons related to health improvement and barriers. Many of the included studies examine reasons not to test because knowledge of barriers would make it possible to adjust the offer of health checks in such way that uptake improves [1, 5, 7, 9, 11–13, 15–18, 20, 21]. However, removing barriers not only facilitates testing for those who want to improve their health but perceive too many barriers to check, but will also result in more people that check because it is 'convenient'.

Justice is Not Just About Uptake

Another line of argumentation behind the efforts to improve uptake is related to justice. When it comes to justice, health checks are often criticized as mainly serving the 'worried well'. Because uptake is higher among healthy people than among those who really need it, inequalities in health would increase rather than decrease due to the offer of health checks: the inverse care law (Hart, 1971). The question raised is which barriers prevent participation of people with a low socioeconomic status (SES). In order to allow equal participation of those of lower SES, special efforts are made to entice them to participate (by making it convenient, offering free food, etc).

Interest and uptake of health checks is indeed low in the studies on low SES communities [11, 12, 18, 19, 20]. However, it appears that one's concern about health and the associated interest in a health check is interdependent with knowledge and economic means to pay for insurance and/or treatment. In circumstances where the latter are insufficient, health checks are not the best approach to improve health. Strickland and Strickland's [12] respondents state they 'do not need' a health check while they medically do. Perhaps respondents highlight that a health check is not what they need most. As the authors of this paper state: when households deal with budgets of $2500 to $5000 per year, food, shelter and basic clothing is considered 'needed'. Indoor plumbing, heat and transportantion is not. Except in the most extreme cases, medical services are considered a luxury [12, see also: Strickland and Strickland, 1996]. The health of people with a low SES would likely improve more by improvement of their general living conditions than by the offer of a cardiovascular health check.

To us, it seems that justice in these instances is about more than equality in uptake. Justice may better be served by ensuring a level playing field where the minimum standards for healthy living are met, rather than aiming at equal access to health checks.

The Different Faces of 'Peace of Mind' and Autonomy

Some people have well-considered reasons for choosing to test or not. However, the same motive can result in opposite outcomes through differences in reasoning: Some people test to reduce their fear of CVD, to be reassured they are healthy. Others are so afraid of CVD that they choose not to test: they are frightened of the possible outcomes. Both groups share the value 'peace of mind' although this results in opposite choices. Peace of mind is also key for those who state that the offer of health checks makes them feel guilty and who therefore refrain from testing [14].

Dependent on whether or not people want to improve their health, health checks can increase as well as decrease feelings of autonomy. For those motivated to improve health, the offer and results of a health check may act empowering: it might motivate them to make the lifestyle changes they were intending to make before. On the other hand, people with different priorities than health improvement perceive even the offer of a health check as an infringement of their freedom to live life as they choose [14]. Information, and even just the offer of information, increases one's responsibility: knowing that there is something that you can do to improve your health entails having to make the choice to do so or not, and subsequently the responsibility for the consequences of this choice.

Before implementing or offering cardiovascular health checks, public health officials and providers of health checks should realize and take into account that people interpret and pursue values such as peace of mind and autonomy in very different ways.

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Supplementary Data

Supplementary data are available at *PHE* online.

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Chapter 2

What is a good health check?

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RESEARCH ARTICLE Open Access

What is a good health check? An interview study of health check providers' views and practices

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Abstract

Background: Health checks identify (risk factors for) disease in people without symptoms. They may be offered by the government through population screenings and by other providers to individual users as 'personal health checks'. Health check providers' perspective of 'good' health checks may further the debate on the ethical evaluation and possible regulation of these personal health checks.

Methods: In 2015, we interviewed twenty Dutch health check providers on criteria for 'good' health checks, and the role these criteria play in their practices.

Results: Providers unanimously formulate a number of minimal criteria: Checks must focus on (risk factors for) treatable/preventable disease; Tests must be reliable and clinically valid; Participation must be informed and voluntary; Checks should provide more benefits than harms; Governmental screenings should be cost-effective. Aspirational criteria mentioned were: Follow-up care should be provided; Providers should be skilled and experienced professionals that put the benefit of (potential) users first; Providers should take time and attention. Some criteria were contested: People should be free to test on any (risk factor for) disease; Health checks should only be performed in people at high risk for disease that are likely to implement health advice; Follow up care of privately funded tests should not drain on collective resources.

Providers do not always fulfil their own criteria. Their reasons reveal conflicts between criteria, conflicts between criteria and other ethical values, and point to components in the (Dutch) organisation of health care that hinder an ethical provision of health checks. Moreover, providers consider informed consent a criterion that is hard to establish in practice.

Conclusions: According to providers, personal health checks should meet the same criteria as population screenings, with the exception of cost-effectiveness. Providers do not always fulfil their own criteria. Results indicate that in thinking about the ethics of health checks potential conflicts between criteria and underlying values should be explicated, guidance in weighing of criteria should be provided and the larger context should be taken into account: other actors than providers need to take up responsibility, and ideally benefits and harms of health checks should be weighed against other measures targeting (risk factors for) disease.

Keywords: Health check, Screening, Ethics, Criteria, Interviews, Qualitative research, Informed consent

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Background

Population screening and personal health checks: Benefits and harms

Health checks identify (risk factors for) disease.[1] Unlike diagnostic tests, they are offered to or requested by people without specific symptoms. [1] Health checks can also be referred to as preventive or presymptomatic tests, medical screening or preventive medical examinations. For ease of reading, 'health check', 'check' and 'test' are used interchangeably throughout this paper.

Health checks may be offered by different providers. If provided by the government we refer to them as population screening programs. In the Netherlands, there are population screening programs for breast cancer, bowel cancer and cervical cancer. In the United Kingdom, there is also screening for risk factors for cardiovascular disease (CVD). Typically, people in the target group receive an invitation to participate. Most population screening programs are provided free of charge.

Health checks may also be provided by other parties, and this is increasingly the case. In the Netherlands, physiotherapists, pharmacies, General Practitioners (GPs), gyms, Non Governmental Organisations such as the Heart Foundation, specialized medical centres and companies offer checks on a wide variety of (risk factors for) disease, including cancer and CVD. Examples include the total body scan, tests for prostate specific antigen (PSA) and genetic tests. Because these tests are not offered to (sub)-populations but to individuals – through advertisements for example – we will refer to them as 'personal health checks' throughout this paper. Note that the distinction between population screenings and personal health checks depends on whether the offer is directed at a population or at an individual. The same test can be used in population screening programs and as personal health check.

Population screening programs and personal health checks can provide insight into one's health status. When risk factors or latent disease are uncovered, preventive action may improve health. However, not all conditions are treatable. In addition, false positive or negative results may lead to unnecessary treatment or unjustified reassurance with potentially negative consequences for health. If the course of disease is hard to predict even accurate diagnosis may lead to overtreatment. Some tests carry risks in themselves, such as invasive tests or tests using radiation. [2] Moreover, health check offers may indirectly result in decreased health solidarity and unfairly distributed health outcomes. [3] The weighing of benefits and harms for individuals and society requires ethical evaluation. [1–3]

Ethicists usually do not distinguish between population screening and personal health checks when it comes to benefits and harms and the weighing thereof. [2, 4–6] This is different however in policy and regulation.

Evaluation of population screening and personal health checks in policy, law and regulation

Traditionally, policymakers and public health professionals use ethical criteria for responsible screening, derived from the Wilson and Jungner criteria, to evaluate whether or not population-screening programs should be offered. [7–10] Criteria for responsible population screening state that the screening should have clinical utility[1], the benefits for the participants must outweigh the drawbacks, the test method must be both analytically valid[2] and clinically valid,[3] participation must be voluntary and based on reliable information, the offer and performance of screening should be in accordance with patient- and consumer rights, and the screening must be responsible in terms of the use it makes of public and collective health service resources. [summary derived from 5] There is discussion about whether or not specific population screening programs meet these criteria, but the criteria themselves are relatively uncontested. [9] In the Netherlands and Belgium there is also legal evaluation of population screening. [11, 12] In the Netherlands this concerns a mandatory permit for screening that uses ionizing radiation, aims to detect cancer or diseases for which there is no treatment or prevention. Grounds to refuse a permit are (i) the screening test is scientifically unsound; (ii) the screening does not conform the legal rules for medical treatment; (iii) the expected benefit of the screening does not outweigh the risks for the participants. To determine the risk–benefit ratio for participants, the Wilson and Jungner criteria are used. [9]

As stated, most ethicists think that the Wilson and Jungner criteria are also applicable to personal health checks. [2, 4–6] However, policymakers disagree on the question whether personal health checks – like population screening – should be regulated and if so, which criteria should be used. For the ethical evaluation of personal health checks, several policy proposals have been made.[4] On a European level quality criteria have been developed [13], in the United Kingdom, principles for direct to consumer genetic tests have been designed that may be applied to all personal health checks across all jurisdictions [14], the Health Council of the Netherlands (HCN) has written on the ethical evaluation of personal health checks [1] and the Royal Dutch Medical Association has published a guideline. [15] The latter has been withdrawn but was in operation during the time of this study. In the Netherlands – as in other European countries – there is limited regulation of personal health checks. [11] Several parties have indicated that more regulation, or more compliance with and oversight of existing laws and regulations, is necessary to protect citizens against harmful effects of personal health checks. [1, 12]

As yet, there is no consensus on the criteria for 'good' personal health checks. The criteria in existing policy proposals vary, but are less stringent than criteria for responsible population screening: For example, none of the published guidelines mentions clinical utility and cost-effectiveness. [1, 13–15]. Clinical validity is only considered a criterion by the HCN [1], analytic validity by the HCN [1] and HGC. [14] Just as criteria for responsible populations screening, criteria for personal health checks mention informed consent. [1, 13–15] The question why criteria for personal health checks divert from criteria for responsible population screening, is answered by the Health Council of the Netherlands stating that 'health gains are not necessarily a precondition for the individual. For the individual, the results obtained may be of use purely as information or they may be valuable in terms of reassurance. Also, cost-effectiveness is not a prime concern for the individual.' [1]

Towards a new ethical framework for personal health checks

There is currently much public, policy and political debate in the Netherlands on the regulation of health checks. [16–19] This study aims to contribute to an ethical framework for responsible offers and use of personal health checks. We aim to formulate context-sensitive yet general criteria that – like the Wilson and Jungner criteria – may be applied to all sorts of tests. Criteria may also help providers in evaluating and adjusting their health check offers.

In order to develop ethical criteria for personal health checks that may be used to inform policy, the experiences and perspective of all stakeholders should be considered as they may identify different values, ethical dilemmas and practical barriers. Here we describe the results of an interview-study of providers' views on criteria for good health checks. The perspective of health check providers is of particular importance, because they – within the limits of the law – determine which checks are offered to whom in which way. First, if their perspective differs in important aspects from criteria, a non-binding guideline may not suffice to improve the offer of health checks. In fact, this is one of the reasons that the aforementioned guideline of the Royal Dutch Medical Association has been withdrawn: its effects were limited because commercial providers of health checks did not endorse it. [20] Second, providers are well positioned to identify practical and ethical barriers in the implementation of ethical (criteria for) personal health checks. Some of these may be removed.

In our interview-study with a wide range of providers, we investigate what they consider criteria for 'good' health checks, whether they differentiate between criteria for population screening and for personal health checks, and we explore what role the aforementioned criteria play in their practices.

Although providers have been involved in the development of earlier criteria and guidelines [1, 13–15] and have been interviewed about the desirability of particular health checks in evaluation studies (e.g. [21, 22]), this is – as far as we know – the first paper on the views of a wide range of providers on general criteria for good health checks (i.e.preventive or presymptomatic tests) would be.

Of course, the criteria as formulated by providers should not be taken as a final say, but used as input in the ethical and policy debates over the right criteria. We therefore also provide an ethical evaluation of providers' criteria and practice.

Methods

Interviews

Twenty semi-structured interviews were conducted in Dutch by Yrrah Stol (YS) in 2015 lasting 45–90 min. With one exception, interviews were conducted at the workplace of providers of health checks. Respondents were asked to share their opinions freely and were assured their answers would be anonymized. They all consented to publication of findings. We asked them what kind of check(s) they offer, their reasons for doing so, and the benefits and potential drawbacks of these checks. Subsequently they were asked an example of a good personal health check, and what general criteria for 'good' personal health checks would be. Similar questions were raised about 'bad' checks. Although we did define health checks ('checks on (risk factors for) disease in people without specific medical indication') we deliberately left open the question of what aspects of a 'good' or 'bad' check would be so that respondents were free to mention test- and disease characteristics, but also features of the provider, offer or context in which this offer is made. Providers were also asked what they would consider desirable policy concerning personal health checks. Finally, we asked them whether their current practice leaves room for improvement and how this may be achieved. (Additional file 1) Before the start of the interview, we told providers interviews would be used to inform an ethical framework for health checks that we are developing to guide policy.

Participants

Interviews were conducted with direct providers as well as managers of health check businesses: GPs (GP), physiotherapists (PHY), health and safety officers (HSO), pharmacists (PHA), population screening program officers (PSPO), screening by GP program officers (GPSPO), independent treatment centres providing insured (ITC-I) and uninsured (ITC-U) care, and Internet based companies (IC). (Additional file 2) They offered the following health checks to the Dutch public: tests for cardiovascular risk factors (sugar, blood pressure, cholesterol, BMI, questionnaire on lifestyle), tests for cancer (PSA test, rectal examination, mammography, cervical smear, stool test), total body scans, and other blood tests (e.g. sexually transmittable diseases (STD) tests, thyroid- kidney- and liver function, vitamin-, mineral- and hormone tests, hepatitis B&C tests).

We chose the range of providers based on our own knowledge of the field. We included both providers of all commonly performed checks (such as cholesterol tests and governmental screenings) and providers of the checks that are currently widely discussed in the Netherlands (such as the total body scan and PSA tests). Although they themselves do not provide personal health checks, governmental screening officers were approached because of their knowledge of the field. Our aim was to include a sample of health check providers that was as diverse as possible because different providers may stress different criteria. We interviewed medical specialists in commercial and regular care,[5] directors and key players of big organisations as well as health check providers in one-man companies, providers that conduct health checks face to face as well as those who supply via Internet. Sex and age of providers were no selection criteria, as we did not consider it likely that these characteristics would influence criteria. We identified individual candidates from our own network, through an internet-search, via other experts on health checks in the Netherlands and via snowballing. Providers were approached by e-mail and then called by telephone to ask whether they were interested to be interviewed. Of the twenty-eight providers that we approached, twenty agreed to an interview. We managed to arrange interviews with major players in the field. However, we did not succeed in including 'small' commercial providers without a (para)-medical background: five of the eight providers that declined were small commercial providers.

Saturation as regards to criteria for health checks was reached long before the last interview.

Analysis

Interviews were recorded and transcribed verbatim. They were coded using NVIVO 10.2.2 for Mac focusing on characteristics of 'good' and 'bad' tests. An initial list of bottom-up derived codes reflecting characteristics of good and bad health checks and a range of other themes (such as information, autonomy and the organization of healthcare) was composed and discussed between YS and Eva Asscher (EA) after 10 interviews. Additional bottom-up codes were added during the analysis, staying close to the content of the answers of respondents. Similar codes were merged. Two interviews were double-coded by EA to ensure agreement about the codes, there was agreement about the codes used. Analysis of codes to results was done by YS in close consultation with EA and Maartje Schermer (MS). Quotes were translated from Dutch to English by YS.

As we concentrate on criteria for good health checks in this paper, we report on provider's reasons for offering checks and their opinion on policy only when relevant.

Results

Criteria for good personal health checks

Providers consider characteristics of the test itself, the disease tested on and how health checks are performed (the offer, provider and target population) part of what makes a test good or bad.

We divided the criteria mentioned by providers in three categories: Minimal criteria were (almost) unanimously mentioned by interviewed providers. These criteria are moreover decisive in the distinction between good and bad test: respondents described tests that do not meet minimal criteria 'bad'. E.g. a good test is reliable and valid, a bad test unreliable and invalid. Aspirational criteria were mentioned by only part of the providers. Checks that do not meet these criteria are not necessarily considered 'bad', respondents merely think that health check offers could be improved by complying with these criteria. Contested criteria are aspirational criteria where providers (heavily) disagree about.

We discuss all types of criteria and illustrate them with quotes. The selection of quotes is based on their conciseness and appeal, and represent different providers. For reasons of anonymity, we may leave aside whether providers refer to their own health checks or the offer of others.

Criteria are summarized in Table 1.

Minimal criteria

1. *Health check results must provide clear opportunities for health improvement*

To benefit users, nearly all providers state that a good check must provide clear opportunities for health improvement:

> First and foremost, you should perform a test only in those cases in which you can act on the results, the condition should be treatable, it should be possible to relieve symptoms [once they present themselves YS]. But preferably that you can detect it in such an early stage that it can be prevented. That, for me, is the main characteristic of a good test (HSO).
>
> In the end, it has to be a treatable condition. (GP).

Table 1 Minimal, aspirational and contested criteria for good personal health checks as formulated by interviewed providers

Minimal criteria	Treatability of (risk factors for) disease: Health check results must provide clear opportunities for health improvement
	Clinical validity: Health check results must be valid and reliable indicators for (risk factors for) disease
	Informed consent: Participation must be voluntary and based on reliable information
	Health checks should provide more benefits than harms
	In case of population screenings: cost-effectiveness
Aspirational criteria	Follow-up care should be provided, including objective explanation of test-results and facilitation in the realization of health benefits
	Providers should be skilled and experienced professionals that put the benefit of (potential) users first
	Providers should take time and attention
Contested criteria	People should be free to test on any (risk factor for) disease, provided they are well-informed
	Assessment before the test: Health checks should only be performed in people at high risk for disease
	Follow up care of privately funded tests should not drain on collective resources

(Risk factors for) disease must be treatable either through preventive lifestyle changes, medical intervention or changes in the environment. Moreover, providers almost unanimously characterise health checks that (also) test for diseases for which no treatment or prevention is available as ‘bad’; these would harm users by causing concern and a loss of experienced health:

> You have to be able to act on it. You need to give a therapy option. If you don’t have one (…) one becomes worried and therefore it is not a good test (ITC-U).

The total body scan[6] is an often-mentioned example of a test that may reveal untreatable conditions.

2. *The health check must be reliable and valid*

The second criterion providers almost unanimously mention is that personal health checks must be reliable and valid tests. Providers stress both the importance of analytical and clinical validity: If the conditions remain the same, results should be consistent, and personal health checks should accurately predict the presence or absence of the (risk factor for) disease. This is operationalized in a high sensitivity and specificity and good positive and negative predictive value for the (risk factor for) disease:

> A reliable, valid test, that is [criterion] one (PHA).

> The higher the sensitivity, the higher the specificity, the better it is (ITC-U).

It is remarkable how many providers stress the importance of combining tests for risk factors: this would give a better indication of disease developing in the future. According to providers, risk factors for cardiovascular disease (CVD) should be considered in combination, and Prostate Specific Antigen (PSA) should be checked in combination with a rectal examination:

> Cholesterol alone is not enough. For only a part of a cardiovascular risk profile, but that’s it. (…) If you want to compose a cardiovascular risk profile.. Then I would say yes that makes sense (HSO).

> 80% of the men referred (…) [to this clinic] with an increased PSA did not get a rectal examination. The first step in diagnosing prostate cancer.. 80% did not get a rectal examination (ITC-I).

Checks that do not meet the reliability and validity criterion are characterized as ‘bad’ by nearly all providers because they may harm individuals. People should not be falsely reassured and false positive test results should be kept to a minimum because they may cause medicalization, unnecessary worries, over-treatment and unnecessary burdens on the health care system:

> R: Sensitivity and specificity are truly essential. (…) I think that there are many health checks in which the tests are such that they result in a substantial amount of false positives. I think yes, many worried people will be referred with all the associated consequences. I: What consequences do you have in mind? R: overdiagnosis to start with, more referrals to health care, perhaps burdensome examinations, a trajectory full of uncertainty (PSPO).

A test on total-cholesterol is an often-mentioned example:

> It tells you nothing, total cholesterol. It can be five or four, you think great, but it could be that the [LDL/HDL] relation is skewed, so these people are left none the wiser: you’re okay. I consider that even worse (ITC-U).

3. *Participation must be voluntary and based on reliable information*

Providers consider it problematic when people feel pressured or are actually pressured to test due to the conflict with self-determination:

> Some people want to know, and others do not at all. People should be free in this decision. One certainly should have the opportunity to say 'No, I prefer not to know' (GPSPO).

Good information is almost unanimously mentioned as characteristic of a good check. Potential users should be informed about the advantages, disadvantages and limitations of the check beforehand to ensure informed consent (or dissent):

> I consider that one of the most important criteria for good health checks, and that is that you provide people with sufficient and reliable information in advance (ITC-U).

> Good information is very important, according to me. And good information may also result in a decision not to test (HSO).

Some providers also explicitly state they consider a check 'bad' when informed consent is lacking.

4. *Health checks should provide more benefits than harms for the individual*

Some providers explicitly mention this overarching criterion:

> The balance between pros and cons, that is crucial to me (PSPO).

> There are two sides to each check. (…) You aim for something that people.. which is quite specific .. where people can act upon, where they can do something about. (...) But the downside, the risk is always that it leads to medicalization (HSO).

Many state that health checks should not cause direct harm and only minimal burden. In fact, they almost unanimously state that the government should forbid the offer of directly harmful tests (eg using X-rays)[7] or should ensure these tests meet high quality standards:

> People need to be protected against unsound or really dangerous tests. So it should be possible to ban unsound or dangerous health checks (ITC-U).

Often this criterion refers not only to the test itself, but also to the whole trajectory of testing and treatment. Many providers express worries concerning overtreatment of prostate cancer which may cause impotence and incontinence while the detected cancer may not have resulted in health problems:

> It results in a nasty urological treatment, that could be useful for some, but is not for the majority (GP).

To assure health benefits and to avoid harm, the presence of disease should have implications for (future) wellbeing.

In case of governmental screening programs, interviewed providers formulate an additional minimal criterion:

5. *Health checks should be cost-effective*

Providers differentiate between personal health checks and governmental screening programs when it comes to the cost-effectiveness of the check. Governmental screening programs should be cost-effective: the costs of the screening program should be in proportion with the expected gain in health.

> Costs certainly play a role in governmental screening programs. The tests should be affordable. (PSPO).

> An individual check up is very different to population screening in this regard. For the moment you'd say 'everybody between age fifty and seventy gets a [free YS] total body scan', you'll make costs of formidable size (ITC-U).

Aspirational criteria

1. *Follow-up care should be provided, including objective explanation of test-results, referral to specialized care and assistance with the realization of health benefits*

Many providers stress that results are meaningless unless properly interpreted and put in perspective. Explanation of results may also prevent harm resulting from overtreatment and unnecessary worries. An often-mentioned example in this regard is the PSA test. Providers should take sufficient time to explain that prostate cancer need not always to be treated but may in some instances better be monitored with regular rectal examinations, PSA tests, biopts and/or MRI's.

Interviewed providers also stress that users need to be referred to specialized care if tests results warrant so.

Finally, to realize health benefits after the test, users should be informed about, advised on, and – according to some providers – if necessary assisted with the realization of treatments and/or lifestyle adjustments:

> If a doctor says "go exercise more", that is one thing, but to actually do it is something altogether different. And I often think that many people really need a big stick and need some advice. It is often easier said than done is my experience. (Physiotherapist).

2. *Providers should be skilled and experienced professionals that put the benefit of (potential) users first*

Many providers think that health checks should preferably be offered and performed by skilled and experienced health care professionals because they have the capabilities to properly inform (potential) users about the benefits and harms of a test, to interpret test results and to explain their relevance to users:

Quality has to do with the quality of the test, and with the quality of the doctor. A test may have a high sensitivity, high specificity, but if the doctor is not able to interpret the results … I always stress, I find it very important that people realize that early diagnosis is a profession. In everybody I investigate I'll find something. Of course, because I'm looking at a body and no one body is built the same, so you'll always find variations on the norm. And it's very important to get to know those variations on the norm so you know when to act and when not to do so. (ITC-U).

Furthermore, some providers state that the interests of (potential) users should come first in the provision of health checks. They warn for (financial) incentives to test or treat in commercial providers, but also in regular care:

> When it comes to prostate cancer, the biggest crime is the robots that those hospital directors have put down. To their urologists, they say 'I'll buy a robot for you if you remove 200 prostates'. That's horrible. (...) Don't do a [PSA] test at a urologists under pressure to operate (ITC-I).

3. *Providers should take time and attention*

In order to properly inform, advise and assist (potential) users before and after the test, providers emphasise the importance of time and empathy:

> You need to take the time to explain. (…) Time, time.. That is of crucial importance to patients (ITC-I).

Contested criteria

1. *People should be free to test on any (risk factor for) disease, provided they are well-informed*

A large number of the providers, including all commercial ones, state that testing or not should ideally be an individual choice. With the exception of directly harmful health checks, people should be able to do a personal health check on any (risk factor for) disease, provided they are well-informed:

> Health is our most precious possession, and every individual, every citizen has the right to make decisions about their own health. And thus to have it examined when he or she wants to. That's just a basic right. (ITC-U).

2. *Health checks should be performed in people likely to benefit most from the check*

In contrast, other providers state that people should not be free to participate in whatever health check, but that it would be best if health checks were performed in people likely to benefit most. To optimize the benefit-harm ratio of health checks, health checks should only be performed in people at high risk for disease. This will enhance the positive predictive value of the test, which depends on the prevalence of disease. Checks moreover should only be performed in those likely to implement health advice. An often-mentioned example is that checking for CVD is only useful when people are willing and capable to implement lifestyle changes that are required to lower risk:

> Preventive research [including health checks YS] also has to do with what people are willing to do with the results (IC).
>
> Only in people who are willing to take the consequences, testing [for CVD risk factors] is useful (ITC-U).

Some health check providers therefore advice to assess risk factors and likelihood of implementing health advice before the test and to perform health checks only in those people most likely to benefit from the test. They warn of commercial providers, but also of patient groups and medical specialists with a particular focus on the disease tested for, who may be:

> very focused to detect so to speak the last patient with cancer left. Very driven to do so. Not surprising of course, for they are confronted with the consequences of cancer for people in their practice. (PSPO).

The downside of this focus would be that they may offer tests to people at low risk for disease, which may result in many false positives.

Benefits other than health, such as reassurance, may also be taken into consideration. According to the providers who state that health checks should only be performed in people who are likely to benefit most, people at low risk who are extremely worried should still be able to test, because reassuring them may improve their wellbeing although it's unlikely health benefits will result:

> If somebody is worried sick, and thinks 'I've got it' [lung cancer], than yes, that person should be given the possibility to check (PSPO).

3. *Follow up care of privately funded tests should not drain collective resources*

To ensure affordable health care, some providers caution about privately provided tests that may cause follow-up in regular health care possibly draining collective resources. The total body scan is often mentioned as an example:

> It [a total body scan] produces a lot of unnecessary additional medical consumption. (…) Obstruction, unnecessary [follow up] research, that is a waste (...) Not just of money but of time. Time of the people who have to do those [follow up] tests, time in the hospital for things that are not useful, which makes other people having to wait longer (GP).

Criteria in practice

So far the focus has been on criteria for good health checks according to providers. This final section is devoted to the role of these criteria in the current offers of health checks. Which checks do – according to providers – meet the criteria for good health checks, and which do not? Do providers themselves comply with criteria? Is it feasible to fulfil these criteria according to providers?

Good' and 'bad' health checks

During the interviews many providers had serious difficulties mentioning a health check that they considered to be 'good'. Many of them mention other forms of prevention instead, such as vaccinations, easily accessible preventive activities such as sports and smoking cessation programs, and tackling the obesogenic environment:

> Uhm, I'm in doubt.. I can not just name one, because you have indeed the false positives and treatment.. it isn't always easy.. You're talking about tests, not about preventive vaccinations, those kind of things, you're really asking for a test (PSPO).

When asked for an example of a 'bad' check however, providers readily named tests, often the total body scan and tests on total cholesterol.

Why providers don't comply with the formulated criteria

Providers reflected on their own offer of tests to emphasise what they think is important in a test, and were asked whether their current practice leaves room for improvement and how this could be achieved. Providers readily admitted they didn't consistently meet their own criteria for good checks. Some of them offer checks that may detect untreatable disease and tests with a low predictive value. They do not always sufficiently inform potential users, the follow up of some of checks drains on collective resources, and follow up care is not always provided. Especially help with lifestyle changes following checks on CVD risks is rare.

Several reasons were mentioned for this gap between theory and practice. First, many providers struggle with the tension between the importance they attach to reliable, valid health checks that improve health, and their belief that potential users – provided they are well-informed – should be free to choose any personal health check they want, including tests that are unreliable, invalid and are unlikely to improve health, for example because (potential) users do not belong to the target group:

> I am a strong proponent of self-determination. If I want to have my creatinine checked, I believe this should be possible. And I also believe that if I want to have my PSA checked – which is such a discussion – I believe I should be able to have my PSA checked. And a GP may think I shouldn't, but then I think this GP needs to explain to me why I shouldn't. But even then I believe I should be able to request that [a PSA check]. If, of course, I fit into a specific group [population]. If I'd be 30, well.. No anyway, then it should still be possible (ITC-U).

Second, especially medical specialists express a strong desire to prevent serious illness and death from disease while (as yet) no test with good predictive value is available:

> Look, a PSA test is obviously not a good test and should also not be used for screening. That's not a good test, especially the specificity is much, much, much too low. But there is nothing better. (...) That is

> a real miserable death, prostate cancer is the most miserable death from cancer that you can imagine. You'll get metastases in your bones, it will take three years, it is terribly painful, it's an enormous decline because it is such a slow-growing killer. So look, and that's exactly what I want to prevent, that misery (ITC-I).

Third, many providers, especially GPs, suffer from a lack of time. In practice they cannot properly inform, advise and assist (potential) users before and after the test:

> I find it difficult in cases in which a patient says: I want my PSA checked, that just takes a moment isn't it doctor? That happened a few times, to then explain as good as possible how it is (GP).

Fourth, although all respondents would like to provide good care, providers other than the government and GPs make (part of) their living selling health checks, so they have an interest that may conflict with offering reliable, valid checks that provide health benefits:

> We are a commercial company as well... yeah. So I mean.. would you in such a situation also think "well, should I do this [offer this test] or not"? Yes that can be difficult, to make honest weightings, therein. Yes, I'm very honest about that (HSO).

A similar conflict is reported concerning the provision of objective and full information to potential users:

> Really, I would.. I think you should give objective information. (...) Look the point is, and that has to do with market forces in health care, you'll always .. the biggest .. uhm... challenge is in recruitment versus information. Recruitment meaning how do you recruit your clients, and how do you give the right information. (...) How do you do a.. recruitment in which you do alert people to potential risks or disadvantages (ITC-U).

Informed consent may be difficult to establish

According to interviewed providers, informed consent is a minimal criterion. As just described, sometimes providers fail to supply potential users with sufficient information. A majority of the interviewed providers however questions whether true informed consent is feasible at all. Even if potential users would be provided with objective, reliable, valid, accessible and understandable information; this would not necessarily enable them to make informed assessments concerning benefits and harms of tests. This is because many people, according to providers, have difficulties with making 'rational' decisions in the context of health:

> What people understand and what people want to understand, you can explain something very well, but sometimes people just want to read something else, so (ITC-U).

The context in which a check is offered is said to have a big influence on decisions (not) to test. When a test is free, easily accessible, if 'everybody' participates, and when potential users trust the provider, people would hardly consider information at all:

> Yes, the more accessible it is, if it becomes common practice, the less people tend to think about what the consequences might be if you do that [testing] (PHA).

According to providers, health related choices are influenced by fear of death (rather safe than sorry). Faced with the possibility of serious disease that can be treated at an early stage, people are willing to accept unnecessary worry and even damage to health that may result from overdiagnosis and overtreatment. Many providers thus explain choices to test for prostate cancer.

> People always tend to believe the worst case scenario. (…) A certain fear to have something, a fear of illness (…) [They take the PSA test] we'll treat them and they will be glad we do. In the meantime they're confronted with incontinence, impotence, that sort of thing. And surprisingly enough, they take it for granted. (...) They'll reason I have prostate cancer and I've been treated .. so I escaped death (GP).

Interestingly, the very same providers also make comments in which nothing echoes the aforementioned nuances to the view of man as rational decision maker:

> If they want to spent their money on that [total body scan YS] instead of on a vacation. Well, why not, that is their choice (GP).

> People should just be smart enough to decide whether or not they participate in checks, ok? (ITC-U).

As long as information is provided, choices would simply reflect what people want. Providers make these comments to justify their own practice, but are also in relation to health checks offered by other providers.

Discussion

Providers' criteria are demanding

When we compare the criteria formulated by the providers with existing criteria for personal health checks and population screening, five points stand out. First, the criteria as formulated by the interviewed providers resemble the criteria for responsible population screening closely. Analytic validity, clinical validity, clinical usefulness, benefits outweighing harms and informed consent are all considered minimum criteria. Providers also state that governmental screening should be cost-effective. Providers, thus, agree with ethicists that the Wilson and Jungner criteria are also applicable to personal health checks. [2, 4–6]

In the regulatory context of personal health checks, the opinions of providers however, give a new perspective. Their criteria are actually more demanding than criteria formulated for personal health checks thus far. Providers consider health benefits and clinical validity minimal criteria for personal health check, as for population screening. In contrast, clinical utility is mentioned in none of the existing criteria for personal health checks [1, 13–15] and clinical validity in only one. [1]

Third, the ideas about follow up care of interviewed providers are more demanding than criteria formulated for responsible population screening and criteria for personal health checks. In population screening people are informed about the meaning of results and referred to specialized care, criteria for personal health checks include 'advice to clients on strategies the client can follow to reduce any further risk of acquiring a condition(s) or its negative consequences.' ([13], see also [14]) Several interviewed providers however advise to *help* users in realizing the actions necessary to reduce risk.

Fourth, it is remarkable that interviewed providers make almost no remarks about privacy and storage of data. Criteria for responsible governmental screening state that offer and performance should be in accordance with patient and consumer rights. Criteria for personal health checks explicitly mention the handling of data. [1, 13–15] We think the fact that interviewed providers seem to take patient- and consumer rights as given could best explain this apparent omission (Additional file 3).

Last but not least, the interviewed providers have specific concerns about informed consent. Although they consider this a minimal criterion, they question its feasibility in practice. According to providers, people would be more influenced by context and emotions than by information in their decisions to test. This is a cause for concern, considering the importance placed on informed consent in the existing criteria for personal health check. In these criteria, informed consent is not only considered as a criterion in itself but also as a condition to ensure that individual benefits outweigh harms because informed individuals would be able to determine whether that is the case. [1, 13–15] According to interviewed providers this is, thus, not realistic. To ensure health checks provide more benefits than harms, they instead mention an individual assessment before the test, help with the implementation of health advice after the test, and providers being skilled and experienced professionals who put the benefit of (potential) users first and take time and attention in their provision of care. Although some proposals for the ethical evaluation of personal health checks mention assessment of risk factors [7, 9] or qualified providers [8, 9], their emphasis is on informed consent.

Providers don't meet criteria: Lessons

Interviewed providers have difficulties mentioning personal health checks that meet their criteria. Moreover, they do not consistently meet the formulated minimal and aspirational criteria in their own practice. Respondents name several reasons for this gap between theory and practice. We discuss their implications for the usability of criteria for personal health checks.

First, primarily the commercial providers struggle with the tension between the importance of reliable, valid checks that improve health and their belief that potential users should be free to choose any test they want, including unreliable, invalid tests that do not provide opportunities for health improvement, *provided they are well-informed.* This contested criterion (nr 1) is hard to reconcile with the minimal criteria, which these providers, thus, often fail to meet. There are commercial motives at play, but non-commercial providers also state that people at low risk that are extremely worried should be able to test, regardless the fact that the validity of test results will be negatively influenced and it is unlikely that health benefits will result. (see contested criterion 2) This apparent dilemma between avoidance of harm and respect for autonomy emphasises that a list of criteria may contain value conflicts that are not easily resolved.

Second, providers are sometimes faced with the dilemma that they want to prevent harm from disease, but have no options except health checks with poor predictive value, which may result in harm due to overtreatment and unnecessary worries. On a population level, it may not be easy to identify when health checks no longer provide more benefits than harms. On the level of an individual user or patient, providers – like individuals themselves – reason it is better to be safe than sorry.

These dilemma's point out that in developing ethical criteria for offering health checks potential conflicts between criteria and underlying values should be explicated and addressed.

Other reasons why providers do not meet criteria point to components in the organisation of health care that may conflict with an ethical provision of health checks: Especially GPs report that they lack time to properly inform, advise and assist (potential) users before and after the test. This has been reported before in studies on preventive care in general practice. [23] They express moral frustration about this situation because they want to provide good care.

Some (semi) commercial providers have an interest that sometimes conflicts with offering reliable, valid checks that provide health benefits and giving objective and full information to potential users. Commercial providers are faced with the question why their practice should be moral if they could make money instead. The question 'why be moral?' may be even more central in the practice of the 'small' commercial providers without a (para) medical background which rejected our request for an interview by stating that this 'would be at the expense of customers who pay € 225 per hour'.

These dilemmas point out that in thinking about the ethics of offering health checks; we should take the larger context into account. It is important to realize the conditions that would facilitate providers to meet the criteria. Other actors, like the government or insurance companies, need to take responsibility here as well.

When it comes to the usability of general criteria for personal health checks there is of course also the general problem of the application of criteria. As mentioned in the introduction, the criteria for population screening may be relatively uncontested, but whether or not specific population screening programs meet these criteria is subject of debate. [9] Agreement about general criteria for personal health checks is thus only a first step towards the ethical evaluation of specific checks. When is a test 'reliable' and 'valid' enough? General criteria must be interpreted for specific tests, and it may well be that different providers will interpret criteria differently or that there will be dissensus when it comes to applying general criteria for specific tests. To our mind, standards should be at least as demanding as those of population screening.

Contested criteria: Ethical evaluation

The criteria as formulated by providers should not be taken as a final say, but used as input in the ethical and policy debates over the right criteria. Their minimal and aspirational criteria are in line with what most ethicists consider to be good (personal) health check offers. [2, 4–6] This is different however, when it comes to contested criteria. In this section we provide an ethical evaluation of these contested criteria and explore their relevance for an overarching ethical framework for responsible offer and use of personal health checks.

Respecting autonomous choice

The idea that people should be free to participate in unreliable, invalid checks on (risk-factors for) disease that cannot be treated *provided that they are well-informed* may be seen as an attempt to prevent harm from checks while respecting autonomous choice. Autonomy is a key value in medical ethics. [24] We briefly discuss how we understand autonomous choices in the context of health checks and evaluate this criterion on this basis.

An autonomous choice is a choice made in freedom, a choice that is in line with somebody's values, with his or her perception of the good life, a choice that ideally is based on reliable information. [2, 24] Interestingly, many providers – commercial and non-commercial – think people would be more influenced by context and emotions than by information in their decisions to test. Indeed people may not be capable of using the information provided during informed consent procedures in decisions to test because they lack the health literacy to do so [25, 26] or because emotions or heuristics override rational considerations. [27].[8]

If providing information to potential users does not necessarily lead to autonomous choices (not) to participate in health checks, how to evaluate these choices? This should depend on whether that choice is conductive to this individuals' own perception of a good life. [2] Most people value health more than anything else. [28] In addition, a choice for a test should be in line with what the individual wants or expects from the check. [29] Many people expect tests to have a good predictive value, to offer opportunities for health improvement and not to inflict any harm [30] and participate for reasons of health. (e.g. [31]).

From this we may conclude that offering tests with a low predictive value that do not provide health benefits is not likely to be conductive to the autonomy of (potential) users. This is because most people value health, expect health check to provide certainty about the presence or absence of disease and test to improve health. [29–31] Moreover, providing information about test- and disease characteristics that are contrary to what people expect will probably not suffice to prevent harm because decisions (not) to test are more often made on the basis of emotions and heuristics than information. [25–27] The idea that people should be free to participate in whatever check, *provided that they are well-informed* is thus not likely to result in respect for autonomous choice while preventing harm from checks.

This is different when potential users would be 'informed' in individual assessments, as some providers suggest in the context of contested criterion 2. In such assessments, risk factors and likelihood of health advice being implemented would be discussed and the individual needs of potential users would be deliberated upon.

[32] This way, unrealistic expectations may be corrected [29] and individual benefits and harms could be determined in the context of individual needs. Such individual assessments – perhaps best comparable to counselling in clinical genetics – would require personal contact and thus take time and attention from providers. They may also require offering less comprehensive tests. For example, it does not seem realistic to discuss all relevant benefits and harms of a total body scan or broad genome-wide testing. [33]

In case of health checks with a low predictive value or checks that do not provide opportunities for health improvement, we thus suggest performing individual assessments as 'alternative' informed consent procedures. This way, it is assured that participating is in line with individual's values and expectations and provides more benefits than harms.

This analysis of autonomous choice and the limitations of informed consent has implications beyond an ethical provision of health checks. In general we think it is important to design informed consent procedures such that they truly function as means to respect the autonomy of (potential) users. [24]

Taking the context into account

The suggestion of some providers to perform in particular cardiovascular health checks only in people who are willing and capable to implement any lifestyle advice could, like a recent, very similar advice from the US Preventive Service Task Force [34], be criticized as 'withholding potential benefit from the population subgroups whose socioeconomic burdens and comorbidities place them in greatest need of help'. [35]. After all, the low SES groups who are, according to interviewed providers, not likely to implement health advice have on average a bigger risk on cardiovascular disease. [36, 37]

However, a different picture arises if we would evaluate this suggestion from a ethical perspective in which the context is taken into account. We think that a true ethical provision of health checks requires weighing benefits and harms of health checks against other measures targeting (risk factors for) disease. Let us weigh the benefits and harms of cardiovascular health checks up to benefits and harms of other measures targeting (risk factors for) CVD: asking people to change their lifestyle if they're not capable to, is not likely to improve their health but may cause worries and feelings of guilt. [3] Low SES groups indeed deserve care, but may need different care than the provision of cardiovascular health checks. [31] It would be more fair and effective to help those people maintaining a healthy lifestyle by changing the obesogenic environment they live in. [38–40] Thinking about the ethics of health checks may thus also result in an advice to implement other measures than health checks, for certain subgroups or in general. To change the obesogenic environment other actors than providers need to be addressed, such as governments and industry. [3]

Limitations of the study

We have chosen a qualitative approach because we are the first to question providers on an ethical provision of health checks and the openness of a qualitative method allows the uncovering of unexpected views. The aim was an in-depth understanding of what providers consider criteria for good personal health checks and potential barriers in the implementation of these.

Although we interviewed a very divers sample of providers, saturation as regards to criteria was reached long before the last interview: they formulated very similar and 'demanding' general criteria. We did not expect this to happen. Despite differences in education(al) level, profession, work field and interest, providers – apparently – have very similar ideas when it comes to the ethics of health checks. Although we cannot exclude the possibility of a social acceptability bias in their answers – respondents were aware that they were interviewed by an ethicist and perhaps did not want to come across as thoughtless – however we do not consider this a likely scenario. The atmosphere during most[9] interviews was perceived by YS and described by respondents as surprisingly open and relaxed.

In addition, providers were aware that their answers would be employed in the development of an ethical framework for personal health checks. Strategically providers had every reason to be somewhat less demanding while showing goodwill to make some adjustments in their offers. Such a position after all would minimize the chances of (governmental) involvement in their practices. That being said, our results may suffer from a sampling bias: 'Small' commercial providers without a (para) medical background who declined our interview requests would perhaps have formulated less 'demanding' criteria. And the two providers of governmental screening programs came up with criteria very similar to criteria for responsible governmental screening, as was perhaps to be expected.

To draw conclusions on how many providers value which criteria for good health checks, the results of this study would need to be quantified.

A potential shortcoming of this study is the relatively short section on criteria in practice as these results are the most interesting from an ethical point of view. The reason why we do not have more material to present is that we wanted providers to be as open and honest about their practices as possible in an interview with an ethicist, and figured they would be more at ease if we did not question them too directly and long about whether and why they (do not) keep to criteria.

Conclusions

Providers are more demanding than existing ethical criteria for personal health checks and state that personal health checks should meet the following minimum criteria: (Risk factors for) disease to which the check is directed should be treatable; Tests must be reliable and clinically valid; Participation must be informed and voluntary; Health checks should provide more benefits than harms; Governmental screenings should be cost-effective. Some providers also formulate aspirational criteria: Follow-up care should be provided; Providers should be skilled and experienced professionals that put the benefit of (potential) users first; Providers should take time and attention. Providers disagreed over the following contested criteria: People should be free to test on any (risk factor for) disease; Health checks should only be performed in people at high risk for disease that are likely to implement health advice; Follow up care of privately funded tests should not drain on collective resources.

Providers do not always fulfil their own criteria. Their reasons reveal conflicts within the set of criteria for good checks, conflicts between criteria and other ethical values, and point to components in the organisation of health care that hinder an ethical provision of personal health checks. Moreover, many interviewed providers consider informed consent a criterion that is hard to establish in practice. An individual assessment in which risk factors, the likelihood of health advice being implemented and the needs of potential users would be discussed is an interesting suggestion for an informed consent procedure that truly functions as means to respect the autonomy of (potential) users. [24]

The results of this study suggest that in thinking about the ethics of health checks, drawing up a checklist of criteria will not suffice. Potential conflicts between criteria and their values should be explicated and preferably help in the weighing of criteria should be provided. Moreover, in the ethics of health checks it is important to take the larger context into account. It is important to realize the conditions that would facilitate providers to meet the criteria. Actors, like the government or insurance companies, need to take responsibility here as well and thus, should be addressed. Moreover, an ethical framework for health checks should enable weighing up benefits and harms of health checks to other measures targeting (riskfactors for) disease. An ethical evaluation of health checks within this larger context may result in an advice to implement or promote other measures than health checks.

Endnotes

[1] The screening and any subsequent interventions should lead to an improved health outcome among people with a positive test result.

[2] The accuracy with which the test measures a specific biomarker.

[3] The accuracy with which the test identifies a particular (risk factor for) disease.

[4] Note that many more guidelines for direct to consumer (DTC) genetic tests exist. [41, 42] We however, only discuss guidelines applicable to all sorts of personal health checks.

[5] In the Netherlands, people need a referral from their GP to be treated or examined by a medical specialist in regular/insured care. In contrast, care by specialists in commercial/uninsured care is accessible without GP referral. Specialized medical care may either be provided in hospitals (regular care) or in independent treatment centres (either insured or uninsured care).

[6] There is currently much public debate in the Netherlands concerning the Total Bodyscan. Thus far, performance is forbidden in the Netherlands. However, it is offered and performed just outside Dutch borders. This may have influenced how often providers refer to this test during the interviews.

[7] The Netherlands has a special law on screening: the Population Screening Act. As explained in the introduction it states that population screening must benefit participants. It operationalizes this through a mandatory permit for (expected) harmful screening: that uses ionizing radiation, aims to detect cancer or diseases for which no treatment or prevention. Grounds to refuse the permit are 1. The screening test is scientifically unsound; 2. The screening is not conform the legal rules for medical treatment; 3. The expected benefit of the screening does not outweigh the risks for the participants. To determine the risk-benefit ratio for participants, the Wilson and Jungner criteria are used. (HCN 2008) During the time of the interviews, the minister of health of the Netherlands deliberated on possible adjustment of the Population Screening Act.

[8] One may wonder why providers state that people should be free to test provided they are well informed, if they think people would be more influenced by context and emotions than by information in their decisions to test. As discussed the very same providers that question informed consent also make rather indiscriminate statements about self-determination: choices would simply reflect what people want. As most providers came across as genuinely committed to the well-being of the users of their test, a mechanism called ‘cognitive dissonance’ may be at play. [43] Cognitive dissonance refers to the psychological stress that results from holding a belief that is contradictory to ones actions. To reduce stress, people

may either adapt their ideas or their actions. [43] To fit their practice in which they perform unreliable, invalid health checks that do not always provide opportunities to improve health but may even harm health, providers may simplify their conception of self-determination. Another or additional explanation as to why providers state people should be free to test provided they are well informed is that they may hold on to informed consent procedures as if it were an ethical anchor. Informed consent procedures as something intrinsically good would then outweigh uncertain harms done by unreliable or invalid checks that do not provide opportunities for health improvement. Although this is an understandable thought given the attention within medical ethics to informed consent [24], informed consent should be understood as a means to respect the autonomy of (potential) users, not an end in itself.

[9] With the exception of two interviewees who seemed on their guard.

Additional files

Additional file 1: Interview guide (DOCX 126 kb)

Additional file 2: Profession and age of health check providers (DOCX 64 kb)

Additional file 3: Comparison of criteria. Comparison between criteria as mentioned by interviewed providers and what is written on these criteria (eg what is mentioned about informed consent) in criteria for responsible population screening and existing criteria for personal health checks (DOCX 114 kb)

Abbreviations

CVD: Cardiovascular disease; EA: Eva Asscher; GP: General Practitioner; GPSPO: Screening at GP's Program Officer; HCN: Health Council of the Netherlands; HSO: Health and Safety Officer; IC: Internet based company; ITC-I: Independent Treatment Centre – Insured care; ITC-U: Independent Treatment Centre – Uninsured care; MS: Maartje Schermer; PHA: Pharmacist; PHY: Physiotherapist; PSA: Prostate specific antigen; PSPO: Population Screening Program Officer; STD: Sexually transmittable diseases; YS: Yrrah Stol

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Availability of data and materials

The data that support the findings of this study are available on request from YS. The data are not publicly available due to hem containing information that could compromise respondent's privacy and consent.

Authors' contributions

YS conducted the interviews and was a major contributor in writing the manuscript. Analysis of codes to results was done by YS in close consultation with EA and MS. All authors read and approved the final manuscript.

Ethics approval and consent to participate

In the Netherlands, ethics approval for this type of research is not required. After being informed about the purposes of this study, providers agreed to participate.

Consent for publication

Interviewed providers were informed about the purposes of the interviews and consented to publication.

Competing interests

The authors declare that they have no competing interests.

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Chapter 3

Good health checks according to the general public

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RESEARCH ARTICLE Open Access

Good health checks according to the general public; expectations and criteria: a focus group study

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Abstract

Background: Health checks or health screenings identify (risk factors for) disease in people without a specific medical indication. So far, the perspective of (potential) health check users has remained underexposed in discussions about the ethics and regulation of health checks.

Methods: In 2017, we conducted a qualitative study with lay people from the Netherlands (four focus groups). We asked what participants consider characteristics of good and bad health checks, and whether they saw a role for the Dutch government.

Results: Participants consider a good predictive value the most important characteristic of a good health check. Information before, during and after the test, knowledgeable and reliable providers, tests for treatable (risk factors for) disease, respect for privacy, no unnecessary health risks and accessibility are also mentioned as criteria for good health checks. Participants make many assumptions about health check offers. They assume health checks provide certainty about the presence or absence of disease, that health checks offer opportunities for health benefits and that the privacy of health check data is guaranteed. In their choice for provider and test they tend to rely more on heuristics than information. Participants trust physicians to put the interest of potential health check users first and expect the Dutch government to intervene if providers other than physicians failed to do so by offering tests with a low predictive value, or tests that may harm people, or by infringing the privacy of users.

Conclusions: Assumptions of participants are not always justified, but they may influence the choice to participate. This is problematic because choices for checks with a low predictive value that do not provide health benefits may create uncertainty and may cause harm to health; an outcome diametrically opposite to the one intended. Also, this may impair the relationship of trust with physicians and the Dutch government. To further and protect autonomous choice and to maintain trust, we recommend the following measures to timely adjust false expectations: advertisements that give an accurate impression of health check offers, and the installation of a quality mark.

Keywords: Health check, Screening, Ethics, Criteria, Focus groups, Qualitative research, Heuristics, Trust

Background

Health checks may identify (risk factors for) disease in people without specific medical complaints [1]. These kinds of tests may also be referred to as preventive or presymptomatic tests, medical screening, preventive medical examinations, or health screenings. For ease of reading, 'health check', 'check' and 'test' are used interchangeably throughout this paper.

In the Netherlands, these tests were previously only offered by the government or General Practitioners (GPs) through population screening programs. Nowadays many parties besides governments and GPs offer health checks on a wide variety of (risk factors for) disease [1].

Since the rise of this medical technology, medical professionals and ethicist have discussed potential benefits and harms [1–6] and guidelines have been developed [1, 7, 8]. In the Netherlands, moreover, there is much public, policy and political debate about whether health

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checks should be regulated and if so, which criteria should be used [1, 9–13]. In the discussion on the ethics and regulation of health checks, the perspective of potential health check users has – so far – remained underexposed.

In order to develop ethical criteria for responsible offers and use of personal health checks, the experiences and perspectives of all stakeholders should be considered as they may value different things. Arguments for positions may complement each other or reveal ethical dilemmas. We reported on the views of Dutch health check providers elsewhere [14]. In this paper we describe the results of a focus group study with members of the general public on criteria for good health checks. The perspective of the general public is of particular importance because they are the ones health checks are offered to; ethical criteria are drawn up in their interest, and so are any regulations. The user's perspective of governmental screening programs e.g. [15], DTC genetic tests e.g. [16, 17] and other specific health checks e.g. [18] has been researched. However, it is also important to know what (potential) users want and expect from health checks in general. After all, guidelines and regulations also include different types of tests [1, 7–9, 12, 13].

In thinking about the ethics of health checks it is therefore important to know what lay people themselves consider to be their interests and which criteria, according to them, may serve these interests. That is not to say that these criteria should as such be included in an ethical framework for health checks. They might, after all, be based on false reasoning or assumptions. The values *behind* criteria and any assumptions could be an important source of inspiration though. To provide understanding about what the general public considers important when it comes to health check offers, we therefore do not only report their criteria for good checks, but also pay particular attention as to why they are mentioned. The preferences and needs of (potential) users may also be used to adapt health check offers to fit those needs and to tailor information provision.

Methods

Focus groups

Four focus groups with six to eight participants were held in Dutch at the Erasmus Medical Centre in 2017, lasting 2 h. One of the groups was conducted in the afternoon, the other three during evening hours. Groups were moderated by the first author and attended and observed by the second author. Participants were asked to share their opinions freely and were assured their reactions would be anonymized. Particular care was taken to include every participant in the discussion.

In the Netherlands, ethics approval or written informed consent for this type of research is not required according to the Medical Research (Human Subjects) Act (WMO) [43]. Participants were informed orally about the purposes of the study beforehand and enabled to ask questions. They gave their verbal consent to participate and to anonymized publication of findings, which was recorded on tape.

We asked participants if they had ever participated in a health check and what their experiences were. Subsequently they were asked what conditions a health check should meet for them to consider participation, or recommend participation to others. We deliberately didn't mention any particular aspects of a check, such as test- and disease characteristics, features of the provider, the offer or the context in which this offer is made, to avoid influencing the response of participants. To prevent groupthink, participants first answered each question individually on paper before it was discussed. During the plenary discussion we asked participants to share 'their' characteristics of a good health check, and to react on the characteristics mentioned by others. We also questioned participants about why they considered these features important. Characteristics were noted on a flip chart. After the plenary inventory, results were compared to a pre-prepared list of potentially relevant characteristics based on literature research and previous empirical work [1, 7, 8, 14, 19].

To stimulate further discussion among participants about characteristics of 'good' health checks, and about the provided arguments, they were then asked to put their own and the provided characteristics of 'good' health checks in order of importance. This was done in two steps. First, they were asked to make a distinction between 'important' and 'very important' characteristics. Second, the 'very important' characteristics were categorized. Discussion among participants was stimulated and they were invited to provide reasons for choices made.

A similar procedure was followed to determine the characteristics of those checks that participants would *not* consider doing or would *not* recommend to others. Finally, participants were asked whether they saw a role for the government and if so what they thought this involvement should be. In all but one group,[1] they first individually answered this question on paper before it was plenary discussed. [Additional file 1].

Saturation in regard to criteria for health checks and any role of the government was reached after the third focus group.

Participants

Participants (26 in total) were selected by a commercial agency that recruits for market research and for academia (CG Selecties), to form a representative sample of the Dutch population [Additional file 2]. Selection took place according to the following characteristics: sex, age, education level (bachelor degree or higher / lower education), occupation (student / employed (different sectors)/ unemployed), origin (native Dutch / (child of) immigrant), residence (big city / village), marital status, children. To facilitate the discussion, we classified participants according to education level (two groups for each level), while groups were mixed when it came to the other characteristics. For this type of research no ethical review is necessary in the Netherlands. Participants received a compensation fee of 45 euros for their participation.

Analysis

Focus groups were recorded and transcribed verbatim with the exception of a few moments during which many participants spoke at the same time. They were coded using NVIVO 11 for Mac focusing on criteria for good health checks, reasons why participants consider these important and opinions regarding the role of the government. An initial list of bottom-up derived codes reflecting criteria, reasons and governmental roles as well as a range of other, unexpected themes (assumptions, information, heuristics, trust) was composed and discussed between the first and second author after a first analysis of the transcripts. Additional bottom-up codes were added during the continuation of the analysis, staying close to the content of the answers of respondents. Similar codes were merged. Using the final list of codes, the second author analysed one focus group to ensure agreement about encoding; there was agreement about the codes used. Analysis of codes to results was done by the first author in close consultation with the second and third author.

Results

Criteria for good health check offers

Participants consider test- and disease characteristics, the way checks are offered and features of the provider to be an integral part of what makes health checks good or bad. Instead of criteria for health checks, we therefore speak of criteria for good health check offers.

The order in which criteria are discussed reflects their importance to participants. It is based on a combination of spontaneously mentioned features of good health checks, argumentation provided, the categorization of characteristics in 'important' and 'very important', and whether participants also described checks that do not meet criteria as 'bad'.

The health check provides certainty about presence or absence of disease

A good positive and negative predictive value is the most important characteristic of a good health check offer according to participants. Certainty about the presence or absence of disease is what they hope to achieve from a test. Health checks that do not provide that certainties are of "no use" (group 1), according to participants:

> *That's the whole point. I'm not going to participate in a test knowing that, well, the results are just guesswork.* (group 1).

Uncertainty about the presence or absence of disease would cause unnecessary worries. Something similar is reported about the detection of risk factors for disease that do not need treatment:

> *I know that my mother got a lot of tests on cervical cancer. And often it was said; 'you have precancerous cells,' while nothing really had to be done. But in the meanwhile she was constantly uncertain and afraid because of that.* (group 4).

Good information before, during and after the health check

Participants consider the provision of information a very important characteristic of a good health check offer. Some of them differentiate between information before, during and after the test; others consider these to be one criterion.

With regard to information before the health check, participants state that they want to be informed about

> *"why this test is being done, what the results might be, what it might mean for someone (group 1), about the test itself; that it is valid and reliable for example (group 2), [about] how it's going to be carried out exactly (…) like, what's going to happen exactly (group 1) [and] about the risk"*. (group 2).

In particular the participants with lower education stress the importance of information about the test-procedure given during the t*Yes, then you'd be sitting there thinking. Now what do I do now..? (group 1).*:

> *Yes, then you'd be sitting there thinking. Now what do I do now..? (group 1).*

After the health check, participants consider it important that test-results are well explained. In case of a positive test-result they prefer to be informed in person by an expert so that they can ask questions. An opportunity to call or come back in case of remaining uncertainties is very much appreciated. After the explanation of test-results, any follow up should be discussed and help with referral should be provided:

> *Imagine a nasty outcome and you're very upset. It's nice if someone's there who can explain exactly what it*

> *means and what the steps are that can be taken. (group 3).*

Especially the participants with lower education stress that information before, during, and after the test should be provided in clear and understandable language:

> *R1: No technical terms. R2: No mumbo-jumbo. (group 3).*

The provider is knowledgeable and reliable

The expertise and reliability of providers is a very important characteristic of a good check offer according to participants. Some of them differentiate between expertise and reliability; other participants consider this to be one criterion.

A health check provider should be knowledgeable and competent, according to participants. By this they mean the provider should be capable and qualified to perform the health check. Most participants think of physicians when they refer to knowledgeable providers:

> *Yes, that people with, let's say, knowledge should do the test. (group 3) Yes and that the result should be assessed by a medical specialist or expert. (group 4).*

A health check provider should also be trustworthy according to participants. He or she should act in the interest of users. Most participants consider physicians to be trustworthy but question the reliability of commercial providers who, they assume prioritize moneymaking over the interests of (potential) users. According to participants, commercial interests may result in offering tests that do not provide certainty about the presence or absence of disease, in performing more tests than necessary, or in carelessness in the performance of health checks.

A reliable provider, finally, has time and attention for (potential) users.

> *R1: That human factor, I think that's very important.*
> *R2: Not feeling like you're just a number to them. (group 3).*

Testing provides opportunities for health benefits

Many participants consider it an important characteristic of a good health check offer that the (risk factors for) disease tested for may be treated or prevented. They consider prevention of disease to be the aim of health checks:

> *I (whilst ordering the criteria): The disease being tested on can be prevented or treated.*
>
> *R1: Yes, very important.*
>
> *R2: Yes, very important.*
>
> *R3: That's the aim. (group 2).*

Most participants would not consider testing for untreatable (risk factors for) disease themselves. However, they can imagine that some people would like to know:- *Well, it could be related to planning, how you lead your life, how you see your future. (group 2)* Participants therefore do not consider health checks on untreatable (risk factors for) disease as 'bad' tests.

Respect for privacy

Participants consider it an important characteristic of a good health check offer that personal and medical data are treated confidentially.

No unnecessary health risks

Participants consider it

> *"important that risks [for users] are minimized." (group 2).*

Moreover, any health risks should be proportional to the severity of the condition being tested and the likelihood of that condition being present.

As it seems, participants consider it unlikely that health checks performed by a knowledgeable and reliable provider will result in damage to health. After all, these providers act in the interest of (potential) users, they assume.

Accessible: Available, easy to perform, affordable and not unnecessarily painful or uncomfortable

Many participants mention accessibility as characteristic of a good check offer. This term may refer to different things: A high price is mentioned as a barrier for participating in a health check. Moreover, it is considered a good thing if users don't have to travel long and if a test is easy to perform. From their own experience, participants stress that pain or discomfort should be avoided as much as possible:

> *When they are examining your breasts and touch your breast with cold hands and then shove it between two freezing plates. (group 3).*

Nevertheless, painful or expensive health checks are not necessarily characterized as 'bad' tests. Whether a test is considered 'good' or 'bad' depends on the health benefits a test may yield.

Accessibility in terms of costs, availability, eases and if possible comfort is considered of extra importance in case of checks provided by the government through population screening programs. This is because:

> *health, whether you are the man on the street or the king, health is the most important, whatever you are, whether you are a trench worker or ... everyone should have equal opportunities. (group 3).*

When it comes to governmental screenings or otherwise publicly funded health checks, participants mention two related additional criteria: these types of health checks should be cost-effective and they should only be offered to or reimbursed for people at high risk for disease:

> *You're not going to take preventive SOA tests in people over 70, you understand, to give an example. It's a matter of risk selection, looking at your costs and possible benefits; very important. (group 2).*

Limiting the offer of governmental screening programs to people at high risk for disease would, according to participants, also prevent unnecessary concerns in people who are offered such a check:

> *We are somewhat older men, we then get that colon cancer test, but you may of course also say well lets test on a lot more that may at some point become relevant. That'll make it much more expensive and you're probably worried for no good reason. So you can also exaggerate in testing. (group 1).*

Assumptions, trust and the use of heuristics

In discussing the criteria for good health checks and a possible role for the Dutch government, participants - especially those with a lower education level - make a striking amount of assumptions about health check offers. In their choice for provider and thus test, they tend to rely on heuristics, more than on information.

In this section, we will discuss these assumptions and the role of heuristics as well as expectations towards and trust in physicians and the Dutch government.

Assumptions about health check offers

Health checks provide certainty about the presence or absence of illnesses

Relatively few participants refer to the predictive value of health checks when first asked for criteria for good health checks. In one of the groups, this characteristic isn't mentioned at all. The moderator introduces it at the time criteria are prioritized. However, once the predictive value of a test is mentioned, every participant immediately agrees that this is a very important, if not the most important feature of a good health check offer. It turns out that many participants just assume that health checks in general give certainty about the presence or absence of disease.

> *R1: Why else would you do the test?*
>
> *R2: Then you don't need the test, right?*
>
> *R3: No.*
>
> *(Respondents speaking at the same time)*
>
> *R4: I always assume its right.*
>
> *(...)*
>
> *R5: I find it strange to imagine that there are tests where the results are already assumed not to be right... (Group 1).*
>
> *I: If you think about characteristics of good tests, so tests you would be happy to do yourself or that you would recommend to somebody else, is it then important that the test provides certainty on the presence or absence of diseases?*
>
> *R1: Yes, absolutely.*
>
> *R2: Very important.*
>
> *I: You consider that very important.*
>
> *R3: Yes, that's the point right? I guess.*
>
> *R4: After a test you want to have an answer on whether you have it or not.*
>
> *R3: You don't do it for fun.*
>
> *I: So you all state this should be on the pile with important...*
>
> *R5: Yes, very important...*
>
> *I: That surprises me a bit because you didn't mention it when we talked about it earlier.*
>
> *R6: Yes maybe because it was so obvious why....*
>
> *R: Yes, why else would you do the test? I think we all just assumed you participate in a test because you want an answer/some certainty, not because you're thinking, hey, let's travel through the MRI-tunnel today.*

> *R5: I've got the afternoon off, so….*
>
> *(Respondents laugh)*
>
> *(group 3)*

Some participants didn't mention the predictive value of a test because they assume knowledgeable and reliable providers only offer tests with a high predictive value:

> *I just assume it's reliable, in a hospital. (group 1).*

Health checks offer opportunities for health benefits

In general, participants seem to assume that health checks test for treatable (risk factors for) disease. They are aware of the possibility to test for untreatable conditions and do not oppose such checks, but tend to associate health checks with prevention, hence, with treatable (risk factors for) disease. When the moderator requests them to discuss health checks for untreatable (risk factors for) disease, they do so, but even after that possibility has been addressed, many participants keep talking about health checks as if they offer opportunities for health benefits by definition.

> *I (whilst ordering the criteria): Certainty about the presence or absence of disease, the reliability of results (...) So you've tested for a disease, the results come in and you know for sure whether you have that disease or not.*
>
> *(...)*
>
> *R: Yes, because then you can do something about it. (group 4).*
>
> *R (whilst discussing aftercare): I think it's also important that they have a step-by-step plan, to solve it so to speak if something is. Yes. well, if something is found that isn't good. That they'd.. that there is an operation or medicine or something like that.... (group 2).*
>
> *R (whilst arguing for commercial health check offers): that, also at a young age, it can be detected early if something is not right in your body, that you can get ahead of it and treat in in an early stage perhaps. I, there are so many people who get sick, at all ages. (group 1).*

Privacy guaranteed

Participants assume that medical data are treated confidentially if they participate in health checks, especially if health checks are performed by knowledgeable and reliable providers:

> *I (whilst ordering of criteria): Data are treated confidentially, privacy.*
>
> R*: Yes. Actually, this is what you assume.. so should that be in the top five..? Yes.. (Group 3).*

In general, therefore, participants assume that most health check offers, or at least health checks offered by knowledgeable and reliable providers, meet the following quality criteria as discussed in the previous section: health checks provide certainty about presence or absence of disease; testing provides opportunities for health benefits; privacy is respected.

Use of heuristics

If participants wanted to do a health check that is in their interests, that will benefit them, they would then turn to a knowledgeable and reliable provider. As discussed in the previous section, physicians are considered knowledgeable and reliable. To discern the expertise and reliability of other providers than physicians (and of physicians that work in commercial settings) many participants – especially those with lower education levels – seem to rely on heuristics more than on information about the reliability and validity of tests, the treatability of disease, and privacy statements.

According to participants, knowledgeable and reliable providers will make sure that accurate information is provided, before, during and after the testing.

> *R1: Yes when I received that bag [poo bag for colon cancer screening YS], that was all included. You are very well informed about what it is and that is very important.*
>
> *R2: Yes, that's the reliability of .... that generates trust. (group 4).*

Knowledgeable and reliable providers, moreover, will make sure that (potential) users are treated with respect and are offered the tests in a well-kept and comfortable environment (though not necessarily too luxurious).

> *R1: If something isn't right at the first contact, or if the site for example isn't any good, I'm already out. If I'd call and so and so is answering the phone who is.. let me put it politely, isn't speaking in a friendly way, yes then..*
>
> *(...)*
>
> *R2: If I call for an appointment and think like ... no way you know, that gives me enough information really.*

> *I: And why would you think no way at that point?*
>
> *R2: I think that if I myself would be the person who would offer those tests, I wouldn't hire somebody that wouldn't treat people the way, the way I'd like to be treated.*
>
> *R3: Yes, it's their calling card after all.. (group 3).*
>
> *R1: A dirty place.*
>
> *R2: Yes. Unhygienic.*
>
> *(...)*
>
> *R3: If I walk into the practice and I'm lying on the treatment table and see dust lying around. Well, I'd say, ok, I'm putting my clothes back on and I'm out of here, you know. It doesn't take rocket science to figure that out.*
>
> *(...)*
>
> *R4: Yes, but also the opposite, if the place is all fancy and glamorous and they offer you champagne and caviar when you arrive. (group 3).*

So participants seem to rely on the information provided, communication style and setting in which health checks are performed, as an indicator for the type of provider and thus test.

Participants do not only rely on their own judgment but also make use of other people's impressions of information provision, communication style and setting. Good or bad reviews on the internet are frequently mentioned as indicators of good or bad tests.

> *R1: Experiences of other people...*
>
> *R2: Yes, bad experiences.*
>
> *(...)*
>
> *R3: And no reviews, I always think... I never trust that, if you can't find any opinions anywhere, I won't believe in it either.*
>
> *R1: Yes, that's a good one. (group 3).*

Expectations towards physicians

As discussed under 'criteria', participants see physicians as knowledgeable providers. In addition, they consider physicians to be reliable providers who will serve the interests of (potential) users of health checks. Physicians – they assume – only offer tests that are in the interest of (potential) health check users. This is because physicians have sworn the oath of Hippocrates.

> *That physicians can offer health checks on a commercial basis is difficult to grasp for most participants.*
>
> *R1: Yes, a licensed physician.*
>
> *R2: Yes, recognized.*
>
> *R3: Not someone who sees a big opportunity out there and uses it to get rich.*
>
> *R4 (joking): Well.. actually, I was thinking about starting up a body scan next week.*
>
> *I: And what if a recognized radiologist, a specialist, sees a big opportunity out there and wants to get rich?*
>
> *R3: Yes, but he is licenced, someone who is licenced, who has confidentially, professional ethics, so he's not a salesman or anything.*
>
> *I: What does it mean that someone has professional ethics, what would that person do and what wouldn't he do?*
>
> *R3: Well, I think professional ethics, that you put your heart into what you do, that you respect it and as a result of that; how do you treat people? That is what I think is meant by professional ethics.*
>
> *R5: That he doesn't focus on the money, but on doing a good job. (group 3).*

Physicians put the interest of (potential) users of health checks or patients first, participants seem to believe. Physicians would therefore not offer tests with a low predictive value for such checks would be of 'no use' (group 1).

Also, physicians will respect the privacy of users in the handling of medical data. After all, they are bound by rules of confidentiality.

> *R: But surely we can assume that privacy is a high priority in the medical world.*
>
> *R: Yes, I would think so too.*

As some people want to know about (risk factors for) untreatable disease (see criterion 4), physicians may perform tests that do not provide opportunities for health improvement, as long as this is in the interest of the particular user. Physicians will however not offer checks that result in disproportionate health risks, because this is not in the interest of (potential) users. (Potential) health benefits will always outweigh (potential) harms, participants believe, if the test is offered by a physician.

Trust in physicians

The expectations discussed above reflect an apparent trust in physicians. For some, this trust seems to be self-evident, others seem to make more of an explicit choice to trust physicians. This participant for example explicates:

> *So the expertise of those who perform the test, but in my view you can count on this if it's in a hospital, it's what you expect compared to going an unofficial place or somewhere where it's just for the money. At least, that's what I assume. (group 1).*

Expectations towards the Dutch government

Participants assume that, at present, laws and oversight are in place to guarantee privacy of personal medical data:

> *R (on (oversight to) privacy policy): I consider that an achievement of our country, that. (Group 2).*

When it comes to the regulation of health checks, almost all participants see a role for the Dutch government, even those who (strongly) oppose a paternalistic government.

> *R1: Well, in any case, no babying, because that's just.*
>
> *I: What would you consider to be babying?*
>
> *R1: All these rules they keep making up.*
>
> *I: So you would say, please no rules when it comes to testing?*
>
> *R1: No, of course, there should be rules. I'm talking about a nanny state.*
>
> *I: Yes. And what is the difference between a nanny state and rules, what kind of rules would you consider to be OK?*
>
> *(...)*
>
> *R1: Monitoring of the reliability of tests [she is referring to the predictive value of tests YS].*
>
> *(Group 1)*

One way or another, many participants expect the Dutch government to protect (potential) health check users from unreliable and invalid tests, unqualified providers and checks that cause health risks.

The most discussed option is a quality mark that would inform potential users where 'good' health checks are offered.

> *I think the government should provide some sort of list with all government-approved hospitals and institutions, of which you can be certain that they offer safe and reliable tests. (group 1).*
>
> *If I just think about it for a moment, what if I wanted to have a health test but really wouldn't know which ones are good and which ones aren't, So if it was published in the news and everywhere that there is a quality mark and if there would be tips like if that and that is the case, you may trust it. I think I'd choose such a test. Otherwise, I wouldn't test, I guess. (group 3).*

To ensure reliability of the quality mark, the Dutch government should carefully and continuously monitor whether providers (still) meet quality criteria.

> *"And make unannounced visits. Because if they know in advance then everything is going to look perfect of course".*
>
> *(Group 3)*

Some participants see more in the prohibition of health checks that do not meet certain criteria, notably, tests that do not provide certainty about the presence or absence of disease.

> *I: But would that mean that the government should also prohibit tests that do not provide certainty about the presence or absence of disease?*
>
> *R1: Yes.*
>
> *R2: Yes of course.*
>
> *R3: Yes.*
>
> *R4: Yes, otherwise you get those witchdoctors...*
>
> *R2: Just like quackery is fought against. (group 1).*

> *R: I think, as a government, if there were ten tests on the market for warts, and none of them show whether you're affected, as a government you should then say: we can't have this on the market. (group 2).*

And a few participants believe that the government should be the exclusive provider of health checks.

> *R: I personally think when it comes to health, that to begin with health care should be removed from commercial environments. It should be a governmental task only. (group 1).*

Trust in the Dutch government

Participants expect the Dutch government to serve their interest and to protect them from unreliable and invalid tests, unqualified providers and checks that cause health risks. From participants' statements about the regulation of health checks, it may be discerned that they also place trust the government in this respect. This is also evident from their expectations concerning the enforcement of privacy regulations and their enthusiasm about governmental screenings:

> *I participate in governmental screenings and so on. And I think it's very important to take part. They should really emphasize that more because there are also people who say 'Oh, I'm not going, why should I?' Well, you should go; it is very important. (group 4).*

Moreover, some participants explicitly state they trust the government. As with the trust in doctors, it seems to be the case that this trust in the government(al institutions) is self-evident for some – these participants do not seem to think about trust, just trust – while others realize they 'choose' to trust, like this participant:

> *Yes, you should expect the government to be impartial. I mean, when you ask this cornershop's guy to rate the vegetables of the next cornershop, he'll say right away that his cauliflower isn't any good, mine is much better. Yes, it doesn't make sense to, you know what I mean. I really think you need an independent party... Things certainly go wrong there as well, but. But I think, yes, you know, as a citizen it is important to expect the government to do the right thing. It doesn't always turn out that way, but you should be able to assume that they will.. (group 3).*

Discussion

We have chosen a qualitative approach because the openness of a qualitative method allows the uncovering of unexpected views and arguments. The aim was an in-depth understanding of what the general public considers important when it comes to health check offers. The many assumptions made and the apparent trust in physicians and government were an unforeseen but important finding. To draw conclusions on what percentage of the general public values which criteria for good health checks, the results of this study would need to be quantified. Extra caution should be taken when it comes to generalizing assumptions of these participants because they are made in a Dutch setting and may reflect characteristics of the Dutch health care system, organisation of governmental screenings and relationship between citizens and government.

If we compare the criteria as formulated by the participants of our focus groups to existing quality criteria for health checks [1, 7, 8] it is striking that the criterion participants deem most important – the predictive value of health checks – is neither mentioned in European guidelines nor in the criteria drafted by the Human Genome Commission [7, 8][2].

Existing quality criteria for health checks have a particular focus on informed consent. It is assumed that if an individual is properly informed, he or she can determine the benefits and harms for themselves accurately and will only participate in testing if the benefits outweigh the harms [1, 7, 8].

However, while participants deem information (before, during and after the test) an important criterion, it is questionable to what extent this information influences their decision to test. They assume that health checks in general – or at least those provided by physicians – have a high predictive value and provide possibilities for health improvement. They trust providers to keep health check data confidential, and tend to rely on heuristics in their choice of provider (and therefore test).

Why these assumptions and heuristics?

That participants make assumptions about health check characteristics and that they would make use of heuristics in their choice for provider and test is perhaps not very surprising, considering that people have limited cognitive resources and therefore employ different strategies to limit the amount of effort necessary to think about their surroundings: Stereotypes and heuristics function as mental shortcuts, simple rules for drawing complex inferences about the characteristics of groups of people (or 'things' such as health checks), or making complex decisions (e.g the weighing of benefits and harms of a specific health check) in a rapid manner [20, 21]. Because of these limitations of cognitive resources as well as the role of emotions in judgments (20, 21], it may not be feasible for people to weigh all relevant benefits and harms of health checks [22, 23]. In fact, because full informed consent may not always be possible, researchers on genetic tests sometimes state that institutional reliability – one of participants' heuristics – rather than consent should be prioritized [24–26].

Why however, would participants have the specific assumptions discussed? Why would they think that health checks give certainty about the presence or absence of disease and provide opportunities for health improvement – at least if they are offered by physicians or providers that are characterized as 'knowledgeable and reliable'? And why would they think that providers would keep health check data confidential? We cannot be sure, but these assumptions may result from a combination of the following: First, governmental screening programs seem to function as a 'benchmark' in people's thinking about health checks: uptake of governmental screenings is relatively high in the Netherlands [27–29]. Many people then, have experience with health checks that have a reasonable predictive value, provide health benefits on population level [30], potential benefits on individual level, and whereby data are treated confidentially. Focus group participants' personal experience with health checks was oftentimes limited to population screenings and they often referred to them when talking about health checks in general.

Second, advertisements for personal health checks do not stand out by attempts to modify any false expectations regarding predictive value, health benefits or privacy. Take for instance the 'national cholesterol-test' that is provided free of charge throughout the Netherlands. It measures the (bad) LDL and (good) HDL cholesterol together while it is their respective levels and their ratio that are important for predicting cardiovascular disease risk. Also, cholesterol levels can fluctuate quite a bit which means that a single measurement is usually not considered reliable [31]. Yet advertisements and banners state: '65% of the Dutch population has elevated cholesterol-levels. What about you?' The explanation on the website and in folders reads: 'an "elevated cholesterol level" actually means a high LDL ad a low HDL level. With only one drop of blood obtained from a finger prick, your cholesterol level can be determined. What are the risks of elevated cholesterol? (…) The LDL cholesterol easily binds to the walls of the blood vessels, causing the vessels to clog. This increases the risk of cardiovascular disease [31].

Finally, the participants of our focus groups portrayed an apparent trust in physicians and the Dutch government when it comes to the offer and regulation of health checks as well as in general, a trust that is also reported in big surveys [32, 33]. It may very well be that participants 'dare' to rely on assumption and heuristics in their choice for provider and test, because they expect and trust physicians to act in their interest, and expect and trust the Dutch government to intervene when health check offers of other providers are misleading or may threaten their health or privacy.

Morally problematic choices

Participants tend to rely on the previously discussed assumptions and heuristics in their decisions to test. In this section, we will argue that this is morally problematic in cases in which heuristics do not work as they are supposed to – as shortcuts to accurate decisions.

Contrary to what participants think, not all tests provide certainty about the presence or absence of disease, whether or not provided by physicians.

The formerly mentioned 'national cholesterol test', for example, is provided amongst others by a pharmacy chain [31] Health checks that provide absolute certainty are almost non-existent, but many tests offered do not even come close. For example, PSA tests seem to indicate the presence of prostate cancer no better than tossing a coin. This 'popular' health check is also offered by GP's and urologists but has a sensitivity of 72% and a specificity of 93% if performed in men older than 50 at a cut off point of 4.0 ng/ml. This means that 65% of the men with positive test results do not actually have prostate cancer, hence, considerably more than half of the men that get tested receive a false result [34]. Additionally, health checks do not necessarily offer opportunities for health improvement. In fact, even if (risk factors for) diseases tested on are treatable, health benefits have only been demonstrated for a very limited number of checks. This may be because people do not (consistently) manage to follow health advice [1]. Last but not least, health check data are not always treated confidentially. Some commercial providers may sell them [35].

As discussed, advertisements do not attempt to adjust false expectations. Furthermore, in another study we found that some Dutch health check providers doubt whether informed consent procedures suffice to adjust false expectations of potential users:

> *What people understand and what people want to understand, you can explain something very well, but sometimes people just want to read something else, so.. (health check provider)* [14].

This situation may well result in people choosing health checks that do not provide certainty about the presence or absence of disease, checks that may not result in health benefits or those that may harm health. Our participants indicate they value health and certainty about their health status. What follows is that choices for health checks may often not be conducive to what people actually want and to what they consider important, and thus cannot be characterized as autonomous in the sense of 'authentic' i.e. in line with one's values, norms and life plans [2, 36].

Inauthentic choices for health checks may not be worth pursuing, but why do we characterize inauthentic choices for health checks with a low predictive value or checks that do not provide health benefits as 'morally problematic? This is because these types of inauthentic choices may severely harm people. After all, some tests – such as invasive tests or tests using radiation – carry risks in themselves; false positive results may lead to unnecessary worry and overtreatment, and false negative results to unjustified reassurance with potentially negative consequences for health [1, 2].

Another reason why we deem choices based on false assumptions morally problematic is that they may violate the relationship of trust between (potential) users and physicians and between citizens and the Dutch government. The participants of our focus groups trust physicians to provide health checks that serve their wellbeing and trust the Dutch government to intervene if health check providers offer tests with a low predictive value, tests that may harm people or if providers would infringe on the privacy of users.

Essentially, they expect physicians and the Dutch government to be well intended towards them, or at least, to be without ill intentions; they rely on this [37][3].

This reliance could be seen as 'a moral relationship that puts a claim on the physician [and Dutch government - YS] to take the expectations of the [(potential) health check user - YS] seriously and to respect them' ([39] pp 178). In order to be trustworthy, providers would therefore have to align their health checks offers to the expectations potential users have. If providers are uncertain about what these expectations are, or offer checks that do not meet expectations, they should clearly communicate this to potential users [39, 40]. In order to be trustworthy, the Dutch government should intervene if health check offers fail to meet reasonable expectations of citizens.

So far, the Dutch government has been reticent except when health checks may directly harm the health of users (such as when X-rays are used) [1, 9, 12, 13]. The trust of participants in the Dutch government to intervene if health checks with a low predictive value are offered, like the national cholesterol test or PSA test, is then largely unfounded.

At present, participants seem to base their idea of what health checks are on governmental screening programs. If too many tests were offered that fail to meet citizens' expectations, this could negatively affect participation in governmental screening programs.

Recommendations

Participants expect health checks to provide certainty about the presence or absence of disease and to provide health benefits, and they believe health check data are treated confidentially. Moreover, they trust physicians to offer tests that meet their expectations and expect the Dutch government to intervene if providers offered tests with a low predictive value, tests that could harm health, or if providers infringed on the privacy of users. From this it may be discerned that participants value certainty about the presence or absence of disease, health, safety, privacy, and their relationship of trust with physicians and the Dutch government.

To prevent people from participating in health checks that are not conducive to their values, and to maintain trust, we make two recommendations.

First, it is important that any false expectations are adjusted as timely as possible, for example in advertisements. We recommend the criterion informed consent in ethical guidelines to be further developed and specified concerning this point. This is because psychological research time and again shows the importance of a first impression [20]. Moreover, the more time and attention people 'invest' in a health check (commitment bias) [41] and the more they feel health check providers have invested in them (foot in the door principle) [42], the less likely it becomes that they will decide not to test after all, even if they've come to realize that the check does not meet their expectations and will not be conducive to their values and goals in life. Legal experts on health checks also advise more supervision to compliance with the Dutch law on misleading advertisements [9].

Second, we would suggest enabling potential users to make use of reliable heuristics in choosing whether or not to test, by creating a new heuristic in the form of a quality mark. This quality mark should indicate whether health check offers meet important quality criteria. This way, potential users can at a glance determine whether health checks have a reasonable predictive value, offer health benefits and whether data are handled confidentially [1, 30].

Conclusions

Dutch citizens who participated in our study consider health check offers to be 'good' when they conform to the following criteria: health checks should provide certainty about presence or absence of disease; good information should be provided before, during and after the health check; providers should be knowledgeable and reliable; testing should provide opportunities for health benefits; privacy should be respected; health risk should be minimized and proportional; and health checks should be accessible. Governmental screenings should be cost-effective and only offered to people at high risk for disease.

Participants make striking assumptions about health check offers, for example that health checks always provide certainty about the presence or absence of illnesses, that they offer opportunities for health benefits and that the privacy of health check data is guaranteed. Moreover, in their choice for provider and test, they appear to rely on heuristics, such as trust in physicians, more than on information.

These assumptions are not always justified but may influence the choice whether to participate in a health check. This is problematic because inauthentic choices for tests with a low predictive value that do not provide health benefits may create uncertainty and cause harm to someone's health; an outcome diametrically opposite to the one intended. Also, this may impair their relationship of trust with physicians and the Dutch government. To further and protect autonomous choice and to maintain trust, we recommend measures to timely adjust false expectations: advertisements that give an accurate impression of health check offers, and the installation of a quality mark.

Endnotes

[1] This was due to time-constrains.

[2] Interestingly, even health check users that deem the predictive value of tests important in their decisions to test and judgement about tests may fail to mention this criterion what asked what potential users of health checks should look for in making their choice [19]. Asked for the characteristics of health check (offers) that were important in their decisions to test and their positive and negative experiences, users in this pilot study mention the possibility of preventive action, whether or not test results provide certainty about the presence or absence of disease, information before, during and after the check, accessibility and the way they are treated by health check providers. Most of these criteria however were *not* mentioned if users were asked what potential users of health checks should look for in making their choice. They then, among others, stressed the treatment by the provider and clarity of information provided [19]; the same heuristics our participants would use in choosing a test!

[3] Note that trust may either be reflected or unreflected [38]. As discussed, some of the participants of our focus groups are conscious about their reliance on physicians and the Dutch government and the vulnerability of doing so. Others do not feel they're taking any risk in trusting physicians or the Dutch government nor think about their vulnerability because from their perspective there is no risk or vulnerability.

Additional files

Additional file 1: Focus group guide. (DOCX 64 kb)

Additional file 2: Characteristics of participants. (DOCX 116 kb)

Abbreviations

GP: General Practitioner; PSA: Prostate specific antigen

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Availability of data and materials

The transcript data that support the findings of this study are available on request from YS. The transcript data are not publicly available due to them containing information that could compromise participants' privacy and consent.

Authors' contributions

All authors were equally involved in the study design. YS moderated the focus groups and was a major contributor in writing the manuscript. EA attended all focus groups and double coded one of the transcripts. Analysis of codes to results was done by YS in close consultation with EA and MS. MS provided valuable suggestions for the structure of the paper and was a major contributor to the line of argumentation in the discussion. All authors read and approved the final manuscript.

Ethics approval and consent to participate

In the Netherlands, ethics approval or written informed consent for this type of research is not required according to the Medical Research (Human Subjects) Act (WMO) [43]. Participants were informed orally about the purposes of the study beforehand and enabled to ask questions. They gave their verbal consent to participate and to anonymized publication of findings, which was recorded on tape.

Competing interests

The authors declare that they have no competing interest.

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Chapter 4

Do health checks empower or discipline people?

Do health checks empower or discipline people?

Practicing care of the self in a context with dominant norms

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(under review)

Abstract

Health checks - tests that identify (risk factors for) disease in people without specific medical indication - are acclaimed to further to ability of (potential) users to exercise autonomy in health-related decisions. Scholars that make reference to the work of Foucault, however, may state that health checks 'discipline' people to take better care of their health. Do health checks empower or discipline people?

Based on an analysis of empowerment theory and disciplinary power, we show that this question cannot be answered in general, but depends on the predictive value of the test, the condition tested on, the way the test is offered, the individuals to whom it is offered, and the context in which it is offered.

Interestingly, some health check offers may be characterized as empowering and disciplining at the same time. This concerns checks that provide opportunities for health improvement, which are offered on a voluntary basis, with reliable and valid information, to potential users with sufficient health literacy and capabilities to implement health advice.

In this paper we try to explain these apparently opposing effects with the help of Foucault's notion of 'care of the self', which pictures the to-be-empowered individual within a potentially disciplining environment.

Introduction

Breast cancer screening, a cholesterol or PSA check, online health-risk questionnaires or commercially offered CT-scans are all examples of ‘health checks’: medical tests aimed at identifying disease, or risk factors for disease, in people without specific medical indication. (Health Council of the Netherlands (HCN) 2015) Such checks may be provided through population screening programs by governments and GPs, or to individuals by other providers as ‘personal health checks’.

Health checks can be offered with different intentions, and may have different - intended and unintended - effects. Much discussed are effects on health, health related behaviour, and autonomy: Do health checks improve health? What is their effect on health related behaviour? Do they increase opportunities to exercise autonomy in health related decisions? Such questions play an important role in health check policy (Bijlsma et al 2014, HCN 2008, 2015, Human Genome Commission (HGC) 2010, Schippers 2015, 2016) and discussions on the ethical evaluation of personal health checks. (Juth & Munthe 2012, Nuffield Council on Bioethics 2010)

Politicians, policy-makers and primarily providers often highlight health checks’ empowering effects. (e.g. bloedwaardentest.nl, prescan.nl, Schippers 2015, 2016) By informing people about their risk for disease and about possibilities to improve their health, health checks are said to further the ability of (potential) users to exercise autonomy in health-related decisions. The idea is that ‘if individuals would possess the knowledge that they (…) have an increased risk of contracting some disease, they are in a better position to plan their lives in accordance with their own perception of a good life.’ (Juth & Munthe 2012 pp 22-23)
This acclaimed empowering effect of personal health checks has been critically assessed however, most notably by scholars that make reference to the work of Foucault. Personal health checks (Ayo 2012, Callon & Rebaharisoa 2008, Lemke 2001, Rabinow 1992, Rabinow & Rose 2006, Rose 2007, Rose & Novas 2005), like governmental screening programs (Armstrong 1995, Lupton 1995), would be instruments through which power is executed *over* people. They would not increase opportunities to exercise autonomy, but ‘discipline’ people to take better care of their health.

In this paper, we will attempt to provide more insight in what it is that health checks ‘do’. Do they indeed empower people to make informed and autonomous decisions regarding their health? Or do they discipline them to change their behaviour and take better care of their health? How can we explain such apparently opposing effects? Answers to these questions will further the discussion on the ethical evaluation and regulation of health checks.

On the basis of reviews on empowerment and primary texts of Foucault, we will first explicate what we take empowerment and disciplinary power to mean. This analysis results in a list of characteristics that have to be met by health checks in order to either empower or discipline people.
Drawing on this theoretical background we will show that the question on health checks’ effects on autonomy and health related behaviour cannot be answered in general, but will depend on the predictive value of the test, the specific (risk factors for) disease tested on, the way the test is offered, the individuals to whom it is offered, and the context in which it is offered.

We will explicate which type of health check offers may empower people, and which may discipline them towards better health related behaviour. As it turns out, some health checks may empower and discipline people at the same time. To explain how health checks may do this, we will introduce Foucault's notion of care of the self which pictures the (to be) empowered individual within a potentially disciplining environment.

Empowering health checks

In this section, we will explicate how empowerment is usually defined by scholars specialized in empowerment in the context of health. Where possible, we deduce from this literature necessary conditions for health checks to have an empowering effect. However, some important characteristics in which health checks vary, such as the treatability of disease, remain undiscussed in this consulted literature. Therefore, starting from the definition and aim of empowerment, we make some suggestions as to which type of health check have the potential or are likely to empower individuals.

Empowerment is a term commonly used in literature on health promotion. Reviews on the topic show that it may refer to a state, process and resulting behaviour or outcome. (Fumagali et al 2015) *Processes* of empowerment generally consist of educating people. (Anderson & Funnel 2010, Aujoulat et al 2007, Holstrom & Roing 2010, Schultz & Nakamoto 2013) The goal is for individuals to reach a *state* in which they are able "to think critically and make autonomous, informed decisions" (Aujoulat et al 2007 pp 3, see also Anderson & Funnell 2010) on what aims to pursue, and on the ways to pursue those aims in the context of health. (Schultz & Nakamoto 2013, Tengland 2008) The *outcome* of a successful empowerment process is "a measurable increase in the patient's ability to make autonomous, informed decisions". (Anderson & Funnell 2010 pp 3) Whether or not people decide according to what is good for their health should be left up to them because "medically oriented and prescriptive outcomes are not congruent with the principles of self-determination and responsibility (…) health care providers should be aware that the patients personal goals may differ from what they believe is best for the patient". (Aujoulat et al 2007 pp 17, 18, see also Anderson & Funnel 2005, 2010, Fumagali et al 2015, Holstrom & Roing 2010, Schultz & Nakamoto 2013) However, empowering patients to self-management is generally believed to lead to improved health outcomes, because "patients generally want to be healthy". (Anderson & Funnel 2010 pp 5) They will therefore use the information provided to better their health.

Health checks can be understood as means in a process of empowerment in two ways. First, information about health checks in general and specific checks in particular, may educate people regarding various health risks, the opportunity to be informed about those risks by taking the test, and any possibilities to avert those risks by following up on health advice if test results would warrant this. Second, the outcomes or results of a health check will inform individuals about their personal health risks and their opportunities for improving their health. The role of health checks in processes of empowerment could be seen as successful if they result in people making autonomous and informed decisions on whether or not they want to participate and whether or not they want to implement health advice in order to improve their health.

The empowerment literature explicitly states that health checks may only empower people if (potential) users have a sufficient amount of health literacy. (Schultz & Nakamoto 2013) Two other necessary conditions are also mentioned: First, people should be able to act on information provided. (Schultz & Nakamoto 2013 pp 5) People should thus be able to implement any health advice, e.g. in financial and practical sense. Second, information provided should be reliable. (Schultz & Nakamoto 2013 pp 9) This may concern the information in health check offers and the reliability and validity of test results.

What remains unclear in the literature is whether information provided by health checks should enable users to take steps to improve their health. Could a health check for an untreatable condition have an empowering effect as well? (Tengland 2008 pp 85) To answer this question, it is important to differentiate between the effects of health check *offers* and health check *results.*

Health checks are oftentimes offered though advertisements, announcements or invitations – unsolicited, that is. This means people are informed about the possibility of having risk factors or diseases without their request. This may further autonomy if people want to know, but may also hamper autonomy if people prefer to remain ignorant; they are then confronted with unwanted and unrequested information. (Chadwick et al 1997, Juth & Munthe 2012) The chance that unsolicited health check offers will empower people depends on how likely it is that the information provided in these offers will be relevant 'to one's ability to lead one's life in accordance with one's plans', whether it fits one's conception of 'the good life', whether it is relevant to one's aims. (Juth & Munthe 2012, Tengland 2008) As people worldwide consistently rate health as a core value (OECD 2015), it is often argued that most people will want to be informed about the possibility to prevent serious illness. (Chadwick et al 1997, Juth & Munthe 2012) Individuals however differ in whether they want to be informed about untreatable conditions. Some will welcome an opportunity to test because knowing enables them to change their life-plans if necessary. In case of positive test results they would for example stop working and start traveling or decide to spend more time with their family. Most however, do not want to be informed about the possibility to test because they don't want to be confronted with or reminded about the possibility of them suffering from untreatable disease. (Bunnik et al 2015, Chadwick at al 1997, HCN 2008, 2015) *Unsolicited*[1] health check offers concerning treatable conditions are therefore more likely to empower people than unsolicited health check offers concerning untreatable conditions.[2] When it comes to the empowering effect of information provided through health check *results*, we see no reason to make a distinction between health checks on treatable conditions versus checks on untreatable diseases. Of course, people may misjudge the impact of these results on their lives. Even if they are well informed and choose to be informed because they think this information can be of use in the planning of their lives "it does not follow that actual revelation of this information will *in fact* provide help in this respect". (Juth & Munthe pp 24) However, the same argument may be made for information about (risk factors for) disease in general. Individuals may think this information will be of use, but end up feeling depressed or confused. (Chadwick et al 1997, Gillespie 2012, Juth & Munthe 2012)

In conclusion, both health check-offers as such, as well as health check results, may empower people because they provide information that could help people in making informed and autonomous decisions regarding their health. Necessary conditions that need to be met for a health check offer to be empowering are that information provided should be reliable and valid; that participation should be voluntary; and that potential users should be sufficiently health literate and able to implement any health advice. The likelihood that health check offers will actually empower people are bigger if they concern treatable diseases or risk factors for disease, and thus provide opportunities for health improvement.

Disciplining health checks

According to some critics, health checks should be understood as disciplining, rather than empowering tools. In this section, we will explicate what Michel Foucault meant with disciplinary power in the context of biopower. Based on this theoretical background we will formulate the necessary conditions that would have to be in place for health checks to have a disciplinary effect on health related behaviour.

The term 'disciplinary power', as well as 'power' in general has, unfortunately, a somewhat negative connotation. Therefore, it may be good to start by stating that Foucault aims to describe power relations between individuals, institutions, and the role of knowledge and norms in interactions between them, without normative judgement. Essentially everybody and everything exerts power and is subject to power in some way or another. That is not necessarily a bad thing, but it is important to be aware of when thinking about what society looks like, what it could look like, how we behave and would want to behave – in thinking about ethics, that is. (Foucault 1982a, 1983)
Disciplinary power, according to Foucault, is a special kind of power that does not suppress people, but 'produces' subjects that embody certain scientific or social norms. (Foucault 1982a) This power cannot be located in a specific organisation, person or technique, but requires a system in which various actors contribute, including the to-be-disciplined subjects themselves. The individual is thus both subject and object of this power at the same time and resistance to disciplinary power is possible. (Foucault 1982a)
In a 'classical' disciplinary process, people are made aware of the importance of norms, the importance of acting on those norms and the right ways to do so. At first, they need to know that they're being observed, and be made aware of any deviations, in order to incite them to follow norms. However, after some time, supervision is no longer needed for they will have internalized the norm and will correct themselves once they deviate. (Foucault 2001/1975) They will have come to consider these norms as their own. (Vaz & Bruno 2003) The likelihood of people internalizing a norm and behaving in accordance with it increases when more and different actors within a disciplinary system disseminate that norm and when spatial arrangements are such that they facilitate behaving according to the norm. Moreover, behavioural change towards a norm often requires thorough practice. (Foucault 2001/1975)
If instances of disciplinary power are directed to benefit the health of subjects, they are part of what Foucault calls 'biopower'; a power that aims to improve the health of the population and the individuals that make part of that, 'to invest life through and through'. (Foucault 1976 pp pp139, 2003) Some examples will show what disciplinary power in the context of biopower may be about and that this form of power is all

around. We wash our hands after visiting the toilet, or we take the stairs instead of the elevator, for example, because we've been disciplined to do so. We don't *have* to, but – most of the time – *choose* to act on those implicit norms of hygiene and exercise because we believe they are right and because we value our health. The more people around us do the same, and the closer the sink is to the toilet, or the more prominent the stairs are positioned in relation to the elevator, the more likely it is that we will behave as we were 'disciplined' to do.

Health checks that offer opportunities for health improvement can be understood as part of a system in which people are disciplined towards better health related behaviour, and thus instances of biopower. In this system, health checks may function as "exams" in which "individuals are made visible" (Foucault 2001/1975 pp 257); they are instruments to observe the health of an individual that aim to reveal any deviations from medical norms regarding which blood values, weight, or other measures are considered healthy. In case of positive test results, users will be given treatment or health advice how to 'normalize' values. Users are thus observed and incited to conform to medical norms at the same time.

Whether or not people participate in health checks and whether or not they implement any ensuing health advice can also be seen as 'exam'. By participating and implementing health advice people may prevent disease, and save society the health care expenditures of either unnecessary doctor visits or care for disease in a progressed stage. (Schippers 2015) Participation in health check and compliance with advice thus reveal whether individuals care about their health and whether they behave according to the societal norm of the responsible citizen who takes individual responsibility for his health. (Armstrong 1995, Armstrong and Eborall 2012, Ayo 2012, Rose 2007)

In order to discipline people towards better health related behaviour in a direct way[3], to be an instance of biopower, health checks first and foremost need to offer opportunities for health improvement. Furthermore, people need to be able to implement any health advice, because if they are not, there is no potential for behavioural change.

The more comprehensive the disciplinary system is – for example because in a certain social environment 'everybody tests' – and the more favourable spatial arrangements are – with the mammography bus in town or checks offered at work – the more likely it is that people will take a test, and hence the more likely that it will have disciplinary effects. (Howson 1999, Stol et al 2016, Willis 2004) With regard to the uptake of health advice, this seems more likely if it is relatively easy to follow and if it is considered 'normal' to do so. If the implementation of health advice requires behavioural change - for example, if one is advised to change one's diet, or start exercising - a health check by itself is unlikely to be effective, research shows. Cardiovascular health checks – that oftentimes result in the advice to stop smoking, start exercising, maintain a healthy diet etc. – seem to be a case in point: so far, health benefits on population level have not been demonstrated, likely because people do not consistently keep to health advice. (Krogsbøll et al 2012, Jørgensen et al 2014, Si et al 2014, HCN 2015) In such cases, the disciplinary system would have to be extended with 'training facilities' in order to be successful.

Finally, people seem to be more likely to test and implement health advice if there exists a societal norm of 'responsible citizens' taking individual responsibility for their health. (Horstman et al 1999, Horstman and Houtepen 2005, Howson 1999, Rose 1996, 2007, Willis 2004)

Do health checks empower or discipline people?

What is it that health checks 'do'? Do they empower or discipline people?
To empower people, health checks should increase their ability to make autonomous decisions on what aims to pursue and on the ways to pursue those aims in the context of health. Above, we have analysed under what conditions health checks can be expected to actually empower people in this way.
To discipline people towards better health checks related behaviour, health checks have to conform to partly the same conditions, as can be seen in table 1. Moreover, attempts to discipline individuals towards better health-related behaviour are likely to be more or less successful depending on the context in which checks are offered.
Comparing these conditions and effects (table 1) we conclude that it is not possible to make a general statement on what health checks do. Their effect will depend on the test- and disease characteristics of the check that is offered, the way it is offered, the individuals to whom it is offered and the context in which it is offered.

Aspect of UNSOLICITED health check offer		Empowering effect	Disciplining effect
Test characteristics	Reliability and validity of results	X	X
Disease characteristics	Treatability of (risk factors for) disease	X	X
Way check is offered	Voluntariness	X	
	Reliability of information	X	
Individual to whom check is offered	Health literacy	X	
	Capability to implement health advice	X	X
Context in which check is offered	Participation is 'normal' and convenient		X
	Societal ideal of man as responsible citizen taking individual responsibility for his health		X

Table 1: influence of different aspects of health checks offers on their empowering and/or disciplining effect. X denotes necessary condition, X facilitating condition.

As it turns out, health check offers do not necessarily either empower or discipline people. Some show neither of these effects, namely checks offered to potential users who are not capable of implementing any health advice. Unsolicited checks on untreatable (risk factors for) diseases will not (directly) discipline people towards better health related behaviour and are not likely to have an empowering effect.

Some health check offers may empower and discipline people at the same time. This is because the necessary conditions for health check offers to empower and discipline people are not mutually exclusive: in comparing conditions, we conclude that all checks that provide opportunities for health improvement, that are offered on a voluntary basis with reliable information to (potential) users with sufficient health literacy and the necessary capabilities to implement health advice may have an empowering *as well as* a disciplining effect. This raises the question whether empowerment and disciplinary power are all that different, or perhaps could also be seen as different descriptions of the same phenomenon? We will return to Foucault in order to explain this apparently paradoxical situation.

How health checks may empower and discipline at the same time

Michel Foucault not only wrote about disciplinary power, but also about people who actively choose to change part of themselves, practicing what Foucault termed 'care of the self'. (Foucault 1982a) In this section, we will explain the notion of care of the self and will show how it may be used to explain that certain health checks offers can both empower *and* discipline people.

In practices of 'care of the self' men seek to transform and change themselves. (Foucault 1983) Foucault describes it as "an exercise of self upon the self by which one tries to work out, to transform one's self and to attain a certain mode of being". (Fornet-Betancourt et al 1984 pp 113, see also Foucault 1982b) Importantly, this work on the self is not imposed on the individual but a choice about existence made by the individual themselves. (Rabinow & Dreyfus 1983)
Individuals that practice care of the self will start by asking themself: "which is the aspect of myself or my behaviour that is concerned with moral[4] conduct?" (Rabinow & Dreyfus 1983 p 111) They will ask themselves about the kind of being which they aspire to be. To answer the question of what part of themselves needs change, individuals will look for inspiration in their environment. Here they will find different "mode[s] of subjectivation, that is, the way people are invited or incited to recognize their moral obligations". (Rabinow & Dreyfus 1983 p 111) Once individuals have determined what part of themselves they want to improve, they will also seek inspiration in their surroundings for the kinds of techniques or means one can use to constitute themselves as a 'subject of ethics'; the kind of people (i.e. healthy, responsible) they aspire to be. (Rabinow & Dreyfus 1983) This may require 'ascesis': a training of oneself by oneself; in this sense, it is truly a matter of practice. According to Foucault, since this process requires both self-reflection and self-control, care of the self is reserved for the small elite of people who actually posses those skills (Rabinow & Dreyfus 1983) "The notion of care of the self (…) suggests an actor who is always consciously aware of what he or she is doing, who is engaging in a reflexive evaluation of the situation and responding accordingly to maximize her or his life changes, who approaches life as if it were a rational enterprise." (Lupton in Petersen & Bunton 1997 pp 105-106)
The social environment is an important source of inspiration for the individual who wants to change part of himself. Therefore, changes in the environment offer new choices to individuals who seek inspiration on which aspects of himself they would like to change, and which methods they may use to effect such change. (Fornet-Betancourt et al 1984, Rabinow & Dreyfus 1983) Foucault stresses that in a context with strong and unidirectional or dominant scientific and social norms, individuals who want to change

part of themselves haven't got much choice. (Fornet-Betancourt et al 1984) In such a context, individuals are likely to make choices about what and how to change about themselves, that will result in much the same behaviour as shown by people being disciplined on those norms. (Fornet-Betancourt et al 1984) Introducing an 'invite' or incite' for specific behaviour in an environment that with strong, dominant ideas about what is important in life, about how to behave and about how certain goals may be achieved, will thus likely influence the outcome of individuals practicing care of the self. In such a context an invite may thus have a disciplinary effect. This insight may, and is used by different parties- ranging from governments to teachers – that aim to influence the choices individuals make. (Foucault 2008) Nicolas Rose calls this process 'governance through freedom'. (Rose 1999a, 1999b, 2007)

Health checks as invite to practice care of the self in a context with dominant norms

Applied to health checks, the theory of 'care of the self' is less abstract than it may appear at first sight. The starting point is individuals who want to change and improve a part of themselves, namely their health.

In the Foucauldian tradition, the choice to improve health has often been conceived as heavily influenced by societal ideas about what people should consider important; the importance of health was seen as being 'imposed' on people. The term 'healthism' has been used in this context. (Greco 1993) We, however, would like to argue that this does not necessarily have to be the case. People differ from each other in many ways, also when it comes to their aims in life or what they consider important. They may, thus, want to better different part of themselves. People however, also share certain values. One of the most important shared values across different societies, social circles, and subcultures is health. As already noted, research shows that most people value health more than anything else. (OECD 2015) It is thus not unlikely that individuals really want to protect or better their health one way or another, and want to make decisions that enable them to do so. This wish may of course be influenced or strengthened by a strong emphasis on health, or on individual responsibility for health in the social environment of the individual. Social norms will influence what and how individuals want to change about themselves. Health checks that provide opportunities for health improvement can be understood as *invites or incites to take 'care of oneself'*, by trying to improve one's health. Health advice following the outcomes of a health check can be understood as an inspiration for how to attain this aim.

The offer of an health check that provides opportunities for health improvement may be seen as an *empowering* act if one emphasizes the choice of individuals to accept the 'invite' to better their health and to be inspired by health advice .To count as a form of 'care for the self' and to have empowering effect, participation should not only be voluntary, but – as explained before – also be based on reliable and valid information. Moreover, individuals should also have a sufficient amount of health literacy and be capable to implement health advice. As noted in the section on disciplinary power, this is not necessarily the case, especially not when health advice requires behavioural change. In other words: to function in an empowering way, the potential user of health checks should make part of what Foucault calls 'the small elite' of individuals who will train themselves until a rationally defined goal is established. We will come back to this point in the discussion.

However, this very same situation may also be evaluated as being *disciplinary* if one realizes that this 'small elite' may indeed have a choice to test and to implement any health advice, but that invites to practice care of the self that fit dominant ideas regarding what is important in life, how to behave and how certain goals may be achieved are more likely to be accepted than rejected. The social norm and ideal of 'responsible citizens' who take individual responsibility for their health, together with the medical norms and scientific evidence that early detection and treatment results in a better chance of prevention, cure or survival, make it more likely that they will accept rather than reject health check offers and implement health advice.

Conclusion and discussion

We may conclude that it is not possible to make a general statement on whether health checks discipline or empower people. Their effect will depend on test- and disease characteristics of the check that is offered, the way it is offered, the individuals to whom it is offered and the context in which it is offered.

Interestingly, if health checks that offer opportunities for health improvement are offered to potential users that are not capable of implementing any health advice, they will neither empower nor discipline people towards better health related behaviour, because there simply is no potential for behavioural change. Also, health checks on untreatable (risk factors for) disease will not discipline people towards better health related behaviour nor are they likely to empower people (although in some cases, they can). Health check offers, thus, do not necessarily empower or discipline people. Some show neither of these effects.

Some health check offers however, may be characterized as empowering and disciplining at the same time. This concerns checks that provide opportunities for health improvement that are offered on a voluntary basis with reliable and valid information to potential users with sufficient health literacy and capabilities to implement any health advice.

We are not the first to notice that health education such as health checks may empower and discipline people with sufficient health literacy and capabilities to implement any health advice at the same time. (e.g. Gastaldo in Peterson & Bunton 1996) We however, have tried to explain why this is the case. Foucaults' notion of care of the self proved to be very suitable for this purpose, as it pictures a to-be-empowered individual in a context with dominant norms concerning what aims to pursue and the ways to pursue those aims. (Tengland 2008)

Invites to practice care of the self in a context with dominant norms concerning what is important in life, how to behave and how certain goals may be achieved are likely to be accepted. People *want* to be healthy and therefore will *want* to take steps to improve health. Moreover, if people value health and want to take steps to improve their health, they then want these steps to be effective. They will therefore *want* to implement scientifically proven effective health advice.

This effect is strengthened but not necessarily different in a societal context in which it is assumed that people ought to take individual responsibility for their health, and in which there are – next to health checks and following up scientifically proven health advices – limited options to do so. If these checks are offered on a voluntary basis, accompanied with reliable and valid information, and offer opportunities to improve health through measures that the to-be-empowered individuals are capable of implementing, it may be said that they are empowered and disciplined at the same time.

Foucault's concept of care of the self moreover draws attention to at least two points that did not receive much attention in the empowerment literature so far:
First, it highlights that processes of empowerment necessarily always take place within a certain societal context. What does it mean if people make 'informed and autonomous decisions' in a context in which certain norms are dominant, and may influence people's aims and the way in which they choose to pursue those aims? Is it possible to provide neutral information to further individual's ability to make 'informed and autonomous decisions' or does information provision inevitably also contains norms - and if so: when does this interfere with 'autonomous decision making'? These questions seem relevant in discussing the meaning and value of empowerment yet consulted reviews barely touch upon these issues.

A second important insight that the comparison of care of the self and empowerment may yield is the notion of the 'small elite': empowering people through information provision may be much harder than suggested.
According to Foucault most people would lack the necessary self-reflection and the 'ascesis' - the capabilities to accomplish long term behaviour change - to practice care of the self, or to be empowered through information provision. Current psychological research proofs him right.
As regards self-reflection: most people, including the so-called 'health literate', indeed are not "always consciously aware of what they are doing", do not "engage in reflexive evaluation of (all) situations and respond accordingly to maximize life changes" and do not "approach life as if it were a rational enterprise". (Deborah Luptons description of individuals practicing care of the self in Petersen en Bunton 1997 pp 105-106) In contrast: people are cognitive misers and usually do not carefully consider each aspect of a certain situation before taking action. More often, they act automatically, and are easily influenced by their (social) environment and emotions. (Baron 1998, Tiemeijer et al 2009, Timmermans 2013) Although 'health literacy' is mentioned as a condition for empowerment (Schultz & Nakamoto 2013) it is, thus, insufficient to guarantee 'rational decision making'. Health literate people too do not necessarily make decisions to participate in a health check, or to implement health advice in a rational and deliberate way, on the basis of information provided.
Foucaults second point was 'ascesis'; the ability to accomplish long term behavioural change. The consulted empowerment literature notes that people should be able to act on information provided. (Schultz & Nakamoto 2013) What remains undiscussed however, is how difficult this may be when 'acting' concerns behavioural change. Not everyone who is able to make informed and rational decisions concerning health ('decisional; autonomy') succeeds in putting these decisions into action (executive autonomy') (Naik et al 2009). Implementing health advice is especially difficult when this concerns life-style changes. (Naik et al 2009, Tiemeijer et al 2009) Smoking cessation and weigh loss are good examples: only 4–10 per cent of those who quit succeed in not smoking for one year or longer (Stivoro, 2013; Trimbos, 2015) and only 20 per cent of overweight individuals succeed in losing at least 10 per cent of their weight and maintain that loss for at least one year. (Wing & Phelan, 2005)
Foucault seems to be right in stating that that care of the self is something only achievable for 'the small elite'. It may in particular be difficult to empower people by

merely providing information concerning the impact of lifestyle on health. Most people would require *help* in achieving such lifestyle change.

We consider it a moral problem that health checks may only empower the 'small elite' towards a healthier lifestyle that will increase their chances for a long life without too much physical discomfort. This is because health is valued universally (OECD 2015), not just by the 'small elite'.
If 'coaching programs', or other extensions of the 'disciplinary system' may help those who do not belong to the small elite to better their lifestyles, this possibility should be considered. It may help people in realizing the health-related aims that they find hard to accomplish by themselves. These type of disciplinary measures may further individuals health and – by doing this – may help individuals to execute their decisions on what aims to pursue, and on the ways to pursue those aims. (Tengland 2008) They may, thus, empower people.

Notes

[1] Note that *solicited* health checks in which people *request* a health check on an untreatable condition, for example because of serious concerns or a family history are quite likely to have an empowering effect (see the paragraph on the effects of health check *results*).
[2] In stating this, we do not mean to say that unsolicited health check offers that untreatable (risk factors for) disease cannot empower people, they sure can: if they people to whom these checks are offered will want to know. The problem is and remains however, that there is no way to find out whether they want to because asking them whether they want to be informed already provides this unsolicited information. If the aim of a process of empowerment is to enable people to make informed and autonomous decisions regarding their health, health check providers should not take the risk of hampering the autonomy of (potential) users by offering health checks on untreatable (risk factors for) disease.
Also, there are people who wish not to be informed on the possibility to test even if this concerns life-threatening *treatable* disease such as hereditary breast- or colon cancer. (Stol et al 2010, Menko et al 2013) Unsolicited health check offers in general thus, may not necessarily be conductive to autonomy, even if people are health literate and able to act on information provided.
[3] That health checks that do not provide opportunities for health improvement do not (directly) discipline people towards better health-related behaviour, does not mean they can't discipline people at all. As we argue elsewhere, they may still contribute to a *system* in which people are disciplined towards better health related behaviour. (Stol et al. 2017)
[4] Foucault defines ethics as the relation one has to oneself. Therefore the part of the individual that the individual wants to act upon is necessarily the focus of 'moral' conduct.

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Chapter 5

Omnipresent health checks may result in over-responsibilization

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Omnipresent Health Checks May Result in Over-responsibilization

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Health checks identify (risk factors for) disease in individuals without a medical indication. More and more checks are offered by more providers on more risk factors and diseases, so we may speak of an omnipresence of health checks. Current ethical evaluation of health checks considers checks on an individual basis only. However, omnipresent checks have effects over and above the effects of individual health checks. They might give the impression that health is entirely manageable by individual actions and strengthen the norm of individual responsibility for health to the point where people hold themselves and others responsible for health outcomes they cannot reasonably be held accountable for. This process of so-called ‘over-responsibilization’ may result in increased feelings of guilt over health, decreased health solidarity and unfairly distributed health outcomes. Moreover, effects on privacy and peace of mind may be observed. Taking into account all possible harms and benefits of health checks in their ethical evaluation requires evaluation of health checks on an individual basis as well as on the level of all checks. Therefore, we urge the amendment of existing ethical evaluation to include the effects of an omnipresence of health checks. We make a first attempt at the formulation of amended criteria.

Introduction: Omnipresent Health Checks

Health checks identify (risk factors for) disease. They are offered to or requested by people without medical indication (Health Council of the Netherlands (HCN), 2015). This includes a wide range of tests: traditional population-based screening programs, checks offered by general practitioners (GPs), insurers or occupational health providers, as well as commercially offered (self)tests. Examples include the mammography and cervical smear, cardiovascular health checks, the total/full body scan, tests for prostate-specific antigen, tests for sexual transmittable diseases (STD) and genetic tests.

The exact offer and demand differs worldwide, but the international trend is that health checks are ‘on the rise’. Traditionally health checks were provided by the government and by GPs through population screening programs. Now, more checks are offered, for more risk factors and diseases, by more providers, to more potential participants (Dumit, 2002; Raffle and Gray, 2007; Cassels, 2012; McCartney, 2012). This is even the case in the Netherlands, a country that is known for its relative reluctance when it comes to screening (Weijden *et al.*, 2007; HCN, 2008; Council for Public Health and Health Care (RVZ), 2008; Hoffman and Poortvliet, 2010; HCN, 2015). So many checks are offered, that we may speak of an ‘omnipresence’ of health checks.

Health checks can provide insight into one’s health status. When risk factors or latent disease are discovered, preventive action may improve health. However, health checks have disadvantages as well.

To evaluate whether or not population screening should be offered, policy makers and public health professionals traditionally make use of relatively uncontroversial criteria for responsible screening derived from the Wilson and Jungner criteria (Wilson and Jungner, 1968; Andermann *et al.*, 2008). They state that the usefulness of detecting a given disease (or its associated risk factors) must be clearly established, that the benefits for the participants must outweigh the drawbacks, the test methods must be both valid and reliable, that participation must be voluntary and based on reliable information and that the screening must be responsible, in terms

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of the use it makes of public and collective health service resources (see e.g. HCN, 2008, 2015). In the few countries that have legislation on population screening (the Netherlands and Belgium) these criteria play a role in legal evaluation of screening as well (Nederlands Normalisatie Instituut (NEN), 2014; Ploem and Dute, 2014). For example, the Population Screening Act in the Netherlands states that population screening must benefit the participants.[1]

The fact that health checks are becoming omnipresent and offered by many more providers than the government, has given rise to debate: Should health checks—like population screening—be ethically evaluated and if so, how? Should distinctions be made between different types of checks? Opinion is divided. A balance is sought between the protection of users against harmful screening while respecting their freedom and self-determination. Health and freedom are key values and constitutional duties in many countries (NEN, 2014; Ploem and Dute, 2014).

The Human Genetics Commission (HGC) of the UK has developed a framework of principles for direct-to-consumer genetic testing services that may be applied to all direct-to-consumer health checks (HGC, 2010). A group of European experts has released quality criteria for health checks (NEN, 2013). The Health Council of the Netherlands (HCN) has argued that the Wilson and Jungner criteria apply 'not only to collective screening in a programmatic context, such as national population screening, but also to individual health checks' (HCN, 2015: 22). The HCN observes however that health gains are not necessarily a precondition for individual health checks as 'for an individual, the results obtained may be of use purely as information or they may be valuable in terms of reassurance' (HCN, 2015: 22). Likewise, health checks paid for by individuals do not have to be cost-effective (HCN, 2015).

These criteria and proposals for ethical evaluation of health checks consider checks on a case-by-case basis. However, the effects of many health checks may accumulate (e.g. Horstman *et al.*, 1999; Verweij, 1999; Rose, 2007). Therefore we will argue that the effects—benefits and harms—of health checks should not only be considered for each individual check, but also for the totality of all checks on offer. In evaluating health checks on a case-by-case basis only, existing ethical evaluation of health checks overlooks the effects of omnipresent health checks that arise additionally at the level of the totality of all checks. Therefore, current criteria for screening risk approving individual health checks while the combined effect of these individual checks does more harm than good.

In this article, we describe and discuss the effects of omnipresent health checks that arise at the level of the totality of all checks: they might give the impression that health is entirely manageable by individual actions and strengthen the norm of individual responsibility for health until people hold themselves and others responsible for health outcomes they cannot reasonably be held accountable for. This process can be called 'over-responsibilization'. This may result in unfairly distributed health outcomes, increased feelings of guilt over health, and decreased health solidarity. Moreover, effects on privacy and peace of mind may be observed.

The wide variety of tests available contributes to these effects. Therefore, we start from the very broad definition of health checks as 'tests on (risk factors) for disease without medical indication'. While discussing the effects we do differentiate between different types of tests.

To ensure health checks indeed provide more benefits than harms—both on the level of individual checks and on the level of the totality of all checks—we argue for the development of ethical evaluation of health checks that operates on an individual basis as well as on the level of all checks. Finally, we make a first suggestion for such an ethical evaluation. We tentatively propose guiding principles and conditions that will help to identify and limit effects of omnipresent health checks, and suggest some additional measures that may counter some of the effects of omnipresent health checks.

The Message of Health Checks and Effects of their Omnipresence

While considering the effects of omnipresent health checks, we may benefit from insights from the field of Science and Technology Studies (STS). Technologies provide insight into the consequences of our actions and enable us to act in new ways (Ihde, 1990; Akrich, 1992; Latour, 1992; Verbeek, 2005). Health checks provide insight into our health status. If risk factors or disease are identified, one may be able to take preventive action. Technologies may also affect morality and identity, whether or not one is an active user of these technologies (Rose, 2007). Often technologies have certain effects that were not necessarily foreseen or intended by those who developed them (Pinch and Bijker, 1984).

Typical STS questions are: What is it that health checks 'do'? What do they 'tell' us about the world? What do they enable us to do? And what is 'the right thing to do' according to these checks?

From this STS perspective it appears that health checks convey the message that health is important—why otherwise would you test? Health could be at risk even if we feel fine, due to risk factors and latent stages of disease. Health can be measured with the check. Damage to health may be prevented, *if* we take the (individual) responsibility to check health. Health checks 'tell' one about risks and urge one to actively take the individual responsibility to check. In the case of testing for amenable risk factors, health checks also appeal to individual responsibility to change these factors if the test results warrant so.

An omnipresence of health checks provides a repetition of health checks' message. The more often this message is repeated, by different providers of health checks (ones GP, the government, ones employer, insurer, commercial companies), in different settings (a health fair, ones office, at the GP, in advertisements, in a letter from the governmental screening program), concerning different health risks (cardiovascular disease, prostate cancer, STD, breast cancer), the stronger it gets.

To examine the effects of an omnipresence of health checks, we studied sociological, anthropological and ethical research on this topic, as well as reports from various government advisory boards. Most of these studies base their results on empirical findings (e.g. Howson, 1999; Horstman and Houtepen, 2005; Armstrong and Eborall, 2012; Gillespie, 2012), others give a more theoretical account on preventive medicine and its possible effects (e.g. Verweij, 1999). This literature indicates that, along the lines of STS theory discussed above, omnipresent health checks may change the perception of health as well as norms on responsibility for health in unintended ways.

In the following description of the effects of omnipresent health checks, we examine three resulting developments in conceptualizations of health and healthcare, and their consequences. First, omnipresent health checks remind people of the possibility of latent illness and risk factors. As a result, people may start to feel 'at risk', and may worry more about health. Second, health checks measure data related to health. When data are combined, the resulting information may gain in importance. To safeguard privacy, health data therefore should be securely and sensitively used and stored. These two effects are briefly discussed. We focus on a third effect in this article: the suggestion of individual control over health that omnipresent checks convey, may lead to what we call over-responsibilization, when people start to hold themselves and others responsible for health outcomes they cannot reasonably be held accountable for. This may have far-reaching consequences: not only for individual well-being, but also for society as a whole: by decreasing health solidarity, and creating a health divide between those that are capable and willing to act upon health advice and those who are not.

Everyone at Risk: Increased Worry over Health

Instead of diagnosing and treating existing health problems health problems, health checks focus on detecting and reducing risks. They are part of, and contribute to, the development of 'surveillance medicine' or 'predictive, risk oriented medicine' (Armstrong, 1995; Horstman *et al.*, 1999; Nuffield Council on Bioethics (NCB), 2010).

Through testing for latent and risk factors, health checks imply that *feeling* healthy no longer means *being* healthy (Chrysanthou, 2002; Dumit, 2002; Rose, 2007). The message is that one can no longer trust one's body to communicate health status (Armstrong, 1995; Verweij, 1999; Gillespie, 2012; Solbjør *et al.*, 2015). Thus, the mere offer of health checks may cause feelings of insecurity because it reminds people of the possibilities of latent illness and risk factors (Rose, 1996; Horstman *et al.*, 1999; Verweij, 1999; Chrysanthou, 2002; Horstman and Houtepen, 2005). People might 'think, wonder and worry about the possibility they may become ill' (Verweij, 1999 pp 96). For example, the advice to repeat breast cancer screening every 2 years gave the women in the focus groups of Solbjør and colleagues an uncertain feeling about their own judgements of their general health. They state that the breast cancer screening causes the feeling of being at risk: 'No, I didn't feel insecure before... Everybody was talking about going to the city bus to have an examination. I thought it was nonsense.... Now I think that... I understand that we are at risk' (Solbjør *et al.*, 2015: 12).

The more health checks are offered, the stronger the message may become that one might not be healthy, as does the corresponding fear (Chrysanthou, 2002). Omnipresent health checks can be seen as putting the whole population under surveillance. Everyone is confronted with the possibility to be 'at risk' (Armstrong, 1995; Rose, 1996; Chrysanthou, 2002; Pickard, 2011; Armstrong and Eborall, 2012; Ayo, 2012; Faulkner, 2012; Gillespie, 2012).

The results of health checks may also cause concern. Findings with unclear clinical implications as well as false positives and incidental findings may do so (NCB, 2010; HCN, 2015). However, a study by Gillespie shows that even 'clear' results on a seemingly innocent cholesterol test may have a big impact on identity and well-being. 'It makes me feel more vulnerable' one woman says. Another states: 'I'm kind of a ticking time bomb' (Gillespie, 2012: 200, 201). Their identity had changed to being 'at risk' (see also Armstrong, 1995; Kenen, 1996; Verweij, 1999). Some people, as a result, desire more screening (Dumit, 2002; Raffle and Gray, 2007; Cassels, 2012), resulting in more insecurity.

Increased concern about health is especially troubling if it focuses on health or health behavior that people cannot influence through individual actions, as we will discuss in the section over-responsibility.

Quantifiable Health: Privacy Risks

Health checks test variables of health that are measurable (e.g. blood values), and do not focus on aspects of health such as 'feeling good', or 'functioning as desired', or other more holistic and performance-oriented concepts of health that many people value (Nielsen *et al.*, 2004; Horstman and Houtepen, 2005; Kendall *et al.*, 2011; Huber *et al.*, 2013). The focus on measurable health in (omnipresent) health checks may increase the already present focus on measurability in healthcare (Howson, 1999; Horstman and Houtepen, 2005; Verhaeghe, 2012).

The more health checks are taken, the more (health) data are generated. When there is such an abundance of data, it becomes more important to safely store these data. When seemingly unimportant data on risk factors are combined, the resulting information may gain in importance. The accumulation and combination of these at first glance innocuous data may result in the identification of people with a wide variety of conditions and risk factors (Dixon and Gellman, 2014; Federal trade commission (FTC), 2014; Council for Public Health and Society (RVS), 2015; Rathenau, 2015). It is therefore not sufficient to be concerned about possible abuse of genetic information and data related to serious diseases (RVZ, 2008; NCB, 2010; HCN, 2015). Although the data accumulation and associated privacy risk is an important effect of omnipresent health checks, for reasons of space and focus we will not discuss this issue further.

Suggestion of Individual Control over Health: Responsibilization

Health checks suggest that health is manageable. They convey the message that by testing and taking appropriate measures, one may prevent disease or prevent it from getting worse (Lupton, 1995; Horstman *et al.*, 1999). This takes place in a context that emphasizes and strengthens the same message, through policy documents like '*choosing* a healthy life' (Ministry of Health, Welfare and Sports (VWS), 2006, see also NCB, 2010; Ayo, 2012), health information in magazines, diet adverts, health and fitness apps. Health seems to become a matter of individual choice through this suggestion of control: it is the result of checking and of following healthcare advice of experts (Armstrong, 1995; Horstman *et al.*, 1999; Rose, 2007). This generates opportunities to protect health (Novas and Rose, 2000). However, it also creates responsibilities.

In the broader societal context, increasing knowledge, the development of ever more technologies and the focus on risk and (in)security (Beck, 1992; Giddens, 1999) put questions of responsibility to the forefront. At the same time there appears to be a shift in the division of responsibility between individuals on the one hand and collective bodies and professionals on the other hand: 'subjects are rendered individually responsible for a task which previously would have been the duty of another—usually a state agency—or would not have been recognized as a responsibility at all'. This process is called 'responsibilization' (Wakefield and Fleming, 2009). The shift is facilitated by the idea that people are 'rational decision makers': provided with the right information, they are supposed to be able to make the 'right', meaning rational, decisions (Tiemeijer *et al.*, 2009; Timmermans, 2013).

Health checks may be considered a result of these societal trends, and at the same time strengthen the focus on risk, the trust in numbers and the norm of individual responsibility for health (Rose, 2007; Armstrong and Eborall, 2012).

What do we mean by the term 'responsibility' in this article? We can make a distinction between prospective responsibility and retrospective or attributive responsibility. '*Prospective responsibility* is about what a person should care about and what he should do. It is an action guide.' (Verweij, 1998: 180). Health checks make a prospective appeal to individuals. *Role responsibility* is a form of prospective responsibility. It refers to our expectations of a specific agent, or more precisely how we think responsibilities should be divided between agents/stakeholders involved in a situation (Dworkin, 1981).

Attributive responsibility or accountability means that the agent is worthy of praise and blame, or owes an explanation about their behavior (Watson, 1996; Eshleman, 2013). *Causal responsibility* means that the behavior of an agent causes (or has a significant contributing impact on) a certain outcome.

Holding somebody responsible in an attributive way is not always justified. We discern four necessary conditions. (i) There should be a causal relationship between the behavior of that person and the health outcome in question (causal responsibility). Next, the person should (ii) understand the action and choices to be made as well as the possible consequences thereof; (iii) act without internal or external controlling influences; (iv) and be able 'to plan, sequence and carry out tasks' associated with this choice (Faden and Beachamp, 1986; Draper and Sorrel, 2002; Naik *et al.*, 2009: 24; Eshleman, 2013). Making a prospective appeal is more often justified than holding someone accountable: all the above criteria still apply, but there is less need for a strong causal relationship. An individual should be able to have an impact, but need not be the only or main one to have an impact. It is often considered more ethically acceptable to make prospective appeals about health than to hold people accountable (e.g. Doughtery, 1993; RVZ, 2000, 2002; Nordström *et al.*, 2013).

By making a prospective appeal to people's individual opportunities to improve their health, health checks create individual responsibility for the choice to participate (Rose, 1996; Howson, 1999; Verweij, 1999; Beck and Bech-Gernsheim, 2002; Green *et al.*, 2002; Willis, 2004; HCN, 2008; RVZ, 2008; Solbjør *et al.*, 2015). For example: women consider breast cancer screening as an opportunity to take responsibility for their health (Willis, 2004). Health checks also generate responsibility for the choice to follow healthcare advice after the test. This may involve consenting to and cooperation with treatment, but also changing lifestyle (Rose, 1996, 2007; Howson, 1999; Verweij, 1999; Horstman and Houtepen, 2005; Gillespie, 2012).

Many people feel the responsibility to test not just for their own interests, but also for that of their relatives. This is the case with genetic tests, but also with non-genetic health checks. As a woman who participates in (non-genetic) breast cancer screening says: 'I mean, I've got two kids and a husband. I don't want to leave them. Not by something that could be detectable' (Willis, 2004, see also Howson, 1999 and Stol *et al.*, 2015 on similar motives for cervical screening and cardiovascular health checks).

Some tests, such as prenatal and newborn screening, exclusively appeal to the responsibility for the health of family members: the responsibility of parents for their (unborn) child.

Mandated health checks, such as those offered to pilots, will make little to no appeal to individual responsibility to test (as this is no longer a choice). However, they do contribute to a general sense of responsibility for health. And as they often focus on cardiovascular risk factors and stress, these tests can appeal to individual responsibility to follow (subsequent) lifestyle advice.

The more checks there are available, the stronger the appeal to individual responsibility for health becomes. It may be beneficial and just if health checks appeal to individuals to take responsibility for their health (Novas and Rose, 2000; Draper and Sorrel, 2002). One could imagine contexts in which individuals have more causal impact on a certain health outcome than other parties do, understand that impact and are capable to take action more than other parties are. A good example is genetic testing for people at risk of hereditary colon cancer, followed by colonoscopy for carriers. Hereditary colon cancer can only be prevented if carriers of the gene are identified by genetic testing and subsequently undergo preventive colonoscopy in which polyps in the colon will be removed before they develop into cancer (Stol *et al.*, 2010; Menko *et al.*, 2013).

However, as we will discuss in the next section, the total appeal omnipresent health checks make on individual responsibility can become so strong that some boundaries become blurred. This may result in a sometimes disproportionate or unjust appeal to individual responsibility.

Over-Responsibilization

All health checks appeal to individual responsibility for health, some of these appeals are justified (such as the genetic test on colon cancer discussed in the previous paragraph), some are not. Omnipresent health checks suggest control over health *in general*: the more opportunities to prevent and control different diseases and risk factors in different contexts, the stronger the belief in control over health generally becomes and the bigger the chance this is perceived to be true *for most tests* (Horstman *et al.*, 1999; Rose, 2007). This is how over-responsibilization arises: people internalize health checks' message of individual responsibility for health and apply it to all checks, irrespective of whether the necessary conditions for a prospective appeal are fulfilled. Because some checks make a justified appeal to individual responsibility, similar appeals from other checks that make unjustified appeals may be taken too seriously.

We discern at least five situations in which omnipresent health checks may result in too much emphasis on individual responsibility for health: situations in which responsibilization may turn into 'over-responsibilization'. First we will describe how the strong norm of individual responsibility for health may result in an unfair distribution of responsibility between individuals and other stakeholders with impact on the health of that individual. Second, we discuss that due to a strong norm of individual responsibility for health, it may become unclear that not all health is in fact manageable by individual actions. Third, even if individuals are able to impact their health, they may not understand *how* to influence it. Fourth, internal and external factors may make it difficult or impossible to exercise that impact. Fifth, we point out that individual actions influencing health may not be feasible for all.

Disproportionate Appeal to Individuals Compared to Other Stakeholders

Health checks make a disproportionate appeal to individual responsibility while other stakeholders with causal impact on disease are not addressed, or are addressed to a lesser extent. A good example is tests for multifactorial diseases. These diseases are caused by an interplay between genetic, individual, social and environmental causes. Other stakeholders as well the individual carry *causal responsibility* for the origin of these conditions. Health checks on multifactorial diseases may overemphasize the relative responsibility of individuals compared with that of collective bodies and professionals, by focusing only on the individual's influence on the course of these conditions (Kenen, 1996; Rose, 1999; Verweij, 1999; Horstman and Houtepen, 2005; NCB, 2010; Kendall *et al.*, 2011; Veldheer *et al.*, 2012). This results in an unfair division of *role responsibility*. Take for instance tests on cardiovascular diseases: The influence of lifestyle on cardiovascular disease does not and should not diminish the role of other parties in reducing risk factors. Lifestyle is heavily influenced by one's daily environment (Dagevos and Munnichs, 2007). As an obesogenic environment makes it hard for individuals to make healthy choices, the government and industry should also act on their responsibilities towards cardiovascular diseases and change this environment (RVZ, 2002; Dagevos and Munnichs, 2007; CEG, 2014).

Even though it is mainly tests on multifactorial diseases that result in this type of over-responsibilization, health checks in general contribute to an individualized model of prevention that may conceal social and environmental determinants of health, such as socioeconomic inequality (Kenen, 1996; Nettleton, 1997; Minkler, 1999; Verweij, 1999; Porter, 2006; RVZ, 2008; Ayo, 2012). This may lead to missed opportunities to control other determinants of health (environmental, psychological, social) and ways to address other parties than the individual, such as the government, healthcare providers, employers and companies that have an influence on the environment we live in (Doughtery, 1993; RVZ, 2002; Dagevos and Munnichs, 2007; CEG, 2014).

Unjustified Appeal When the Individual Has No Causal Impact

Health checks make an unjustified appeal to individual responsibility when people do not have influence on the onset and course of disease, which they often do not. Developing an illness is frequently bad luck; in other instances, it may be due to exposure to polluted air or to inherited genetic defects that are beyond individual control. Hereditary breast cancer, for example, is not preventable by individual actions other than agreeing to mastectomy, yet many of the women at genetic risk for breast cancer that were interviewed by Scott and colleagues felt responsible and tried to prevent the gene from being 'triggered' by modifying their lifestyle (Scott *et al.*, 2005).

Unjustified Appeal to Individuals When They Lack Necessary Understanding

Health checks make an unjustified appeal to individual responsibility when people do not understand which health checks are useful and how to follow up on healthcare advice after the test (Dumit, 2002; RVZ, 2002; Verweij, 2005; NCB, 2010; Cassels, 2012). Unfortunately, this is often the case (RVZ, 2008; HCN, 2015). Many people—estimates run up to a quarter of the population—do not understand basic health information (Meijman, 2006). Information about risks is hard to comprehend for almost everybody: among other things, people have a tendency toward binary thinking (you either get the disease or not) (e.g. Henderson *et al.*, 2006). Moreover, if people do understand information on tests and healthcare advice it is often difficult to determine whether information is reliable. Especially commercially offered tests are often promoted with exaggerated promises concerning their potential to safeguard health.

Unjustified Appeal to Individual Due to Internal or External Controlling Influences

Health checks make an unjustified appeal to individual responsibility when the health-related choices people make are influenced or even determined by internal or external controlling influences. An example of an internal controlling factor is addiction. Many unhealthy behaviors have a component of addiction. Tests that result in lifestyle advice concerning addictions can be said to make an unjustified appeal to individual responsibility for health. Over 80 per cent of the smoking population wants to quit; only 4–10 per cent of those who quit succeed in not smoking for one year or longer (Stivoro, 2013; Trimbos, 2015).

An example of an external controlling influence is work. Many employees experience severe stress, and some are subjected to hazardous substances or cannot avoid inhaling car exhaust fumes. Health checks that result in lifestyle advice concerning work-related risk factors can also be said to make an unjustified appeal to individual responsibility. After all, what realistic choices do the individual employees have? Again, this is an unfair attribution of *role responsibility*. Instead of the employee, the employer should be reminded of his responsibility.

Unjustified Appeal for Individuals Who Lack Necessary Capabilities

Health checks make an unjustified appeal to individual responsibility when people lack the capabilities to exercise health-related choices. This may concern financial means to pay for an operation or medicine, but also the capacity to plan and execute health behavior such as treatment adherence and changes in lifestyle (Tiemeijer *et al.*, 2009; Naik *et al.*, 2009). Psychological research shows that decisions are mainly based on heuristics, emotions and automatic reactions. ‘Many of us, in many situations, do not turn out to be rational decision makers who consider all relevant information in such a thorough way as to come to an optimal decision’ (Timmermans, 2013: 19 translation by Y.S., see also de Vries, 2000; Tiemeijer *et al.*, 2009 or any psychological handbook). Changing habits—and this is what adherence and in particular lifestyle comes down to—is not impossible, but much harder than it at first appears, and for people who lack ‘the capacity to plan, sequence and carry out tasks’ (Naik *et al.*, 2009: 24) associated with these changes truly impossible. After all, a change of lifestyle requires one to bypass automatic reactions to stimuli that one is surrounded by. It is one thing to decide that one wants to live a healthier life; it is something altogether different to actually exercise that choice continuously for the rest of your life.

It is even harder, sometimes impossible, for particular groups of people. Lifestyle is shaped by one’s upbringing and social economic living conditions (van Gunsteren, 2002; Tiemeijer *et al.*, 2009). And ‘origin, circumstances and environment partly determine the parameters within which a person has space for self-reflection and self-governance’ (Schermer, 2007: 17). These are important arguments for many authors, problematizing the capabilities needed to exercise health-related choices, consequently, the appeal health checks make—in these cases—may be called unjustified (Minkler, 1999; RVZ, 2002; Verweij, 2005).

Consequences of Over-responsibilization

We will now turn to the consequences of over-responsibilization, for both society and individuals.

Increased Inequality in Health

As people differ in their understanding of available information regarding health, financial means and capacity to plan and execute health behavior (Tiemeijer *et al.*, 2009; Naik *et al.*, 2009), the same check may result in over-responsibilization for some while it does not for others. This especially concerns appeals made to individual responsibility to change lifestyle.

People with lower socioeconomic status (SES) generally have lower levels of health literacy (Meijman, 2006) and less opportunity to control the circumstances and events that influence their lives (Minkler, 1999). Social determinants interact with psychological factors: people with higher education are more prone to think they are able to influence their lives and do so more often (Dryden *et al.*, 2012; CEG, 2014). As people with low SES have an unhealthier lifestyle and poorer health to begin with (Dryden *et al.*, 2012), health checks may increase the already existing gap between those who are healthy and have the capacities to succeed in taking preventive actions, and those who do not (RVZ, 2008); the so-called inverse care law (Hart, 1971).

This effect is reinforced by the rise of the individual model of prevention in general at the expense of a more collective approach to healthcare because everybody can profit from collective interventions, including people with low SES.

Feelings of Guilt

Omnipresent health checks may result in unnecessary feelings of guilt (Verweij, 1999; Gillespie, 2012; Dehue, 2014).

People may hold themselves responsible if they develop disease because they interpret the prospective appeal health checks make as attributive responsibility.

It is even more problematic when people start holding themselves responsible for disease if they are only partly responsible or not responsible at all. That is, if the necessary conditions for attributive responsibility are not fulfilled.

Indeed, some feelings of guilt are a reason to participate in health checks: According to Tijmstra, the prospect of a feeling of attributive responsibility is a key reason why people test: they do not want to feel guilty if they develop illness that could possibly have been avoided by taking a health check (Tijmstra, 1989, 2004).

Feelings of guilt can also keep people from further screening and preventive measures (Gillespie, 2012; Dehue, 2014). For example, many of Gillespie's interviewees with high cholesterol levels choose to avoid future screening 'in order to ease the stigma and guilt associated with their risk status that resulted from attributions of personal responsibility for their risk status' (Gillespie, 2012).

The more health checks are offered, the stronger the appeal to individual responsibility and corresponding feelings of guilt becomes.

Decreased Health Solidarity

Just as we hold ourselves responsible if we were to develop disease, we might start to hold others responsible for deteriorating health if we *think* they could have done something to prevent this (NCB, 2010).

Even though health checks merely make a prospective appeal, blame may be put on people that develop disease, as if it was their fault. People that do not comply with the norm of individual responsibility for health may come to be seen and treated as 'the irresponsibles' (Rose, 1996).

The dominant opinion may become that people ought to participate in health checks and may be morally blamed if they do not (Horstman *et al.*, 1999; Verweij, 1999; Dumit, 2002), and that people should change their health behavior if necessary or take preventive measures. If they do not, it may be considered their own fault if they get ill (Lupton, 1995; Schwartz *et al.*, 2004; Horstman and Houtepen, 2005; Rose, 2007; Kendall *et al.*, 2011).

The more health checks there are available, the stronger the feeling of individual control over and individual responsibility for health, therefore the less solidarity in society toward those who fall ill, especially those who failed to comply with the norm of testing (NCB, 2010). If this concerns people who, according to the criteria described above, cannot be held accountable for their health (related behavior), this is even more worrisome.

The perception of testing as socially responsible behavior that develops in this way, feeds back into the previous discussed feeling of individual responsibility for health.

Toward an Ethical Evaluation of Health Checks That Does Include the Effects of the Omnipresence of Health Checks

By evaluating health checks on a case-by-case basis only, existing ethical evaluation of health checks overlooks the effects of omnipresent health checks discussed in this article.

We argue that omnipresence effects should be incorporated in the ethical evaluation of health checks, for it would be wrong to approve of individual checks if the combined effect of these individual checks does more harm than good.

Individual health checks should be evaluated *in the context* of the other checks that are on offer. Namely, in the context of governmental screening programs, tests offered in the medical setting, checks offered by insurers, non-governmental organizations, employers and the commercial offers of checks.

To include omnipresence effects in the ethical evaluation of health checks we propose some guiding principles, and conditions. We also suggest other measures that may counter some of the effects of omnipresent health checks.

We also mention several potential problems and challenges of the implementation of these principles and conditions. Providing more than these first suggestions of how to take omnipresence effects into account is beyond the scope of this article though, amongst other reasons because it would require an in-depth discussion on screening cultures, political climates and legislation of different countries.

Proposed Guiding Principles and Conditions

The first guiding principle enables one to ethically evaluate the effects—benefits and harms—for the totality of checks on offer:

(1) The benefits of the totality of health checks on offer should outweigh the harms of the totality of these checks, for individuals and society as a whole.[2]

Two further principles are intended to limit over-responsibilization:

(2) The health problem on which the health check focuses must be better modifiable by addressing individuals than by addressing other stakeholders.
(3) The health problem on which the health check focuses must be better modifiable by offering this check than though measures other than health checks.[3]

We also formulate conditions that may be implied in evaluating individual health checks and are intended to limit over-responsibilization:

(4) Health checks that may result in lifestyle advice should be connected to programs in which individuals are offered assistance with lifestyle changes.
(5) Health checks that result in advice of which the implementation requires capabilities that the average person does not possess, or efforts that cannot reasonably be expected, should not be offered.

Measures to Redistribute Responsibility

To move toward a fair distribution of responsibility for health, we propose some additional measures:

Most diseases in Western societies are multifactorial (World health Organisation (WHO), 2013). Individuals should be informed on their (often relative) influence on the causes and development of these diseases.

Other parties than individuals, such as industry, schools and employers, should be appealed upon to act on their responsibility to prevent disease. For example, by realizing non-smoking schoolyards and healthy offerings in canteens, by not exposing employees to hazardous substances, nightshifts that are not strictly necessary or too much stress, by stimulating bicycle commuting, and by lowering the salinity in food.

Governments themselves, local and national, finally should also accept their part of the responsibility to prevent disease, either through stimulating or restricting policy.

For example, by prohibiting people from smoking in public spaces, by making sports and healthy food both easily accessible and affordable and by limiting the influence of (lobbyists of) industry on policy.

Implementation of Guiding Principles and Conditions

The implementation of the guiding principles raises questions that are difficult to answer: Is it possible to be aware of and to take into account all health checks and other measures on offer, and their relative effectiveness? When do omnipresence effects become problematic? What action is taken if omnipresent health checks result in more harms than benefits—should one prohibit the offer of more checks; provide more information; install alternative measures that do not appeal to individual responsibility as counterbalance? And who is to decide and act on these issues?

In response to these questions, we can at present make no further statements than asserting that none of the risks of an omnipresence of health checks should be considered as overriding all other considerations. As in individual evaluations of health checks, it is about carefully weighing up of the benefits and harms. When health is substantially improved due to certain checks, decreased peace of mind might be accepted. However, when health checks do not improve health, the mere value of reassurance and information may not compensate for effects of over-responsibilization.

In this context, it is interesting to note that where the health benefits of health checks are often taken for granted, the scientific evidence is mixed and often absent. Screening programs on breast, cervix and colon cancer appear to reduce mortality (Quinn *et al.*, 1999; Hewitson *et al.*, 2008; Independent UK Panel on Breast Cancer Screening, 2012), although scholars also question whether the lives saved are worth the harmful effects of overdiagnosis and overtreatment (Maanen, 1999; Olsen and Gøtzsche, 2001; Miller *et al.*, 2014). Studies that have been performed on cardiovascular risk factor screenings conclude that no health gains are to be expected at population level (Krogsbøll *et al.*, 2012; Jørgensen *et al.*, 2014; Si *et al.*, 2014). No evidence at subgroup level is available (HCN, 2015). Evidence on the health benefits of other health checks such as the total body scan and many genetic tests is completely absent (NCB, 2010; HCN, 2015).

Another important question is who should be responsible for the implementation of principles and conditions.

Health checks are offered by the government, by medical professionals, and commercial companies (that may also have medical professionals in service). All three types of providers can choose to apply the conditions to their own health check offers.

Constitutional duties state governments have a duty to protect the health, privacy and freedom of their citizens (NEN, 2013; Ploem and Dute, 2014). Respecting free choice also implies taking into account that not all choices are made freely and to draw conclusions from this.

Medical professionals are bound by medical ethical principles and guidelines stating they should promote well-being, avoid harm, respect the privacy and autonomy of their patients and promote justice (Beauchamp and Childress, 2012). They know from experience that most people do not act as rational decision makers and often do not succeed in changing their lifestyle.[4] Respecting autonomy implies not asking people to plan and execute changes in lifestyle on their own, when they lack the capacity to do so (Draper and Sorrel, 2002; Naik *et al.*, 2009). We therefore believe that these types of providers have a responsibility to consider the implementation of these principles and conditions.

Commercial companies have less moral responsibility in relation to their offers of health checks. They function in a free market and are not bound by professional codes of ethics. However, they can choose to self-regulate and devise their own guidelines, codes and quality certificates, in which they can implement these conditions. The chances of them complying will likely increase if they also have a financial or promotional ‘stake’ to do so.

Governments are not only providers of health checks, but also function as regulators. They may impose a legal requirement to implement certain guiding conditions for all health check providers. This may be justified by the already mentioned constitutional duty to protect the health of citizens and the constitutional duty to protect the privacy and freedom of citizens (NEN, 2013; Ploem and Dute, 2014). These duties may also justify stimulating or restricting policy to redistribute responsibility for health.

Conclusion

In evaluating health checks on a case-by-case basis only, existing ethical evaluation of health checks overlooks the effects of an omnipresence of health checks discussed in this article. Thereby they risk approving individual checks when the combined effects of these individual checks do more harm than good.

In this article, we described and discussed the effects of omnipresent health checks:
they might give the impression that health is entirely manageable by individual actions and strengthen the norm of individual responsibility for health to the point where people hold themselves and others responsible for health outcomes they cannot reasonably be held accountable for. This process can be called ‘over-responsibilization’. This may, among other things, result in increased feelings of guilt over health, decreased health solidarity and unfairly distributed health outcomes. Moreover, the omnipresence of health checks may have effects on privacy and peace of mind.

We have not aimed to provide an exhaustive list of omnipresence effects, nor a final categorization. Our primary aim is to highlight the existence of such effects and to argue for their inclusion in the ethical evaluation of health checks.

To include omnipresence effects in the ethical evaluation, we tentatively propose some guiding principles and conditions and discussed who would be responsible for implementing them. This should be understood as a first step toward the inclusion of omnipresence effects in the ethical evaluation of health checks. We hope this article will evoke further discussion on this important topic.

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Conflict of Interest

None declared.

Notes

1. It operationalizes this through a mandatory permit for (expected) harmful screening: that uses ionizing radiation, aims to detect cancer or diseases for which no treatment or prevention. Grounds to refuse the permit are (i) the screening test is scientifically unsound; (ii) the screening does not conform the legal rules for medical treatment; (iii) the expected benefit of the screening does not outweigh the risks for

the participants. To determine the risk–benefit ratio for participants, the Wilson and Jungner criteria are used (HCN, 2008, 2015).

2. A comparable criterion can be found in Dutch criteria for responsible vaccination (HCN, 2013). However, an important difference with health checks is that the government is the only provider of vaccinations in The Netherlands, such that the burden and benefits of the program in its totality is easier to define.
3. Similar criteria are mentioned by the UK National Screening Committee and in public health ethical frameworks (Kass, 2001; Childress *et al.*, 2002; UK National Screening Committee, 2010).
4. In fact, Dutch GPs are working on a guideline to integrate cardiovascular screening with help to change lifestyle (Badenbroek *et al.*, 2014).

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Chapter 6

Ethical evaluation of unsolicited personal health check offers

Ethical evaluation of unsolicited personal health check offers

Taking the capacities of potential users and the societal context into account

Yrrah H Stol, Maartje HN Schermer

(under review)

Introduction

With health checks we mean tests to find disease or risk factors for disease in people without specific symptoms or another medical indication. Governmental screening programs are health checks offered to populations. The national screening program in the Netherlands, includes screening for breast- bowel- and cervix-cancer. In the United Kingdom, there is also a screening program for risk factors for cardiovascular disease (CVD). Typically, people in the target group for a screening program receive a personal invitation to participate. Most population screening programs are provided free of charge.

Health checks are also offered to individuals, for example by employers, health insurers, physiotherapists, pharmacists, general practitioners, independent treatment centres and online. Examples of these ‘personal’ health check offers include cholesterol tests that are offered in shopping malls or other public places, all sorts of blood and urine tests that may be ordered online, electrocardiograms, lung function and prostate cancer tests offered to employees by their employer, a variety of self-test that may be bought at pharmacists or drugstores, and total body (MRI)scans.

To distinguish health checks offered to individuals from governmental or population screening programs, we refer to them as ‘personal health checks’ throughout this paper. Most personal health checks are offered unsolicited through (online) advertisements, announcements or invitations. Their offer may also be a response to the expressed concerns of an individual in the context of a physician-patient relationship (e.g. a man worrying about prostate cancer asking his general practitioner for a test on Prostate Specific Antigene (PSA)), or can be related to a family history of disease, e.g a clinical geneticist offering a test for Huntington disease to the daughter of an affected woman. Note that the very same tests, for example checks for cardiovascular risk factors, may be offered in population screening programs as well as personal health checks.

In this paper we mainly focus on unsolicited personal health checks.

Health checks may provide benefits and harms. Preventive action after the detection of risk factors or latent disease may improve health, whilst invasive tests or tests using radiation carry health risks. Unnecessary follow up tests or –treatment as well as unwarranted reassurance may also have negative consequences for health. (Juth & Munthe 2012, Raffle & Grey 2007)

The benefits and harms of health checks, however, do not only relate to health. Health check offers also affect other important values such as autonomy, equality in health, psychological wellbeing and privacy. (Gezondheidsraad 2008, 2015, Juth & Munthe 2012, Raad voor de Volksgezondheid en Zorg 2008, Raffle & Grey 2007, Verweij 1999) For example: health check results may reassure people but may also create unnecessary worry.

What is a ‘good’ health check? Which type of health check offer provides as much benefits as possible and minimizes harm? What sort of health check offer realizes the most and most important values at stake while causing no or minimum damage to others? What measures should be taken to realize such health check offers?

When it comes to population screening programs, typically checks that comply to the normative framework based on the Wilson and Jungner criteria are considered ‘good’ tests. (Andermann et al 2008, Gezondheidsraad 2008, Wilson & Jungner 1968)

For personal health checks, however, these questions have not been answered conclusively. Although several proposals have been made, opinion varies about the ethical criteria for personal health checks. (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010)

The growing offer and use of personal health checks in the absence of consensus about quality criteria inspired us to investigate the ethics of (unsolicited) personal health checks. In previous empirical and theoretical studies, we have identified values at stake, investigated the effects health checks have on these values and suggested measures to promote an ethical offer of (unsolicited) personal health checks. (Stol et al 2016, 2017a, 2017b, 2018, Stol & Schermer 2018 under review)

This research has shown that to realize values, not only test- and disease characteristics such as predictive value and treatability of disease are important. Features of health check providers, the way checks are offered, and the societal context in which they are offered are relevant as well.
One and the same test for disease can do more harm or good to particular values depending on who is offering that test, and in which way this is done. It matters, for example, whether providers are qualified, obtain a proper informed consent and handle data confidentially.
Similarly, the very same check, offered in the very same way, may be considered more or less 'good' depending on the societal context or country in which it is offered. Checks' potential to benefit health, for example, depends for a large part on the presence of accessible health insurance, or another system through which treatment-costs may be reimbursed. If checks are offered in a societal context with 'omnipresent' health checks, it should be taken into account that privacy risks are increased and 'over-responsibilization' of individuals may negatively affect psychological wellbeing, equity in health and solidarity. (Stol et al 2017a)
This is why we often speak of 'health check *offers'* throughout this paper. Hereby we refer to a particular check offered in a particular way in a particular societal context.
Finally, it is important to take the capacities of potential users into account. People mostly do not act as rational decision makers when it comes to deciding about health checks, or implementing health advice. (Tiemeijer et al 2009, Tmmermans 2013)
Therefore, information provision alone, such as in traditional informed consent procedures, will not suffice to further autonomous choice and improve health related behaviour.

In this paper, we give an overview of the values at stake in health check offers, and the effects health check offers have on these values. Next, we present an ethical framework of conditions that unsolicited personal health checks - including their provider, offer, and the societal context in which they are offered - should meet such that the balance of positive over negative effects on values is as favourable as possible. This ethical framework may be used to evaluate and improve unsolicited personal health check offers.

Health check offers' effects on values

Health check offers do not only affect health, but also equality in health, autonomy, trust in physicians and governments, the division of responsibility for health, solidarity for health, privacy and psychological wellbeing.

For each of these values, we will review health check offers' effects, indicate which features of test, disease, provider, offer and societal context may influence these effects, and formulate criteria or conditions for 'good' unsolicited personal health check offers accordingly.

Together the conditions described form an ethical framework for unsolicited personal health checks that will be discussed in the next section.

Health

Health checks may have large health-benefits through prevention or early treatment.

A necessary condition for health benefits to occur is that the test focuses on preventable or treatable (risk factors for) disease. (criterion 1)

Population screening programs on breast-, cervix- and coloncancer appear to reduce mortality on population level. (Hewitson et al 2008, Independent UK panel on Breast Cancer Screening 2012, Quinn et al 1999)

Testing a treatable condition however does not necessarily result in health improvement, not even if offered to populations at high risk for disease, as is the case with population screening programs. Checks on cardiovascular risk factors do not improve health in high risk populations (Jorgensen et al 2014, Krogsbøll et al 2012, Si et al 2014) and the potential health benefits of screening programs for Prostate Specific Antigene (PSA) are highly contested (Andriole et al 2009, Martin et al 2018, Schroder et al 2009) For many other, personal, health checks, such as genetic tests and total body scans, evidence on any health benefits is completely absent. (Gezondheidsraad 2015, Nuffield Council on Bioethics 2010)

One reasons why checks on treatable conditions do not necessarily lead to improved health is that people may not have taken the health check with the intention to improve their health, but for other reasons (Stol et al 2016). Other reasons include that they may not (sufficiently) understand the health advice given (Henderson et al 2006, Meijman 2006), or not have the financial means to pay for follow up tests, treatment or medication. (Stol et al 2016) Implementation of health advice often requires a change in habitual behaviour (lifestyle, daily medication) but it is well-known that this is very hard for most people. (Naik et al 2009, Tiemeijer et al 2009)

To improve the uptake of treatment and health advice following a health check we state that follow up care should be provided: explanation of health check results and health advice, and the offer of (reference to) assistance with the implementation of health advice (criterion 7)

To enable providers to take the time necessary for this follow up care, a re-organisation of (the financing) of health care may be required (criterion 14). The promotion of health literacy (criterion 8), and the reimbursement treatments and assistance with lifestyle changes (criterion 9) may also improve health check offers' positive effects on health.

Health check offers may also cause damage to health; as a direct consequence of the test (e.g. a bowel perforation during a colonoscopy, carcinogenic effects of ionizing radiation) or because test results are not a reliable indicator of disease. False negatives may result in unwarranted reassurance that may cause people to belittle symptoms that develop later which in the worst-case scenario may result in preventable death. False positive results may be followed up with invasive diagnostic tests that may cause iatrogenic harm (overdiagnosis). In addition there is the risk of treatment of conditions that would not have caused health problems during life (overtreatment). (Gezondheidsraad 2015, Juth & Munthe 2012, Raffle & Grey 2007) It is for example well known that health checks on breast- and prostate cancer can cause health damage through overtreatment, and scholars question whether the lives saved are worth these harmful effects. (Andriole et al 2009, Martin et al 2018, Miller et al 2004, Olson & Gøtsche 2001, Schroder et al 2009)

To limit health check offers' potential to harm health, health checks should provide relative certainty about the presence or absence of disease and the need for treatment. For this reason, they should have a good positive and negative predictive value, preferably be performed in high-risk populations only, if possible, risk factors should be tested and considered in combination, and the course of disease should be known. (criterion 3) Moreover, any risks of the check or follow up tests or treatment should be proportional to the (risk factors for) disease tested on. (criterion 2)

Knowledgeable and experienced providers and a test-setting that meets relevant quality standards (criterion 4) may also help to prevent health check offers' damage to health. A societal context in which there is some form of regulation of health check offers that may cause direct harm or may harm health in the follow up trajectory (criterion 11) and a quality mark (criterion 12) finally may protect people from participation in health checks that may cause harm to health.

Equality in health

Inequality in health may be increased by health check offers: people with poorer health and a low Social Economic Status (SES) participate in health checks less often and find it harder to comply with treatment- or health advices. (Dryden et al 2012, Raad voor de Volksgezondheid en Zorg 2008)

Reasons for this include a lack of information, different priorities, and less (financial) capabilities. (Centrum voor Ethiek en Gezondheid 2014, Stol et al 2016)

In the previous section on health we formulated conditions to improve the uptake of treatment- and health advice. (criteria 7,8,9,14)

A feature of the societal context that may prevent an increase in inequality in health due to health check offers is subsidization of checks that may lead to substantial health improvement, including further research and (help with) the implementation of health advice, or the offer of these checks as governmental screening programs. Probably, it would be most effective to implement other health policy measures instead or next to health checks. (criterion 10) Collective interventions aimed at improving living conditions and targeting unhealthy living environments improve the health of everyone, including the people with low SES. (Capewel & Capewel 2017, Capewel & Graham 2010, Masters et al 2017)

Psychological wellbeing

Health check offers may negatively affect psychological wellbeing because they confront and/or remind people of the possibilities of latent illness and risk factors: feeling healthy is not the same as being healthy. (Armstrong 1995, Verweij 1999) This is more likely if this would concern untreatable conditions. (Chadwick et al 1997, Juth & Munthe 2012)

Therefore, health checks on (risk factors for) disease that cannot be prevented or treated should not be offered unsolicited. (criterion 1)

Note that this recommendation is not applicable to health check offers that take place within a physician patient treatment relationship. In such a context, the offer of a health check on untreatable (risk factors for) disease to patients with serious concerns and/or a family history may actually increase psychological wellbeing because testing may be the only way to ease concerns about the potential presence of this condition.

Another way in which health check offers may negatively affect psychological wellbeing is because they create a certain responsibility to act upon the opportunity to improve health. (Stol et al 2017a) As we will further discuss in the section on the division of responsibility for health, this may result in a situation in which people expect themselves and others to participate in health checks, to change their health behaviour, or take preventive measures, and blame themselves or others if they do not. As a result, non-test-users may be seen and treated as 'the irresponsibles' (Rose 1996) and develop feelings of guilt.

To prevent these possible negative effects on psychological well-being, it would help to promote health literacy so that people can better understand their own as well as other parties' influence on health (criterion 8). Also, visible appeals to other actors than individuals should be made to take their responsibility for health (criterion 13).

Health check results finally, may also affect psychological wellbeing: they may reassure people, or give them a feeling of control: the possibility to either improve health through implementing health advice or to adjust life plans in case of an untreatable condition. (Juth & Munthe 2012, Novas and Rose 2000, Stol et al 2016) Health check results may also cause concern. This is quite likely in case of findings with unclear clinical implications, false positive results and incidental findings (Gezondheidsraad 2015, Stol et al 2018). However, reliable results too may result in worries and decreased wellbeing: people report feeling vulnerable and at risk. (Gillespie 2012)

In order to prevent unnecessary worries, it is important that health checks provide relative certainty about the presence or absence of disease and the need for treatment. (criterion 3)

If people are not (financially) capable of implementing health advice concerning treatment or lifestyle changes after a test, this will likely result in worries over health, as well as feelings of guilt. (Gillespie, 2012)

For conditions that will facilitate the uptake of treatment and health advice, please see the section 'health'. (criteria 7,8,9,14)

Autonomy

Autonomy is generally understood as 'the capacity to be one's own person, to live one's life according to reasons and motives that are taken as one's own and not the product of manipulative or distorting external forces (…) an individual's ability to govern himself'. (Christman 2018 pp1)

Health check offers may affect autonomy in different ways.

First, the offer of a health check may be in accordance with 'reasons and motives that are taken as one's own' (Christman 2018 pp1), like the desire to improve one's health. If this is the case, the unsolicited provision of information about the possibility of having (risk factors for) disease will empower individuals. However, unsolicited health check offers may also be conceived as 'distorting' (Christman 2018 pp1). If people who don't want to be informed are confronted with a choice whether to take a test or not, this information

on the possibility for testing may negatively affect their feeling of self-determination. (Menko et al 2013, Stol et al 2010, Stol et al 2016) As almost everybody values health (OECD 2015), it is often argued that most people will want to be informed about possibilities to prevent serious illness, but not about (risk factors for) disease that cannot be prevented or treated. (Chadwick et al 1997, Juth & Munthe 2012)
To protect and further autonomy, tests on serious (risk factors for) disease that result in proven health benefits should thus be brought under the attention of the public while there should be no unsolicited offers through (online) advertisements or invitations for health checks that focus on untreatable or unpreventable conditions. (criterion 1)
Note that within a physician-patient treatment relationship, the offer of a health check on (risk factors for) untreatable disease to patients with serious concerns and/or a relevant family history may actually be conductive to autonomy. This is, however, a completely different situation from that in which ignorant people are – through advertisements, announcements or invitations – confronted or reminded of the possibility of them having a serious untreatable condition.

Second, the extent to which potential users make an autonomous decision about whether to participate in a health check, may be influenced by the type of checks offered and the way potential users are informed about the characteristics of a test. An autonomous choice for a test may be considered a choice made in freedom, a choice based on reliable information, and one that is in line with somebody's values. (Beachamp & Childress 2012, Juth & Munthe 2012)
(Perceived) freedom to test is compromised if testing or not testing would have consequences, e.g. for insurance, or may result in stigma (see section on 'solidarity') or if other people might find out whether an individual was tested or not, for example if checks are offered at work and this is discussed during a coffee break.

We agree with the Health Council of the Netherlands that to further an informed choice, potential health check users should be informed about: the prevalence of the disease or disorder in the target group, the natural course and the variation in the severity of the disorder, the specificity, sensitivity and predictive value of the test method to be used and the impact of the test, the available options to users if a health problem would be demonstrated, any favourable and unfavourable psychological, social and other consequences of the offer, participation or non-participation in the health check for the user, family members or groups in society, the chance of false-positive or –negative results, overdiagnosis and incidental findings, and the possible consequences thereof , and finally the costs associated with the health checks. (Gezondheidsraad 2015 pp 106) (criterion 5)
General information provision alone however, is not likely to suffice in ensuring that people make choices that are in line with their values. Communicating risk for disease is notoriously difficult (e.g. Henderson et al 2006, Tijmstra 1989). Moreover, emotions and heuristics usually play a more important role in decision-making than information. (Tiemeijer et al 2009, Timmermans 2013). For these reasons, many authors have questioned whether people who partake in health checks fully understand the consequences of their participation. (Nijsingh 2007, O'Neill 2002)
Previous research showed that when it comes to health checks and their follow up trajectory, people seem to value health, certainty about the presence or absence of disease and privacy. They also expect health check offers to be in line with these values. (Stol et al 2018)

To increase the likelihood that health check offers are in line with people's values and expectations, health check offers therefore should ideally provide more benefits than harms for health (criterion 2) through treatment- or health advice that most people are able to comply with, provide certainty about the presence or absence of disease and need for treatment (criterion 3) and personal and medical data should be treated confidentially (criterion 7).

If health checks do not conform to these criteria, informed consent procedures should aim to correct the - in these cases: false - expectations of potential users. To begin with, advertisements should not unnecessarily appeal to emotions and should inform potential users about health check characteristics that deviate from what they might expect. For example, it should be mentioned when a check has a low predictive value. Likewise, informed consent procedures should focus on adjusting expectations if necessary. In addition, individual assessments may be offered using for example the deliberative model of Emanuel and Emanuel to determine whether health checks fit the vales of the potential user. (Emanuel & Emanuel 1992) These recommendations apply all the more when testing is very easy, because in these situations, people oftentimes do not seem to consider benefits and harms at all but simply check 'because the test was offered'. (Stol et al 2016) (criterion 5) Note that informing people such that they will only use checks that fit their values does not seem possible for comprehensive health checks such as total body scans, genome sequencing or other packages of tests that contain checks with a different predictive value, or effects on health. Moreover, it will take more time and may run contrary to commercial motives.

The organization and financing of health care should enable and incline at least providers in regular care to take the time for informed consent procedures. (criterion 14) Other measures that may contribute to a societal context in which autonomous choices for health checks are furthered, include the promotion of health literacy (criterion 8), legislation on misleading advertisements and informed consent that applies to all health check providers (not merely physicians) (criterion 11) and the installation of a quality mark (that focuses on health benefits, predictive value and privacy) enabling potential users to determine easily whether health checks meet their expectation and fit their values. (criterion 12)

The results of a health check, finally, may also affect autonomy. Results may empower people, by providing the opportunity to improve health through implementation of health advice, or by enabling them to adjust their life plans to future disease in case the condition is not treatable. However, this is only the case if people are actually capable of implementing health advice or adjusting life plans, that is, if health check results indeed enable them to 'govern themself' the way they want to. (Stol & Schermer 2018)

For that reason, measures to improve the uptake of treatment and health advice (criteria 7,8,9,14), will also further autonomy.

Trust in physicians and governments

Trust is a necessary condition to provide (public) health care. If health check offers do not live up to people's expectations, this may negatively affect citizens' trust in physicians and the government, especially if they don't communicate clearly enough that health check offers do not meet the expectations of the general public.

People trust physicians to offer checks that are in line with their expectations, and the government to intervene if providers would offer checks that do not provide certainty, may harm health or if their privacy would be at risk. (Stol et al 2018) However, as we have seen, not all health provide certainty, they do not necessarily improve health, and personal and medical data may not always be treated confidentially. (Nuffield Council on Bioethics 2010, Rathenau 2015)

The criteria discussed in the previous section on 'autonomy', how to deal with (false) expectations, are also instrumental in protecting and stimulating trust. (criteria 2,3,5,7, 11,12,14)

The division of responsibility for health

The offer of health checks increases individual responsibility for health, since it provides people with the opportunity to learn about risk factors and possibilities to improve their health. Hence, it creates a certain responsibility to act upon this opportunity in order to improve (population) health and help contain healthcare costs.

This 'responsibilization' may be justified if the individual indeed has a substantial causal impact on a certain health outcome and is capable to take action to improve this. However, since this is not always the case, health checks may also result in 'overresponsibilization' of individuals. (Stol et al 2017a) Health checks then contribute to an individualized model of prevention in which social and environmental determinants of health, such as socioeconomic inequality and the obesogenic environment are concealed. This may lead to missed opportunities to address other parties than the individual, such as the government, employers and companies that have an influence on the environment we live in. The risk of over-responsibilization is especially large when a great amount of health checks is offered, and a general message of individual responsibility for health is communicated through policy measures and in popular culture.

For example: many users of health checks on cardiovascular risk factors receive the advice to change their lifestyle. However, the fact that there is an influence of lifestyle on cardiovascular disease does not and should not diminish the responsibility and role of other parties in reducing risk factors. Lifestyle is heavily influenced by one's daily environment (Dagevos and Munnichs 2007). As an obesogenic environment makes it hard for individuals to make healthy choices, the government and industry should also act on their responsibilities towards cardiovascular diseases and change this environment to prevent an unfair distribution of responsibility for health. (Stol et al 2017a)

To prevent an unfair distribution of responsibility for health, other actors than individuals should be addressed and be called upon to take their responsibility for health (criterion 13). Moreover health literacy should be promoted so that people can better understand their own as well as other parties' influence on health (criterion 8).

Solidarity

Health check offers may negatively influence mutual solidarity between individuals in matters of health and illness and any arrangements based upon this, such as health insurance. Due to the just described increase in individual responsibility for health, the opinion may become that people *ought* to participate in health checks (Horstman et al 1999, Verweij 1999), and that people should change their health behaviour if necessary or take preventive measures. If they do not, it may be considered their own fault if they get ill. (Horstman and Houtepen 2005, Lupton 1995) This may negatively affect autonomous choice and possibly (equality in) health if such an attitude would lead to policy proposals to raise health insurance premiums or to stop reimbursing treatments for people who do not take regular health checks.

To prevent that health check offers negatively affect solidarity this way, we refer to the conditions in the section 'division of responsibility for health' (criteria 8, 13)
If health check offers would result in unnecessary further research or treatment, for example after false positive results, this may drain collective resources and therefore negatively affect care for those in need. (Gezondheidsraad 2008, 2015, Raad voor de Volksgezondheid en Zorg 2008) At present, this does not seem to be the case (de Hoon et al 2017), however this may change if the uptake of more comprehensive health checks such as the total body scan would increase.
These negative effects on solidarity can be prevented through the offer of health checks that provide relative certainty about the presence or absence of disease and the need for treatment (criterion 3)

Privacy

Health check offers form a privacy risk: the more checks there are performed, the more personal and health data is generated that should be stored safely to prevent abuse. This does not only concern the results of, for example, tests on sexually transmitted diseases or information about untreatable disease. When seemingly unimportant data on risk factors or other health issues are combined, the resulting information may gain in importance. (Rathenau 2015)
Privacy risks may increase because (potential) participants seem relatively naive about privacy risks. (Stol et al 2018)
To prevent mis- and abuse of data, health check providers should handle data confidentially, and the societal context should contain privacy legislation including supervision and enforcement. (criterion 7,11)

An ethical framework for unsolicited personal health check offers

We have discussed the effects of health checks offers on the values at stake, indicated which features of the test, the disease, the provider, the offer, the potential user and the societal context may influence these effects. We have also formulated conditions that unsolicited personal health checks, their provider, offer, and the societal context in which they are offered should meet such that the balance of positive over negative effects on values is as favourable as possible.

In this section, we present these conditions as an ethical framework for unsolicited personal health checks. With the help of this framework, it can be analysed whether and why certain health check offers are ethically justifiable or not, and what measures can be taken by whom to improve these offers.

Next to criteria that concern the test, disease, provider and the way in which a test is offered, we also include conditions that concern the societal context in which health check are offered. This is because the very same check, offered in the very same way, may have a different effect on values dependent on the societal context or country in which it is offered. In the introduction, we mentioned the mediating factor of reimbursement of treatments on health checks potential to improve health. Something similar may be argued for the health literacy of potential users, or the presence of legislation on privacy.

Because the conditions we set to the societal context are crucial for health check offers to be justifiable, we choose to incorporate these in our framework, instead of mentioning them as accompanying policy measures or the like.

Although all values that may be affected by health check offers are important, we, like other medical and public health ethicists – consider health, equality in health, privacy and autonomy key values. (Beauchamp & Childress 2012, Childress et al 2002, Grill & Dawson 2017, Kass 2001) Moreover, we prioritize prevention of harm to values that most people hold, over the furthering of values of a minority. There certainly are people that value 'information as such' even if this would concern information about untreatable risk factors for disease (Bunnik et al 2015), and there are people who want to use health check offers that are likely to result in more harm than benefits for health. An unsolicited offer of checks on unpreventable (risk factors for) disease and checks that provide more harm than benefits to health may thus further their autonomy. However, these tests are not in accordance with the values of most people (Chadwick et al 1997, Juth & Munthe 2012, OECD 2015, Stol et al 2018); their unsolicited offer may cause harm to those people's health, autonomy and psychological wellbeing. Therefore, we recommend against this. (criteria 1 and 2)
To be clear: this only applies to unsolicited offers through advertisements, announcements and invitations for personal health checks for which the criteria from this framework have been drawn up. Within a treatment relationship a check on untreatable (risk factors for) disease may be offered on indication. The same applies to health checks (including follow up) that may harm health and are not likely to offer opportunities for health improvement. In these cases, providers should offer an individual assessment in which it is discussed whether the test is conducive to the potential participant's values.
Note that criteria are not one on one applicable to governmental screening programs either, and incomplete for their ethical evaluation. At least, proven health benefits and a responsible use of collective resources are missing.

The conditions in **bold** are minimum criteria that aim to prevent serious harm to the key values health, equality in health, privacy and autonomy. We consider health check offers that do not meet these conditions 'bad' and advise governments to protect people against the effects of these health check offers, if necessary by means of a ban. All other conditions may be understood as aspirational criteria. Health check offers that meet minimum and aspirational criteria can be considered 'good' and their offer is ethically justifiable.
If criteria would conflict minimum criteria overrule aspirational criteria. This is notably the case with criterion 2 and 3. Aspirational criterion 3 'health check provides relative certainty about the presence or absence of disease and the need for treatment' may be overruled by the minimum criterion 'health check and follow up trajectory provide more benefits than harm to health'. So, if two tests are available of which one has a better predictive value but results in disproportional health risks, preference should be given to the test with a less favorable predictive value. The same applies to situations in which no test with a good predictive value is available, but there is no other way to prevent serious disease than through testing with the health check with a less than desirable predictive value.

Criteria concerning the test characteristics of the unsolicited personal health check and the (risk factors for) disease tested on:

1. **Health check provides opportunities for health improvement; the condition tested for should be treatable**
2. **Health check and follow up trajectory provide more benefits than harm to health**
3. Health check provides relative certainty about the presence or absence of disease or risk factor, and the need for treatment. For this reason, they should have a good positive and negative predictive value, preferably be performed in high-risk populations only, when possible, risk factors should be tested and considered in combination and the course of disease should be known.

Criteria concerning the provider and offer of unsolicited personal health checks

4. **Providers are qualified and the and setting in which health check is in accordance with professional standards**
5. **Informed and voluntary consent: all information provided about the health check should be basic, factual and tailored to (adjusting any false) expectations of (potential) users. If health check offers and their follow up trajectory may harm health, this includes the offer of an individual assessment in which it may be verified whether participation in the check is in line with the values of the potential user.**
6. **Follow up care: explanation of health check results and health advice, and the offer of (reference to) assistance with the implementation of health advice**
7. **Privacy: Personal and medical data are confidentially handled**

Criteria concerning the societal context in which unsolicited personal health checks are offered

8. **Promotion of health literacy**
9. **Reimbursement of health checks with proven benefits for health, including follow up research, treatment or help with lifestyle adjustments**
10. **Offer of (public) health measures that benefit everyone's health**
11. **Legislation including oversight and enforcement that applies to all health check providers (not merely physicians) on confidential handling of personal and medical data, misleading advertisements and informed consent. Some form of regulation of health check offers that may cause direct harm or may harm health in the follow up trajectory (e.g. a permit).**
12. Quality mark focused on expectations of (potential) users, including supervision
13. Visible appeals to other actors than individuals to take responsibility for health
14. Organization and financing of health care enables and inclines providers to keep to criteria 1-7

The criteria in the first two categories are implementable by providers of unsolicited health checks. Those concerning the societal context in which unsolicited personal health checks are offered, however, are not - with a possible exception of condition 8 and 12.

It is a fair question whether governments (who are in a position to realize these criteria) will actually take that responsibility, and whether is it justifiable to make this appeal towards them, given that they – by definition – do not offer personal health checks. We will discuss this issue of implementation and responsibility in the last section of this paper. In this section we limit ourselves by stating that this is an *ethical* framework for unsolicited personal health checks that aims to indicate under which conditions their offer is ethically justifiable. For that matter, an ethical framework is different from a policy framework, in which considerations concerning implementation are already incorporated.

We choose to present an ethical framework rather than a policy framework because we think the discussion on the ethical evaluation of personal health checks and their regulation will benefit from an 'ideal' picture to go from. This to enable all actors involved (notably providers and government) to see where they choose or are necessitated to diverge from this – ethically speaking – 'perfect'[1] picture and to provide argumentation for such divergence.

Comparison to other proposals for the ethical evaluation of health checks

In this section, we will compare the conditions from our ethical framework to criteria mentioned in three (policy)proposals for the ethical evaluation of personal health checks thus far: those by the Health Council of the Netherlands, The European Committee for Standardization and the Human Genetic Commission. (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010) In discussing similarities and differences, we will highlight how we aim contribute to the discussion on the ethical evaluation of personal health checks so far. We will focus on how conditions we set aim to improve the realization of well-known criteria, and on conditions that are (relatively) new.

First, we endorse the commonly used criteria that health checks should provide more benefits than harms for users, should only be performed with an informed consent (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010) and should have a good predictive value (Gezondheidsraad 2015). However, we want to emphasize that the realization of these criteria depends on the expectations and capacities of (potential) users, the setting in which health checks are offered, as well as on the totality of health checks on offer.

Contrary to what existing proposals for the ethical evaluation of health checks (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010) seem to suggest, we do not think that mere information provision will ensure that people only participate in health checks that will provide them more benefits than harm. Communication about risk for disease is difficult, potential users have rather unrealistic expectations about health check offers and information plays a limited role in health related decision-making. (Tiemeijer et al 2009, Timmermans 2013), something which is also observed by health check providers (Stol et al 2017b).

The idea behind informed consent as a condition to ensure that benefits of health checks outweigh harms for users is that information would enable potential users to determine whether health checks are in accordance with their values. When it comes to health check offers, most people value health, certainty and privacy. (OECD 2015, Stol et al

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[1] By stating 'perfect' we by no means want to suggest these are the definite best criteria for unsolicited health checks. Separation of the 'ideal' picture and considerations about implementation will facilitate discussion about both.

2018) The safest option to respect and further these values would therefore be that checks provide certainty about the presence or absence of disease, benefit health and cause no infringements to privacy. In any case we think that health checks that are likely to cause more harm than benefits to health as a direct result of the test or in any follow up trajectory should not be offered unsolicited and that the privacy of users should be respected. A confidential handling of data is mentioned in all proposals thus far. (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010) (11) We also state that conditions tested for should be treatable (2) and – like the Health Council of the Netherlands (Gezondheidsraad 2015) that some form of regulation, such as a permit, is necessary for health check offers that may cause direct harm or may harm health in the follow up trajectory (11).

Another way to help people to participate only in checks that are in accordance to their values, and that takes into account the limitations of informed consent, is to adjust information provision – beginning with advertisements, announcements and invitations – to the expectations of people. (5) A quality mark focused on the expectations of potential users may help in this respect, because this may function as a heuristic. (12) Legislation applicable to all health check providers should prevent misleading advertisements and ensure good informed consent processes. (11) These recommendations apply all the more to relatively easily assessable health checks, because participation seems less considered in these settings. (Stol et al 2016) These conditions are mentioned in none of the existing proposals for the ethical evaluation of personal health checks. (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010)

To realize health benefits and a favourable benefit harm ratio, it is also important that treatment- and health advice is being implemented. Different from previous frameworks (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010), we therefore stress the importance of follow up care including the assistance of *help* with implementing treatment- or health advice (6) and the reimbursement of proven effective treatments or help with lifestyle adjustments. (9) Information provision during follow up care may in some instances also result in patients who waive further diagnosis or treatment that is likely to result in more harm than benefits for health.

To realize informed consent and the implementation of health advice we, different than proposals so far (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010), also advise to critically evaluate the way health (related) care is financed and organised (14); where possible, providers should be enabled and inclined to meet criteria 1-7.

Finally, existing proposals evaluate health checks on a case-by-case basis only (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010) but the combined effect of approved checks may do more harm than good. (Stol et al 2017a) We therefore include criteria to limit 'omnipresence' effects. (8,9,10,13)

In contrast to the frameworks of the European Committee for Standardization and the Human Genetic Commision, we propose substantial quality norms, and not merely procedural criteria.

The European Committee for Standardization states that providers should 'specify' the clinical purpose, the burden and harms of the test procedure (criterion 3.4) and the positive and negative predictive value (criterion 3.5). (Bijlsma et al 2014) Likewise, the Human Genetic Commission states that providers should inform potential users about

the relation between a genetic variant and a disease, condition or trait (4.2). (Human Genetic Commission 2010)
Thus, as long as providers 'specify' so, and 'inform' potential users, health check offers don't need to have any clinical purpose, may result in severe burden or harm, and may not have any predictive value at all. And still meet the criteria in these frameworks. (Bijlsma et al 2014, Human Genetic Commission 2010)
In contrast, we – like the Health Council of the Netherlands (Gezondheidsraad 2015) – state that tests should have a good positive and negative predictive value (3), and that health checks, including any follow up trajectory, should provide more benefits than harm to health. (2)

Finally, other than proposals thus far (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010), we think health check offers' effects on non-users should be included in their ethical evaluation because these people are also affected by this unsolicited information about (risk factors for) disease. To prevent harm to the autonomy and psychological wellbeing of non-users, we state that unsolicited personal health check offers should provide opportunities for health improvement. (1)
Moreover, we also include the effects of the *totality of checks on offer.* This is because 'omnipresent' health checks may cause damage to the division of responsibility for health, equality in health, solidarity, psychological wellbeing and privacy. (Stol et al 2017a) Most apparent conditions in our framework that aim to limit these effects are those concerning (public) health measures that benefit everyone's health (10) and appeals to other actors than individuals to take responsibility for health (13).

Implementation of framework

The proposed framework with which the offer of health checks may be ethically evaluated includes a variety of criteria. How these criteria and conditions to promote an ethically justifiable provision of health checks should be implemented, is a different question. Its answer will differ across jurisdictions and requires expertise in health law, health policy making and governance – not ethical expertise. We therefore limit ourselves to the following:
In the Netherlands, implementation of the proposed criteria relating to the test, disease, provider and offer seems possible, at least in theory. The Healthcare Quality, Complaints and Disputes Act obliges all health check providers (including the non-medical professional) to comply with professional standards. If the proposed measures relating to the test, disease, offer and provider would be acknowledged and authorized as such a standard, this would be a major step towards implementation of this part of the framework.
With regard to the suggested policy measures: there is always room for improvement, but in the Netherlands, minimum criteria are more or less fulfilled. Health literacy is promoted, proven effective treatments are reimbursed as is some help with lifestyle adjustment (like quit smoking programs), and public health measures that benefits everybody's health, such as a ban on smoking at work, are taken. Room for improvement primarily lies in updating existing legislation on privacy, informed consent, advertisements and health checks that may cause harm to health. Legislation should apply to all health check providers should (not merely physicians), compliance should be actively monitored (currently, (potential) users need to file complaint before action is undertaken) and not only checks that cause *direct* harm, for example through ionizing

radiation should be subject to authorization, but also those checks that are likely to cause harm in any follow up trajectory. To offer these checks, a permit or something similar should be required.

In the Netherlands, the question of regulation of personal health check offers has been subject of debate for over ten years. (Gezondheidsraad 2008, 2015 Raad voor de Volksgezondheid en Zorg 2008, Schippers 2015, 2016) Personal health check offers are – by definition – no governmental initiatives. To what extent should they be subject to governmental policy? How to balance the constitutional duty of many countries to further and protect public health and thus to protect citizens against harm from health checks to – if bans would be necessary – limiting potential users' freedom of choice?

We think and hope that the differentiation we make between unsolicited personal health check offers on the one hand, and solicited checks in physician-patient relations on the other, may be a way out the ethical dilemma between prevention of harm and respect for autonomy. Limiting the offer of unsolicited personal checks to those concerning treatable risk factors for disease that provide more benefits than harms will be in accordance of the values of most (potential) users and non-users. Those who feel limited in their freedom of choice may still request a test at their physician. If this check is in accordance with their values (which will be discussed during the individual assessment), if they thus really want it, and if this – all potential consequences considered – is likely to cause them more benefits than harm, they are free to use it.

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General discussion

A good health check isn't good enough

In this discussion, I will answer my research questions, make recommendations for the regulation of personal health checks in the Netherlands, discuss the strength and weaknesses of this thesis and make suggestions for further research.
I will also suggest how the ethics of and policy on health checks and other technologies may benefit from a broader ethical approach.

Answers to research questions

The overall aim of this research project was to answer the question: What is a good health check and when is the offer of health checks ethically justifiable?

The goal was to formulate an ethical framework for health checks that may be used to evaluate and improve health check offers.

As explained in the introduction, health check offers affect more values than just 'health'. It was thus important to gain insight in which values may be influenced by the offer of health checks and to examine the mediating effects of different aspects of health check offers and other relevant variables on the values at stake.
For this purpose I have tried to answer the following research questions:
1. Which values are influenced by health check offers?
2. Which aspects of health check offers mediate their effects on values, and in which way?
3. Are there any other relevant variables that may influence health check offers' effects on values? And how do they mediate health check offers effects on values?

The focus was on *personal* health checks, as opposed to population screening programs, and especially on *unsolicited* checks and tests.

Furthermore, in the research conducted for the development of the ethical framework for health checks I paid special attention to three issues that seemed underexposed in the discussion around the ethical evaluation and regulation of personal health checks so far. These issues may be translated in three additional research questions:
4. What are health check offers effects on non-users?
5. What may be said about (potential) health check users capabilities to make rational decisions about participation in checks and to follow up treatment- and health advice?
6. What is health check offers' efficacy and desirability in relation to other health related measures?

To answer these research questions, I used a variety of methods.
A substantial part of this thesis is based on qualitative research among (potential) users of health checks and health check providers, because knowledge about their needs and perspective seemed limited. I interviewed a broad range of providers, including major players in the field, on their practice, their views on 'good' personal health checks and on regulation of these checks. In focusgroups with (potential) health check users I questioned them, too, about what a 'good' personal health check is, whether these checks should be regulated and if so, how.
Next to studying reports from advisory boards, as well as ethical, sociological and anthropological research on health checks, preventive medicine in general and their

effects, I also conducted a focussed literature review on studies reporting about motives to participate or not to participate in cardiovascular health checks. Finally, I used Foucauldian theory to gain more insight in what aspects of health check offers and other relevant variables mediate their effect on values, in particular health and autonomy.

In the following paragraphs, I will answer each research question subsequently. I will illustrate them with the most relevant results of my research.

1. Which values are influenced by health check offers?

Health check offers may affect health, equality in health, psychological wellbeing, autonomy, trust in physicians and governments, the division of responsibility for health, solidarity for health, and privacy.

In chapter six, health check offers' effects on these values are described in detail, based on all the research described in this thesis.

2. Which aspects of health check offers mediate their effects on values, and in which way?

Concerning the check itself, important mediating aspects are: the treatability of the condition tested for; the potential benefits and harms of the check itself, and of potential follow up trajectories; and the extent to which tests provide certainty about the presence or absence of disease and the need for treatment, i.e. their sensitivity, specificity and predictive value.

Both providers (chapter 2) and (potential) users (chapter 3) unanimously mention these test- and disease characteristics as features of 'good' health checks.

As regards to the offer of health checks, I found that the following aspects are important: the expertise and reliability of the provider; the safety of the setting in which checks are performed; the accessibility of the test; what sort of information about the check is provided in advertisements, and other public offers; what sort of information is provided within informed consent procedures, and how this is done; whether or not follow up care is provided in which health check results and health advice are explained; whether or not users are offered assistance with the implementation of health advice; and whether or not personal and medical data are confidentially handled.

Accessibility increases the chance that people will participate in a health check (chapter 4). However, if health checks are very accessible, people may test just because 'the test was offered' (chapter 1). It may be questioned whether these are informed and autonomous decisions.

Chapter two and three on health check providers and potential practice and perception of a good test show that to enable informed decisions to test, and to prevent harm to health and privacy, information before and during informed consent procedures, including any advertisements, announcements or invitations, should be tailored to (adjusting any false) expectations of (potential) users and not unnecessary appeal to emotions. Providers may also offer individual assessments in which it may be verified whether participation in the check is in line with the values of the potential user.

The health check providers interviewed in chapter two also stress the importance of follow up care. They state that many health check users need help with the implementation of health advice, in particular if this concerns lifestyle advice, for health checks to actually benefit health.

In chapter six, the mediating effect of all these aspects is explained in more detail.

3. Are there any other relevant variables that may influence health check offers' effects on values? And how do they mediate health check offers effects on values?

The characteristics of (potential) users play an important role in health check offers' effects on values. This includes their expectations and capacities in general (which I will discuss as answer to research question 5) as well as differences in health literacy, Social Economic Status (SES), lifestyle, and capacity to act on decisions made ('executive autonomy', Naik et al 2009).

Chapter one shows that people with (very) low SES often have different priorities than cardiovascular health checks, such as heating or shelter. Also, they may lack insurance such that they may not be able to afford a check or any follow up care. The offer of these checks will not benefit their health if living conditions are not improved. Instead, they may increase inequalities in health as people with low SES usually have poorer health to begin with.

Health check offers and health advice that require capacities that people do not possess, are examples of what I call 'over responsibilization' in chapter five: instances in which people's individual responsibility is called upon while the necessary conditions to justifiably make such appeals are not fulfilled.

Features of the societal context in which health checks are offered also play a mediating role. These include: education; the availability and accessibility of health insurance and what that covers; other preventive measures available; the content of relevant legislation on privacy, advertisements, informed consent and potentially harmful checks; the safeguards and oversight mechanisms that are in place; the organisation and financing of health care; and existing social-cultural norms concerning individual responsibility for health and participation in health checks.

Due to these mediating factors, it is fair to state that a good health check (offer) in itself isn't good enough. Health checks cannot be evaluated in isolation from their societal context. Even if the test and offer would meet all the criteria of the framework (chapter 6 and below) concerning test, disease, provider and offer, its effects on values will differ depending on the societal context (often: country) in which it is offered: It matters whether treatments are reimbursed, whether (potential) users are health literate, and what sort of legislation on e.g. privacy is present.

The health check providers interviewed in chapter two don't meet their own criteria for good health checks in practice. Amongst other reasons they mention a lack of time for informed consent and follow up care, and commercial interests. These reasons point to components in the (Dutch) financing and organisation of health (related) care that hinder an ethical provision of health checks, like a lack of (paid) time to provide good counselling. Moreover, it may be questioned whether non-binding criteria will suffice to improve the offer of personal health checks if such important conditions are not met.

Legislation on privacy, advertisements, informed consent and potentially harmful checks seems necessary to protect the values health, certainty and privacy of potential users and to prevent harm to their relationship with physicians and the government whom they trust to respectively provide and see to the provision of checks that are in line with these values. (chapter three)

In chapter six, the mediating effect of both the characteristics of users and the societal context is summarized.

4. What are health check offers' effects on non-users?

Proposals for the ethical evaluation of personal health checks thus far state that the benefits of health checks should outweigh the harms for *users*. (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010) As it appeared that health checks could also affect non-users, for example because follow up care may drain on collective resources, I also researched health check offers effects on non-users. Research on the motives people have to test or not to test (chapter 1), a study into the characteristics of health check offers that may influence any empowering or disciplining effects (chapter 4) and literature research on the effects on health checks' 'omnipresence' (chapter 5) shows that not only a check itself and any follow up trajectory may cause benefits and harms, but also its *offer*. Many personal health checks are offered unsolicited through advertisements, announcements or invitations. They confront or remind users and non-users of the possibility that they may feel healthy, but suffer from these latent conditions. Especially when this concerns checks on unpreventable, untreatable (risk factors) for disease, this may negatively affect autonomy and psychological wellbeing in non-users

Non-users may also be affected by health check offers through effects of over-responsibilization of individuals, as is discussed in chapter five. The offer of health checks provides people with the opportunity to learn about risk factors and possibilities to improve their health. Hence, it creates a certain responsibility. If health checks are omnipresent, this effect may become so strong that people start holding themselves and others responsible for health outcomes they cannot reasonably be held accountable for, which may negatively affect values like autonomy, psychological wellbeing, equality in health, and solidarity.

5. What may be said about (potential) health check users capabilities to make rational decisions about participation in checks and to follow up treatment- and health advice?

At the start of this research, I questioned whether people truly act as rational decision makers when it comes to the choice for a test or to implement any health advice, as proposals for the ethical evaluation of health checks thus far seem to suggest (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010)
As I argue in chapter four, only a 'small elite' of people actually behaves like rational decision makers. The users from the introduction – Marjan who tested because her friends did, Frederique who thinks she has a cancer that does not need treatment and Jan who was so relieved about his heart being ok that he forgot a spot on his lung – they are no exceptions but the rule.

The literature review on motives to participate in or refrain from health checks, described in chapter one indeed shows that potential users do not always make considerate decisions. People may test just because 'the test was offered'. Social norms too – is testing considered 'normal'? – may play an important role in decisions to test, as I show in chapter four.

The health check providers I interviewed in chapter two also state that people do not consider information rationally but are heavily influenced by the setting in which health checks are provided and emotions such as fear for disease or death. For this reason, they consider informed consent a criterion that is difficult to establish in practice. This idea was further confirmed in the focus group research described in chapter three: Potential users not only value a good predictive value, more benefits than harms for health and privacy, but simply *assume* most health check offers meet these criteria. They have serious difficulties in believing this is not always the case.

Rational decision makers would decide not to test if information provided indicates that testing is likely to result in harm. 'Real' people may not carefully consider that information, because they assume their health will be improved by taking a test or because they have their mind somewhere else and automatically go with the flow. And even if they would, this information does not necessarily lead to 'rational' choices because they are scared to get ill or die, and therefore are rather 'safe than sorry', even if this means their health may be damaged through overdiagnosis and overtreatment. Hence, exclusive reliance on informed consent procedures to protect (potential) users from bad or harmful tests, is unwise.

Instead, I argue that all information provided about health check offers should be focussed to adjusting any false expectations of users. (chapter three, see answer to research question 2) A quality mark focussing on the values of potential users may also provide help in this respect.

Not only do people make not-so-rational choices to participate in health checks, reasons (not) to implement health advice are not necessarily 'rational' either. From literature research, I learned that people may not (sufficiently) understand the health advice given and as with decisions (not) to test, emotions and heuristics usually play a more important role in decision-making than information. (e.g. Tiemeijer et al 2009)

Hence, overreliance on health checks as a means to improve health seems doomed to lead to disappointment.

6. What is health check offers' efficacy and desirability in relation to other health related measures?

In chapter five, the effects of 'omnipresent' health checks are explored. They may result in 'over-responsibilization of individuals, as discussed in answering research question four. Which in turn may lead to increased feelings of guilt over health, decreased health solidarity and unfairly distributed health outcomes. Moreover, effects on privacy and psychological wellbeing may be observed.

Existing proposals for the ethical evaluation of personal health checks consider health checks on a case-by-case basis only (Bijlsma et al 2014, Gezondheidsraad 2015, Human Genetic Commission 2010) and hereby run the risk of approving individual checks while the combined effect of these checks may do more harm than good.

As mentioned in the introduction, the offer of personal health checks is seen as a (potential) public health problem: citizens should be protected against their risk. In public health ethics and policy, the effectiveness and desirability of a certain measure is usually discussed in relation to the effectiveness and desirability of other measures focussing on the same health problem. (Childress et al 2002, Grill & Dawson 2017, Kass 2001) Proposals for the ethical evaluation of health checks thus far, however, do not mention any weighing of health checks effectiveness and desirability in relation to other health related measures.

I consider this an omission. Because 'good' health checks in the sense that they provide the most favourable balance of positive over negative effects on values, do not necessarily realize much 'good' or values in an absolute sense. Other measures might be much more successful in realizing relevant values than health checks are.

The efficacy of many health check offers is doubtful at best, while their potential to harm health, equality in health and other values such as peace of mind, privacy and a basic trust in physicians is real. At the same time, measures that are aimed at targeting the obesogenic environment, ban smoking or the improvement of living conditions seem to be very effective and are less likely to harm values. (e.g. Capewell & Capewell 2017, Capewel & Graham 2010, Masters 2017)

Public health policy makers and ethicists, to my opinion, should be concerned with realizing health related policy that brings about as much (health related) good as possible. I therefore have become convinced that the ethics of health checks may benefit from a broader ethical perspective. To realize values as best as possible, the effects of health check offers on values should be compared to the effects of other health related measures. If these measures would result in a more favourable net effect on all values involved, they should – ethically speaking – be preferred over health checks. Therefore, I think it would be good if public health policy makers would base policy, either restricting or stimulating measures, on the basis of a comparison of the effects of these measures on values.

As an ideal to strive for, I think health directed policy would best compare the effects of all health related measures on values – governmental ánd private initiatives – and would work towards the implementation of those measures with the most favourable net effect on all values involved.

Although in some of the chapters of this thesis, the option of 'other measures' does come across (see for example chapter 1), this research was first and foremost directed at the development of an ethical framework that would provide providers of health checks and policy makers with concrete leads to improve current practice. As this focus didn't allow me to discuss the option of comparing health check offers' effects on values to that of other health related measures before, I want to take the opportunity to do this – briefly – here. After discussing how health related policy directed at the realization of values may take shape, I will discuss some of the problems this type of research and policy may encounter. To conclude I will argue why I think this approach is nevertheless worth following.

Examples of health related policy directed at the realization of values

Health related policy directed at the realization of values may take various forms. I will give two examples and start with one that is most easy to implement: In the Netherlands, the national program prevention of the Ministry of Health Welfare and Sports 'it is all about health' (www.allesisgezondheid.nl) provides a platform for all private organisations that undertake activities relating to prevention, including those that offer personal health checks. An organisation that implements and executes a new initiative receives a 'pledge', an event that is often accompanied with a lot of attention from the media. There are no quality criteria to join this platform, nor is there any oversight or control to the (beneficial or harmful) effects of initiatives. Yet, organisations that receive these 'pledges', as well as their professional colleagues may refer to it as an 'award' (personal communication with health check providers) and the average media-consumer may easily get the impression that the Ministry of Health approves the initiative in question. Why *not* set quality criteria to initiatives? Why not invite the private organisations to provide an overview of (expected) effects on a number of values, have public health policy makers assess their probability (e.g. by means of Ten Have et al 2013), and only give a platform to initiatives that indeed (are likely to) contribute to the prevention of disease without disproportional risks to health and other values involved?

Second, public health policy makers may actively search for alternative privately initiated measures with a more positive benefit harm ration with regard to all values involved if a certain personal health check does not meet the criteria of the framework (chapter 6 and below), and stimulate the implementation of these measures instead of the check.
They may also compare the effects of these checks with some well known private ánd governmentally initiated health related measure, such as subsidized bikes, canteens in which food is rearranged, visible and attractive stairs next to elevators (Thaler & Sunstein 2008), the improvement of living conditions and the policy based measures aimed at targeting the obesogenic environment mentioned above.

Of course, personal health checks are – by definition – no government initiatives. However, why would that withhold public health policy makers and ethicist from comparing the effects of health checks on values with that of other health related measures (that may or may not be governmental initiatives)? Why would this be a reason not to state that preference should be given to those measures that result in the most favourable net effect on all values involved? Why should any regulation of health checks be limited to health check offers that may cause harm to health (Gezondheidsraad 2015, Schippers 2015, 2016) and not include the stimulation of other, more effective and desirable measures?
In the next paragraph, I discuss some of the reasons why.

Difficulties with this type of research and policy
Comparing the effects of different technologies, measures, or interventions on values is not an easy task. The effect of a specific technique on one value may already be hard to establish, as the fierce discussion on the health-benefits of PSA screenings shows. (Andriole et al 2009, Martin et al 2018, Schroder et al 2009) Also, scholars don't necessarily agree on the meaning of values, nor ways to 'measure' effects on these values. And even if this would be the case, how to weigh the different values involved? Practical barriers may include the necessary interdisciplinary work and comprehensive overview of alternatives available. Hesitations about the implementation of the conclusions of this type of research may also be an inhibitory factor: proposals for and the outcomes of ethical research projects are often reviewed on their implementability; their direct potential to improve a current practice.

Although I hope that the examples described above show that implementation of health related policy directed at the realization of values doesn't have to be too complicated, the optimalization of this kind of policy to the 'ideal' sketched above may be difficult to realize indeed.
This is because it requires a comprehensive overview of all health related measures available, and their effects, as well as coordination between different policymakers and policy-departments. Those working on the regulation of (personal) health checks now often have no connection to those working on, e.g. healthy food or other public health measures. These things are difficult to realize, if only because this would involve various ministries which their own organization and financing. (personal communication with policy makers)
In the following paragraph I will discuss why a broader ethical approach is worth following anyway.

Why a good health check isn't good enough
The fact that the 'ideal' type of health related policy directed at the realization of values seems an as of yet unattainable ideal, does not have to affect the use of this ideal. Different than only offering 'implementable' ethical recommendations, suggesting an ideal to strive for may serve several goals. First, it endows actors involved with the possibility ánd responsibility to examine whether they would want to divert from an – ethically speaking – ideal situation, and to argue why. Second, it makes it possible to discuss both the ideal and considerations about implementation. In giving only 'implementable' recommendations it may remain unclear what the ideal situation is and that the recommendations may include compromises. Explicitly distinguishing the ideal situation and then arguing for (the need for) any compromises is more transparent. Third, this explicit discussion may result in better-informed ethical analysis ánd policy regarding health- and personal health checks.

As regards to the described problems concerning research that compares the effects of different measures: If the envisaged outcome of this research 'merely' concerns an indication for desirable policy (and this is how I envision this type of research), they shouldn't be too big obstacles. First, effects don't need to be 'quantified'. Knowing that the health benefits of PSA screening are questionable is enough. Second, comparison of effects on values should be possible as long as scholars clarify what they understand different values to mean. And third, as to the weighing of values: I think it would be best to make any ethical dilemmas explicit such that policy makers are enabled to make – and justify! - their own choices.
In previous work on the societal relevance of biotechnological trends for example, me and my co-author Annemiek Nelis compared and discussed the societal impact of eight biotechnological trends, including the $1000 genome – a health check – to enable politicians to formulate policy priorities. By means of a Delphi method a broad panel of 'societal experts' (ranging from theatre directors to future explorers to economists) identified the fifteen probably most pressing societal issues in 2020 (ten years later, a time in which the biotechnological trends of which we were asked to investigate the impact would have a good chance to be applicable technologies). In a series of meetings, citizens, experts and stakeholders were then asked whether and how each of the biotechnological trends would contribute to the societal issues. We then described the impact – positive and negative - that the biotechnological trends were likely to have on

these issues and advised to take (stimulating or restrictive) measures accordingly. (Stol & Nelis 2010)

I think such an approach is worth following also for other health related measures and technologies such as health checks. In thinking – no matter how elaborate etc. – about how health check offers may be improved such that the balance of positive over negative effects on values is as favourable as possible, without considering the option of implementing or stimulating the implementation of other health-related measures (instead) we ethicists run the risk of 'approving' situations in which 'good' health checks are offered, whereas the world would be a better place if policy makers would be enabled to work towards the implementation of those measures with the most favourable net effect on all values involved.

Recommendations for the regulation of personal health checks in the Netherlands

In the introduction I've described the Dutch discussion on the ethical evaluation and regulation of personal health checks of the last decade.

The framework with criteria introduced in chapter 6 (see textbox) is intended to help policymakers and health checks providers to evaluate and improve health check offers.

Focussing on the proposal of the minister (Schippers 2015, 2106) for the regulation of personal health checks, I want to make three more general recommendations: First, the interests of users *and non-users* should be protected.

Second, it is not enough to protect people against *direct* harm that may be caused by personal health checks. Instead, advantages of a health check offer *and any follow up trajectory* should outweigh disadvantages. This is because much of the harm health checks may cause to health and other values is due to overdiagnosis and overtreatment.

Third, an ethically responsible offer of most health checks cannot mainly be left to providers. This is unrealistic because providers have commercial reasons not to agree with or not to keep to quality criteria and moreover may be so focussed on the prevention of (serious) disease that they settle for checks with a low predictive value, as discussed in chapter two and above. Moreover: it will not suffice. This is because providers are not in a position to realize framework criteria 8-14.

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The conditions in **bold** are minimum criteria. I consider health check offers that do not meet these conditions 'bad' and advise governments to protect people against the effects of these health check offers, if necessary by means of a ban.

1. **Health check provides opportunities for health improvement; the condition tested for should be treatable**
2. **Health check and follow up trajectory provide more benefits than harm to health**
3. Health check provides relative certainty about the presence or absence of disease or risk factor, and the need for treatment. For this reason, they should have a good positive and negative predictive value, preferably be performed in high-risk populations only, when possible, risk factors should be tested and considered in combination and the course of disease should be known.
4. **Providers are qualified and the and setting in which health check is in accordance with professional standards**
5. **Informed and voluntary consent: all information provided about the health check should be basic, factual and tailored to (adjusting any false) expectations of (potential) users. If health check offers and their follow up trajectory may harm health, this includes the offer of an individual assessment in which it may be verified whether participation in the check is in line with the values of the potential user.**
6. **Follow up care: explanation of health check results and health advice, and the offer of (reference to) assistance with the implementation of health advice**
7. **Privacy: Personal and medical data are confidentially handled**
8. **Promotion of health literacy**
9. **Reimbursement of health checks with proven benefits for health, including follow up research, treatment or help with lifestyle adjustments**
10. **Offer of (public) health measures that benefit everyone's health.**
11. **Legislation including oversight and enforcement that applies to all health check providers (not merely physicians) on confidential handling of personal and medical data, misleading advertisements and informed consent. Some form of regulation of health check offers that may cause direct harm or may harm health in the follow up trajectory (e.g. a permit).**
12. Quality mark focused on expectations of (potential) users, including supervision
13. Visible appeals to other actors than individuals to take responsibility for health.
14. Organization and financing of health care enables and inclines providers to keep to criteria 1-7.

Strenghts and limitations

One of the strengths of the research described in this thesis is its strong empirical component. For an important part, the criteria in the ethical framework are based on the needs of potential users, the vision of providers about what 'good' checks are, and the preconditions that hinder them to provide these checks.
Another is the – at times – perhaps what unorthodox approach. I'm not a 'classical' medical ethicists but have an interdisciplinary background in psychology, health sciences and philosophy of science. This is reflected in the issues I considered to be underexposed in the discussion around the ethical evaluation and regulation of personal health so far: their effects on non-users, the capabilities of (potential) users and a comparison with other health related measures. Taking those issue into account has, to my mind, added to the existing ethical debate.

These strengths, however, also have a flipside.
That the criteria for 'good' personal health checks have a strong empirical basis in the needs of (potential) users, the vision of providers on good health checks, and any

barriers that may withhold them from offering these checks only, does not mean that these criteria will necessarily be 'supported' by these and other stakeholders. This is because keeping to criteria may run counter commercial motives of providers (chapter two), may hinder 'innovation' (Schippers 2015, 2016) and – at first sight at least – may limit the individual freedom of choice of potential users for checks that do not meet criteria. However, as discussed in chapter six, criteria in fact *protect* freedom of choice because most people don't *want* to use checks that don't meet criteria, but may be inclined to do so due to false expectations, misunderstandings and emotions, when these checks are offered unsolicited. (Chapter 3) Notwithstanding my critical remarks uttered above about criteria that should be 'implementable', the possibility that my criteria may not all be warmly welcomed or widely supported by stakeholders, is a limitation of my research. It is one, however, that I accept.

The second flipside I find more important. Because I wanted to do 'something else' and focus on less-explored areas and approaches, I paid less attention to theoretical insights from medical ethics, public health ethics and business ethics than envisioned in the original research plan. It may very well be that this has gone at the expense of important insights I could have found in these literatures.

Finally, this thesis is called 'a good health check isn't good enough'. But what, exactly, is a health check and where was my research focussed on, precisely?

With health checks I mean tests on (risk factors for) disease in people without medical indication, as may be read in almost every chapter. However, chapter one focuses only on reasons to participate or not to participate in cardiovascular health checks. These checks could be offered as part of populations screening programs, as unsolicited personal health checks, or be requested by potential users. In my empirical research, I questioned providers (chapter 2) and (potential) users (chapter 3) on criteria for 'good' health checks in general. They themselves differentiated between population screening programs and personal health checks and focussed on screening (tests performed by a professional, see the Introduction) rather than self-tests. Chapter four in which I discuss Foucaults theory of care of the self focuses on unsolicited health checks provided (and performed) through population screening programs or other providers, thus excluding self-tests. The fifth chapter on omnipresent health checks is about all sorts of health checks and the criteria in the framework presented in chapter six finally are directed at unsolicited personal health checks.

These subtle differences in focus had good reasons. For example: a literature review on motives to test including all sorts of health checks would have been an up to impossible task and omnipresence effects such as over-responsibilization of individuals originate in and are strengthened by a diverse offer of health checks. Moreover, unsolicited versus solicited, personal health checks versus population screening programs, and screening versus self-tests partly require different criteria. However, in some of the chapters I could have been more explicit about my subject matter.

Further research

Some of my recommendations require further research: In any case, the expectations of potential health check users that health checks provide certainty about the presence or absence of disease, benefit harm and form no privacy risk should be confirmed in further (international) qualitative studies and be quantified by means of survey research. And - if possible: real life, experiments should be conducted on the influence of different advertisements, announcements or invitations, informed consent procedures and individual assessments on the autonomy of decisions to test or not to test.

There are also aspects of the ethics and regulation of health checks I barely touched upon or did not did not research at all: I have discussed health check offers effects on *adult* users and non-users, mainly focussed on screening rather than self-tests and make only small suggestions on how this framework may or should be implemented.
This is primarily a matter of focus: Health checks for children evoke extra ethical questions such as proxy informed consent, late onset disorders, conflicts between the interest of the individual child and the whole family etc. (e.g. Borry et al 2006). Next, self-tests are regulated in different ways and the responsibility for their offer is divided between manufacturer and seller. (Ploem & Dute 2014) Finally, law is not my area of expertise. I simply miss the legal knowledge necessary to make sensible remarks concerning the implementation of criteria.
That being said, these aspects do need attention.

Finally, I hope that my suggestion to take a broader ethical approach in researching health checks may inspire ethicists, ELSI (Ethical Legal and Social Issues) researchers and policy makers. This is because not only research and proposals on the ethical evaluation of health checks consider health checks in isolation from other health related measures. Unfortunately, this seems to be the case in much research on the ethical impact of technologies, measures, or interventions. Despite the fact that this focus may have good reasons - after all, insight in the effects of a certain technology, measure, or intervention, and ways to improve its net effect on values, requires specific expertise, fieldwork and so on – it yields the same risk as that described above: 'approving' situations (those in which the technique, measure or intervention in question is offered in an ethically justifiable way) while the world would be a better place if other measures would be offered alongside, or instead.
If ethicists and policy makers are concerned with realizing policy that brings about as much good as possible, a good technique isn't good enough if other measures result in a more favourable net effect on values.

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Summary

Health checks are medical tests that test for (risk factors for) disease in people without medical indication. They may be offered through population screening programs, or to individuals. An example of a population screening program is the screening on breast cancer for which women between 50 and 75 receive an invitation to participate. Examples of 'personal' health checks offered to individuals include stands in public places such as supermarkets in which people are invited to have their cholesterol tested, preventive medical screenings offered to employees, and 'total body' (MRI) scans that are advertised for in newspapers and on television. Health checks may also be requested for or offered in response to expressed worries about latent disease or a family history of a specific condition. This thesis about the ethics of health checks focuses mostly on *unsolicited personal health checks*.

Health checks may provide benefits in terms of health improvement or reassurance but can also result in damage to health, unnecessary worries or unwarranted reassurance. They may, in other words, do both harm and good.
This thesis opens with an introduction to the Dutch debate on the ethical evaluation and regulation of personal health checks that prompted this research into the ethics of health checks.
The leading research question was: What is a good health check and when is the offer of health checks ethically justifiable?
The goal of the research was to formulate an ethical framework for health checks that may be used to evaluate and improve health check offers.
Because health checks affect more values than just 'health', it was important to gain insight in which values may be influenced by the offer of health checks and to examine the mediating effects of different aspects of health check offers and other relevant variables on the values at stake.

The five studies described in this thesis (chapter 1-5) all contribute to answering the research questions and provide building blocks for the framework (chapter 6).
The first chapter is a literature review on the reasons people have to participate in or refrain from cardiovascular health checks.
Potential users do not always make considerate decisions. People may test just because 'the test was offered'. Next to the setting in which health checks are offered, the societal context also plays a role in decisions to test. We argue that in certain social circumstances, health and justice are better served with other measures than the offer of cardiovascular health checks.

Subsequently the results of interviews with providers of a wide range of health checks and focus groups with (potential) health check users are discussed.
Chapter two reports on how providers define 'good' health checks, i.e. checks that are likely to benefit users, and on their practices and experiences. Chapter three reports on how potential users define 'good' health checks, i.e. checks they would want to participate in or that they would recommend to others.
Almost unanimously, health check providers and (potential) users state that health checks should have a good positive and negative predictive value; that health checks including follow up tests and treatment should provide more benefits than harms for health, and that informed consent should be obtained before the test. Also, providers

should be knowledgeable and reliable, putting the interest of potential users first and taking time and attention. Next to these criteria, providers stress the importance of follow up care such as help with lifestyle changes to achieve health benefits. Potential users consider privacy key.

Interestingly, many of the interviewed providers offer checks they themselves consider ‘bad’.

Their reasons reveal conflicts between criteria, conflicts between criteria and other ethical values. They also point to components in the (Dutch) financing and organisation of health (related) care that hinder an ethical provision of health checks, like a lack of (paid) time to provide good counselling, and commercial interests.

Providers state that people do not consider information (about health checks and any follow up) rationally but are heavily influenced by the setting in which health checks are provided and emotions such as fear for disease or death. Providers therefore consider informed consent a criterion that is difficult to establish in practice. This idea is confirmed in the focus groups: (Potential) users not only value a good predictive value, more benefits than harms for health and privacy, but *assume* most health check offers meet these criteria because they trust physicians and the government to respectively provide and see to the provision of checks that are in line with these values. They have serious difficulties in believing this is not always the case.

To further autonomous choice we recommend: advertisements and informed consent procedures to focus on the adjustment of any false expectations, the installation of a quality mark, and the offer of individual assessments. Legislation on privacy, advertisements, informed consent and checks that (directly or in any follow up) may harm health, moreover seems necessary to protect the values of (potential) users and their relationship of trust with physicians and the government.

Chapter four and five are primarily about the societal context in which health checks are offered.

In chapter four Michel Foucaults theory about ‘care of the self’ is used to answer the question whether health checks empower or discipline people. Relevant aspects of health check offers are distinguished. Test- and disease characteristics, but also the capacities of potential users to understand health check offers and to implement health advice, and features of the societal context in which health checks are offered turn out to be decisive in health check offers’ effects.

In chapter five, the effects of health checks’ omnipresence is discussed. Existing ethical evaluation considers the benefits and harms of each health check separately. However, sociological, anthropological and ethical research on this topic points out that omnipresent health checks may, amongst others, result in over-responsibilization of individuals: they strengthen the norm of individual responsibility for health to a point where people may hold themselves and others responsible for health outcomes they cannot reasonably be held accountable for. This may negatively affect psychological wellbeing, equity in mind and solidarity. Also, effects on privacy may be observed. To ensure an ethical provision of health checks, we argue that it is not only important that benefits of individual health checks outweigh harms, but that also the benefits of the totality of health checks on offer should outweigh the harms of the totality of these checks, for individuals and society as a whole.

In the final chapter six most of the findings regarding the effects of health check offers on values are summarized, and an evaluative framework is presented.

Health checks may affect health, equality in health, psychological wellbeing, autonomy, trust in physicians and governments, the division of responsibility for health between individuals and other actors involved, solidarity for health, and privacy. The effects of health checks on those values are mediated by test- and disease characteristics, as well as the provider of the test, the way in which it is offered and the way in which follow up care is organized. They are also mediated by characteristics of potential users and – last but not least – the societal context in which they are offered.

The mediated impact of health check offers' on the eight identified values is described. Moreover, it is shown that a 'good' health check by itself isn't good enough because its effects on values will differ depending on the societal context (often: country) in which it is offered: it matters whether treatments are reimbursed, whether (potential) users are health literate, and what sort of legislation on e.g. privacy is present.

On the basis of these results, a framework is presented with which the offer of health checks may be ethically evaluated and improved.

The thesis concludes with a Discussion in which special attention is paid to three issues that seem underexposed in the discussion around the ethical evaluation and regulation of personal health checks so far.

Unsolicited and 'omnipresent' health checks do not only affect users, but non-users as well. Therefore, they also need protection against potential harms brought about by (an omnipresent offer of) health checks.

Only a 'small elite' of people actually behaves like rational decision makers when it comes to decisions about participation in checks and to follow up treatment- and health advice. Emotions and heuristics usually play a more important role in decision-making than information. Hence, reliance on informed consent procedures to protect (potential) users from bad or harmful tests, is unwise, and overreliance on health checks as a means to improve health seems doomed to lead to disappointment.

Finally, health check offers should not be evaluated in isolation from other health related measures. Most have no proven beneficial effect on health, while their potential to cause harm to health and other values is real. A good health check isn't good enough if other health-related measures would result in a more favourable net effect on all values involved.

Samenvatting

Health checks zijn medische testen die (risicofactoren op) ziekte kunnen opsporen in mensen zonder specifieke klachten of indicatie. Ze worden zowel als bevolkingsonderzoek aangeboden, als aan individuen. Een voorbeeld van een bevolkingsonderzoek is dat op borstkanker waarvoor vrouwen tussen de 50 en 75 worden uitgenodigd. Voorbeelden van 'health checks voor individuen' zijn stands in supermarkten of stations van waaruit mensen wordt gevraagd of ze hun cholesterol willen laten testen, preventief medische onderzoeken die aangeboden worden op het werk en 'total body' (MRI) scans waarvoor wordt geadverteerd in kranten en op TV. Mensen kunnen ook zelf om een test vragen of er een aangeboden krijgen, omdat ze aangeven zich erg veel zorgen te maken over hun gezondheid, of omdat er een ziekte in hun familie voorkomt. Dit proefschrift over de ethiek van health checks richt zich met name op *ongevraagd aangeboden health checks voor individuen*.

Health checks hebben voor- en nadelen. Vroege opsporing kan tijdige behandeling mogelijk maken en daarmee gezondheidswinst opleveren. Health checks kunnen mensen ook geruststellen. Aan de andere kant kunnen dit soort testen ook schade toebrengen aan de gezondheid, en tot onnodige zorgen dan wel onterechte geruststelling leiden.
In de Introductie van dit poefschrift wordt het Nederlandse debat rondom de ethische evaluatie en regulering van health checks voor individuen uiteen gezet, aangezien dit de aanleiding was voor dit onderzoek.
Onze belangrijkste onderzoeksvraag was: Wat is een 'goede' health checks en wanneer is het aanbod van health checks ethisch gezien te verantwoorden?
We wilden een ethisch framework voor health checks ontwikkelen dat gebruikt zou kunnen worden om health checks ethisch te evalueren en – waar nodig – te verbeteren. Omdat health checks meer waarden dan alleen 'gezondheid' beïnvloeden, was het belangrijk om zich te krijgen op welke waarden dat zijn, en te onderzoeken door welke variabelen deze effecten gemedieerd worden.

De vijf studies die in dit proefschrift beschreven worden (hoofdstuk 1-5) dragen allemaal bij aan het beantwoorden van deze onderzoeksvragen en vormen de basis voor het ethische framework (hoofdstuk 6).
Het eerste hoofdstuk is literatuuroverzicht van redenen waarom mensen wel of juist niet meedoen aan cardiovasculaire health checks.
Potentiele gebruikers maken niet altijd afgewogen beslissingen, maar testen ook 'omdat de test werd aangeboden'. Naast de setting waarin testen worden aangeboden, speelt ook de maatschappelijke context een rol in beslissingen om wel of niet mee te doen. We stellen dat gezondheid en rechtvaardigheid in sommige omstandigheden beter bevorderd kunnen worden door andere maatregelen dan cardiovasculaire health checks.

Vervolgens worden de resultaten besproken van een interviewstudie onder health check aanbieders, en een focusgroep-studie met (potentiele) gebruikers.
Hoofdstuk twee gaat over wat aanbieders onder een 'goede' health check verstaan – dat wil zeggen testen die gebruikers waarschijnlijk ten goede komen – en over hun praktijk en ervaringen. In hoofdstuk drie bespreken we hoe (potentiele) gebruikers over 'goede'

health checks denken – testen die ze zelf graag zouden willen doen of anderen zouden aanraden.

Aanbieders en (potentiele) gebruikers zijn het er vrijwel unaniem over eens dat health checks een goede voorspellende waarde zouden moeten hebben; dat testen èn een eventueel vervolgtraject de gezondheid meer goed dan kwaad zouden moeten doen; en dat voor de test moet worden nagegaan of deelname vrijwillig en goed geïnformeerd is ('informed consent'). Daarnaast zouden aanbieders deskundig en betrouwbaar moeten zijn, het belang van potentiele gebruikers voorop moeten stellen en de tijd voor hen moeten nemen. Aanbieders benadrukken ook nog het belang van 'vervolgzorg' voor het realiseren van gezondheidswinst, zoals hulp bij het implementeren van leefstijladvies. Potentiele gebruikers vinden privacy erg belangrijk.

Opvallend genoeg bieden veel van de geïnterviewde aanbieders testen aan die zij zelf als 'slecht' karakteriseren. De redenen die ze hiervoor aanvoeren laten zien dat criteria voor 'goede' health checks met elkaar en met andere ethische waarden kunnen botsen. Aanbieders wijzen er ook op dat de manier waarop de Nederlandse gezondheidszorg georganiseerd is, en wordt gefinancierd, een ethisch aanbod van health checks kan bemoeilijken. Als voorbeelden noemen ze een gebrek aan (betaalde) tijd voor informed consent en vervolgzorg, en commerciële belangen.

Aanbieders stellen dat mensen niet op een rationele manier met informatie (over health checks en een eventueel vervolgtraject) omgaan maar sterk beïnvloed worden door de setting waarin health checks worden aangeboden en emoties zoals angst voor ziekte en dood. Ze denken daarom dat informed consent in de praktijk moeilijk te realiseren is. Dit idee wordt bevestigd in de focusgroepen: Potentiele gebruikers vinden het niet alleen belangrijk dat checks zekerheid bieden over de aan- of afwezigheid van ziekte, de gezondheid ten goede komen en dat hun privacy gerespecteerd worden, *ze gaan er ook vanuit* dat de meeste health checks in overeenstemming zijn met deze criteria. Dat komt omdat ze artsen en de overheid vertrouwen dat ze dit soort testen aanbieden dan wel erop toezien dat dit gebeurd. Ze kunnen bijna niet geloven dat dit niet altijd het geval is.

Om een autonome keus voor testen te bevorderen denken we dat advertenties en informed consent procedures zich zouden zich moeten richten op het bijstellen van eventuele verkeerde verwachtingen; er een keurmerk voor health checks zou moeten komen; en dat aanbieders 'individuele assessments' aan zouden moeten bieden. Daarnaast lijkt wetgeving rondom privacy, advertenties, informed consent en testen die (direct of in een eventueel vervolgtraject) gezondheidsschade op kunnen leveren, noodzakelijk om de waarden van potentiele gebruikers en hun vertrouwen in artsen en de overheid te beschermen.

Hoofdstuk vier en vijf gaan vooral over de maatschappelijke context waarbinnen health checks worden aangeboden.

In hoofdstuk vier wordt Michel Foucaults theorie over 'zelfzorg' gebruikt om de vraag te beantwoorden of health checks mensen empoweren of juist disciplineren. We onderscheiden verschillende aspecten van aangeboden health checks die bepalend zijn in het beantwoorden van deze vraag. Dit zijn: test- en ziekte-kenmerken, de capaciteiten van potentiele gebruikers om aangeboden health checks en eventueel behandel- of gezondheidsadvies op waarde te kunnen schatten en te kunnen implementeren, en kenmerken van de maatschappelijke context waarbinnen health checks worden aangeboden.

In hoofdstuk vijf worden de effecten van health checks' alomtegenwoordigheid besproken. Bestaande voorstellen voor de ethische evaluatie van health checks beoordelen de voor en nadelen van elke test apart. Uit sociologische, antropologische en ethische literatuur over dit onderwerp blijkt echter dat alomtegenwoordige health checks ertoe kunnen leiden dat er een te groot beroep wordt gedaan op de individuele verantwoordelijkheid: ze kunnen de norm van individuele verantwoordelijkheid voor gezondheid dusdanig versterken dat mensen zichzelf en anderen verantwoordelijk gaan houden voor gezondheidsuitkomsten waar ze redelijkerwijs niet verantwoordelijk voor zíjn. Dit kan negatieve effecten hebben voor het geestelijk welbevinden van mensen, tot (meer) ongelijkheid in gezondheid leiden en een verminderde solidariteit. Alomtegenwoordige health checks brengen ook privacy risico's met zich mee. Om een ethisch te verantwoorden aanbod van health checks te garanderen, is het daarom niet alleen belangrijk dat individuele testen meer voor- dan nadelen hebben, maar ook dat het totale aanbod van health checks in de maatschappij meer voor dan nadelen oplevert, voor individuele mensen en voor de samenleving als geheel.

In het laatste en zesde hoofdstuk vatten we de meeste van onze bevindingen samen, en presenteren we een framework waarmee health checks geëvalueerd kunnen worden. Health checks kunnen effect hebben op gezondheid, gelijkheid in gezondheid, geestelijk welbevinden, autonomie, vertrouwen in artsen en overheden, de verdeling van verantwoordelijkheid voor gezondheid tussen individuen en andere betrokken actoren, solidariteit en privacy. Deze effecten worden gemedieerd door kenmerken van de test en de aandoening waarop wordt getest, maar ook door de aanbieder van de check, en de manier waarop de check wordt aangeboden en eventuele vervolgzorg is georganiseerd. Health checks' effecten op waarden worden ook beïnvloed door de kenmerken van potentiele gebruikers en tot slot door de maatschappelijke context waarbinnen health checks worden aangeboden.
We beschrijven deze gemedieerde invloed van health checks op geïdentificeerde waarden en laten zien dat een 'goede' health check op zichzelf niet goed genoeg is. De manier waarop testen waarden beïnvloeden is namelijk afhankelijk van de maatschappelijke context (vaak: het land) waarin ze worden aangeboden: het maakt verschil of behandelingen vergoed worden, of (potentiele) gebruikers gezondheidsgeletterd zijn en of er bijvoorbeeld privacywetgeving is.
Op basis van deze resultaten wordt een ethisch framework gepresenteerd waarmee aangeboden health checks kunnen worden geëvalueerd en eventueel verbeterd.

In de discussie die dit proefschrift afsluit wordt aandacht besteed aan drie kwesties die in bestaande voorstellen tot ethische evaluatie en regulering van health checks onderbelicht lijken.
Ongevraagde en alomtegenwoordige health checks beïnvloeden niet alleen gebruikers van health checks, maar ook niet-gebruikers. Zij verdienen net zo goed bescherming tegen eventuele schadelijke effecten van (alomtegenwoordige) health checks.
Slechts een 'kleine elite' van mensen gedraagt zich als rationele beslismaker als het gaat om keuzes voor health checks of het implementeren van behandeling- en gezondheidsadviezen. Emoties en heuristieken spelen over het algemeen een grotere rol in besluitvormingsprocessen dan informatie. Het is daarom onverstandig om ervan uit te gaan dat informed consent procedures (potentiele) gebruikers zullen beschermen tegen slechte of schadelijke testen. En een eenzijdige inzet van health checks ten behoeve van de (volks)gezondheid zal tot teleurstellingen leiden.

Tot slot zouden health checks niet los van andere gezondheid gerelateerde maatregelen moeten worden geëvalueerd. Voor de meeste checks is een positief effect op gezondheid niet aangetoond, terwijl ze gezondheid en andere waarden wel degelijk kunnen schaden. Een goede health check is niet goed genoeg als andere gezondheid gerelateerde maatregelen een gunstiger effect hebben op alle betrokken waarden.

C.V.

Yrrah Stol started her scientific training in 1999 at Leiden University with medical school. After completing her first year she switched to psychology, because she was 'more interested in people than in their legs'. A course on consciousness aroused an interest in philosophy and in 2003, she started to attend lectures at the 'Oudemanhuispoort', University of Amsterdam. Classes became a study, and in 2006 she graduated in both psychology (cum laude) and philosophy.
The medical world still attracted her, and she decided to subscribe for another master: in preventive health sciences at the Free University, Amsterdam. As part of this master program, she conducted research at the department of clinical genetics. She interviewed clinical geneticists on their views and practices concerning informing family members of so called 'index' patients with hereditary breast- and colon cancer. The results were remarkable and published in the Journal of Medical Ethics.
While finishing her thesis, she was asked her for a project in which the societal relevance of biotechnological trends – identified by the COGEM, Gezondheidsraad and CCMO, would be researched. In close consultation with Annemiek Nelis, Radboud University, she decided to turn the 'traditional' impact-question around: instead of reasoning from technologies, this study focussed what these technologies may contribute to a variety of societal issues.
She then got the opportunity to obtain a PhD at the department of philosophy of science, University of Amsterdam. Yrrah however found it hard to merely describe, as philosophers of science do. She wanted to take position as well, and therefore quit to resume her work on informing family members of patients with hereditary disease. In the meanwhile she started teaching at the Institute of Interdisciplinary Studies.
Here she also got to develop and coordinate education about ethics, philosophy of technology and philosophy of science. Machiel Keestra, one of the coordinators of this Institute, encouraged her to apply for the PhD position on health checks that resulted in this thesis.

Name PhD student: Yrrah Stol Erasmus MC Department: Medical Ethics and Philosophy Research School: OZSW	PhD period: 2013 – 2018 Promotor(s): M.H.N. (Maartje) Schermer, E.C.A. (Eva) Asscher Supervisor: M.H.N. (Maartje) Schermer

1. PhD training

	Year	Workload (ECTS)
General courses		
Systematic literature research (Medical Library, ErasmusMC)	2013	0,2
Research Integrity (Department of Medical Ethics and Philosophy)	2014	0,3
Specific courses		
Perspectives on social freedom – core issues in political philosophy (Landelijke OnderzoeksSchool Wijsbegeerte (OZSW))	2013	5
Winterschool Ethical Theory and moral Practice (Landelijke OnderzoeksSchool Wijsbegeerte (OZSW))	2014	6
Ethics of health and care (Landelijke OnderzoeksSchool Wijsbegeerte (OZSW))	2014	5
National conferences		
OZSW conference, Nijmegen. Oral presentation: Assessment of health checks from a business ethics perspective	2014	1
4TU. conference, Delft. Oral presentation: Overresponsibilization	2016	1
International conferences		
ESPMH Congress, Debrecen. Oral presentation: Disciplining health checks as tools for self care	2014	1
ESPMH Congress, Ghent. Oral presentation: The effects of omnipresent health checks	2015	1
Presentations – other		
Expert meeting Incidental Findings, Rotterdam. Oral presentation: This may be why people want to know	2015 2015	1 1
Science-cafe Rotterdam. Oral presentation: A health check, why not?	2016	1
Pharmacists meeting, Utrecht. Oral presentation: Interviews with helath check providers. The role of the pharmacist.	2017	1
Trainng general practitioners, Hoogeveen. Oral presentation: A good health check	2018	1
ErasmusMC/Lindeboom Instituut, Den Haag. Oral presentation: A good health check according to health check providers and (potential) users		
Other		
Contribution to evaluation of KNMG health check directive	2017	0,5
Organization expert meeting health check providers	2017	1
Organization symposium, Den Haag	2017	2

2. Teaching activities

	Year	Workload (ECTS)
Diversity of ethical dilemmas, BA Medicine	2013-2017	2
Bachelor Essay, BA Medicine (grading)	2013-2107	3
Neonatal screening, BA Medicine	2014-2107	1
Ethics of prenatal screening, BA medicine	2014-2017	1
Supervision of theses, minor Ethics of health care	2015-2017	1
Lecture *Health Checks*, minor Ethics of health care	2015-2016	0,5
Lecture *Ethics of prevention*, minor Ethics of health care	2015-2016	0,5
Lifestyle and responsibility, MA Medicine	2015-2017	1,5
Supervision of thesis MA Medicine	2013-2014	2,5
Post-academic ethics classes for clinical geneticists and genetic counselors in training	2015-2017	2