

# **Periodic health examination by Austrian general practitioners: developing Patient Information Forms and Health Summary Sheets**

Technical Report

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# 1 Introduction

Periodic Health Examinations (PHE) are executed by General Practitioners (GPs) or in the situation of Occupational Health Examinations at the worksite. In the United States of America, Canada, Australia and New Zealand PHE are still provided at the level of Primary Care. Task forces in these countries (a.o. the US Preventive Task Force, the Canadian Task Force on Preventive Health, the National Preventive and Community Medicine Committee of the Royal Australian College of General Practitioners and the New Zealand Guidelines Group) reorganised these examinations according newly developed evidence-based guidelines.

In European countries professional opinions differ about the effectiveness, usefulness and satisfaction of a periodic health examination. Together with Germany is Austria one of the only two EU countries that have a standardised PHE in the basic package of its social insurance system. Every insured person (which are nearly all citizens) from age 19 on has a right to a health examination once a year (until age 19 people fall under child and school health). The examination is done by a GP and is free at the point of delivery. GPs receive a remuneration of currently €70 for each examination. It is estimated that approximately 800.000 out of a total of approximately six million eligible Austrians per year have a PHE. Apart from the PHE, there is programmatic screening for cervical and breast cancer.

The system of this PHE was already developed in the 1970's. Since then lots of new insights into the role of GPs in monitoring the state of health of populations and into the role of periodic health examinations in enhancing the health of populations have been developed. Therefore, the current system is not based on up-to-date evidence and not fully used as an instrument in monitoring and enhancing the health of the population.

The organisation of Austrian social insurance carriers feels that the PHE still (and probably more than in the past) appeals to a demand of the insured population and wants to continue the PHE. However, at the same time there is need to re-examine the format of the PHE and to bring it in line with the latest insights in (preventive) medicine and health care. How can the current periodic health examination by Austrian general practitioners (GPs) be modernised and brought in line with the principles of evidence-based medicine? This question has been raised by the umbrella Organisation of Austrian Social Insurance Carriers.

Internationally in health care there is a movement to base both micro-level clinical decisions as well as macro-level (insurance) policy decisions as much as possible on research evidence. Over the past thirty years there has been a tremendous growth of knowledge in the field of medicine and health care. Also

the possibilities to process information in health care have increased. Risk profiling of patient groups by combining information from different sources, using electronic medical records, has a large potential in surveillance and preventive care. Where evidence lacks, international consensus or converging international experience provides grounds to rationalise decisions.

Several parties in the health care field have an interest in modernising the format of PHE in Austria. The Organisation of Austrian Social Insurance Carriers and the federal and state health authorities have a statutory responsibility for the health of the population and the quality and affordability of health care. The general practitioners have a financial interest in doing PHEs. But the most important interest is with the people who visit a GP for a PHE. They may have different reasons for doing so, but common in their reasons will be that they expect to benefit from it for their health. Currently, the PHE is not used for epidemiological research or public health information collection.

The content of the Austrian Periodic Health Examination is studied by various working groups of experts in different domains of health and health care. They will base their guidelines and policy on the available international evidence on PHE and preventive activities in Primary Health Care at the level of General Physicians.

During the process of a PHE information has to be collected from the patient to be able to establish an individual risk profile for several illnesses and to guide the physician in her or his preventive actions and diagnostic examinations. The results of the risk profiles and further examinations have to be recorded. The actual forms used in the Austrian PHE consist of a form registering the anamnesis of the patient (Anamneseblatt, figures and , p) and for males and females a separate form (Befundblatt, see figure p) to register the results of different examinations.

The modernisation of the PHE includes also the development of new forms. In the new PHE information is collected by GP's to evaluate the risk profile of the patient. Some of the information is given by the patient him- or herself on a form called the Patient Information Form (PIF) (sometimes called the Patient Risk Anamnesis). This form may be used as a Health Education Tool to give the patient feedback on his/her own health risk profile. The risk profile according to age and sex subgroups is transmitted on a Health Summary Sheet (HSS), together with the results of further examinations.

The Organisation of Austrian Social Insurance Carriers wants to develop useful efficient instruments to be used by patients and general practitioners according to the following principles:

- A form on paper will still be used; the possible development of a computer form comes at a later stage,
- Patients will put anamnestic information and information about personal risk factors on a specific form; this form will also be used as a feedback

instrument or health education tool for the patients themselves (Patient Information Form),

- The GP will register the risk profile(s) of the patient on a separate form, the Health Summary Sheet, partly based on the information given by the patient on the PIF, partly based on further examinations. The form will give indications on further screening examinations to be performed based on the newly evidence-based developed PHE policy guidelines.

This technical report advises the commissioner of the project about innovations concerning the system of PHE, more specifically about the screening questions to be asked to patients, so far as possible based on international evidence and experience with PHEs. The report is based on the relevant literature and websites on the internet, examples of PHE forms, screening instruments used in PHE and Health Interview Surveys in various parts in the world.

The main question to be addressed in this report is: How can the current periodic health examination forms used by Austrian general practitioners (GPs) be modernised and brought in line with international evidence and experience?

The main research question will be divided in two sub-questions:

- What criteria must be fulfilled for a feasible PHE instrument?
- What is the international experience with the instruments used?
- How to develop a form that combines the purposes of a screening instrument for the physician and a health education tool for the patient

The first sub-question is important, because the system and the instruments of the PHE must be feasible in a general practice context, and specifically the Austrian context. Issues to consider are the length of the PHE, possibilities (or need) to computerise it, sources of information (patients' statements, medical record, physical examination), public health use of population level information etc.

The second sub-question relates to international experience. Especially outside Europe experience has been built with PHE, either on a voluntary basis (as in the US) or on a programmatic basis (as e.g. in Australia). The international experience will be used as much as possible, but with an open eye to the specific context of Austrian general practice.

The third sub-question is about the modern approach to give feedback to the patient about his/ her own health risks, a health education approach to make the patient more responsible for his/her own health. The Patient Information Form to be developed should at the same time be useful for the physician and the patient.

The project will be done in co-operation with the Organisation of Austrian Social Insurance Carriers and the major part of the work will be done by them. The Organisation of Austrian Social Insurance Carriers contacted NIVEL because of their expertise with research and health care in General Practices, and their experience with the development of questionnaires. So, this work will only give

a partial answer to the whole issue of an evidence-based PHE and the instruments needed. The work of NIVEL was limited to certain domains of the total PHE (see methodology section) and limited to the development of screening questions at patient level. Where possible advice might be given for the development of a new questionnaire.

This report will remain technical in the sense that it presents per domain an overview and description of the available evidence found through a systematic search of literature and websites on the internet. The listed results are summarized and commented upon. Finally a selection of questions to be included in the PHE forms, will be presented. A copy of the available questions or questionnaires are brought together in an appendix for each domain.

This technical report lists a limited number of items indicating health status, disease and risk factors and the ways to measure these in a PHE. Together with the parts that are being done by the Organisation of Austrian Social Insurance Carriers itself, this report forms the reasoned outline for a renewed PHE in Austria. It can be used by the Organisation of Austrian Social Insurance Carriers to base its reasoned decision on about changes in the system of PHE.

## 2 Methodology

In this section we will explain the approach followed during this research process and the different steps followed:

- Framework for analysis
- Framework for collection or selection of evidence or information in general
  - Feasibility in general practice settings
  - Basic characteristics of questions to be selected
  - Comparison or development of questions
- Health Summary Sheets and Patient Information Forms
- Tasks for NIVEL and domains to be included
- Presentation of results

### **Framework for analysis for the Periodic Health Examination (PHE)**

To be able to perform the job for which we were contacted, we needed a framework to guide our activities.

In working out a framework we distinguished three levels of abstraction. At the highest level of abstraction, one could raise the point of the public health value of a PHE, the suitability of general practice to perform PHE etc. The framework at this level of abstraction will be developed during and after the project, as a way to evaluate our activities and to communicate them to an international audience.

Here we restrict ourselves to two further levels of abstraction: the feasibility of application in general practice and the selection of information to be used in grounding our advice on the separate topics.

The contents of the forms used up to now in the Austrian PHE have to be redesigned, as much as possible based on existing evidence. The task of NIVEL in this process is to:

- ▶ collect and summarize evidence or basic information at the level of GP's concerning periodic screening or case finding activities and examinations.
- ▶ translate evidence into information or questions to be asked to patients on the PHE- forms

*Framework per topic:*

- ▶ Collection of evidence based guidelines for PHE at GP's level (US, Canada, UK, Australia, New Zealand, Netherlands)
- ▶ If no guidelines exist: collection of screening or case-finding evidence at GP or population level
- ▶ Available questionnaires from different sources (see further)

*Framework for development of forms:*

- ▶ Health information surveys and Health examination surveys
- ▶ Specific screening forms / health check forms / Health Summary Sheets (US, Canada, UK, Australia, New Zealand, Netherlands)

**Framework for collection and selection of evidence and information in general**

The approach followed during the research was based on the methodology of a systematic review consisting of the following steps:

- A. Comprehensive and systematic searching of the evidence,
- B. Selection of the material (questionnaires and questions) based on selection criteria,
- C. Compiling the evidence.

*A Searching the evidence:*

The following sources of information were systematically screened, using appropriate keywords for each specific domain:

- ▶ Scientific literature databases (PubMed, Psycinfo, NIVEL catalogue) to collect information about guidelines, forms, questions, questionnaires used in PHE and screening activities at GP/primary care/public health-level and the evaluation or validation of these items.
- ▶ Search for questions in the European Health Information Surveys/ Health Examination Surveys database. This database covers all interview questions and protocols examinations of national health population surveys in EU member states and EFTA/ EEA countries as well as Canada, Australia and USA.
- ▶ Websites of relevant organisations from Preventive Task Forces and similar ones and GP-organisations in the above mentioned countries (US, Canada, UK, Australia, New Zealand, Netherlands) to collect information on guidelines, HSS and PIF
- ▶ Literature about the validation of existing questionnaires about domains to be included in the HSS and PIF.
- ▶ Literature about the development of questionnaires.
- ▶ Contacting experts of these organisations if needed information cannot be found or downloaded from the websites.

The commissioner of the project provided the NIVEL researchers with downloaded materials of guidelines available at different sites, especially the guidelines from the US Preventive Task Force and the Canadian Task force on Periodic Health Examination.

### *B Selection criteria:*

The following criteria were used in the selection of questions out of questionnaires to be used in the new instruments for the PHE:

- ▶ Feasibility in general practice settings
- ▶ Basic criteria for development and use of questions to be asked in the population of a general practice (Streiner criteria)
- ▶ Where questionnaires and questions are not validated, above mentioned criteria are used to compare similar questions in different questionnaires and to decide on their usefulness or to decide on a reformulation of a specific question in the context of this research

#### *- Feasibility in general practice settings*

It is of vital importance that the PHE and the HSS to record its outcomes are tuned to the situation of GPs. A few examples will make this important requirement clear. First, if information is recorded on the forms, it has to be in a way that is related to possible actions by GPs (or other health care providers). This means that subtle distinctions that have no consequence for (further) diagnostic or treatment decisions, are not necessary. A second example: in a number of fields diagnostic questionnaires have been developed. However, although these forms usually are evidence based and well validated, they are not feasible in a PHE in general practice, because they take too much time to be conducted. This is especially a problem, given the fact that the PHE addresses many different health problems and conditions.

This leads to the following general requirements:

- the information to be recorded on the PHE forms must be categorised in a way that is meaningful from the point of view of follow-up decisions by GPs;
- the information to be collected from patients must be reasonably easy to collect within the context of a PHE in general practice.

#### *- Basic criteria for questions to be selected or to be developed (taken from Streiner, 1994)*

- Questions that will be selected for the PHE should not require reading skills beyond that of a 12 year old so that patients from all educational and socio-economical levels will be able to understand the information requested.
- Ambiguity should be avoided and if a specific time frame or any other variable is called for, it should be spelled out explicitly.
- Double-barred questions should be avoided too: questions that ask two or more questions at the same time, and each of it may be answered differently.
- The same with using medical jargon: even more common terms as 'hypertension' may be misunderstood.
- Also value-laden words have to be avoided, as should negatively worded items.
- Questions should be as short as possible, without losing comprehensibility.

As the questions we selected based on these criteria are in English or into English translated from Dutch, an important task for the Austrian team remains the correct translation of these questions into German, taking the same criteria in consideration. Pre-testing of the questionnaires in the patient population of a general practice, testing wording, time, comprehensibility, flow and order of questions will be required before implementing the questionnaire in the frame of the PHE.

- *Comparison or development of questions*

As most questionnaires found were not validated, it was difficult to compare the questions used in the different questionnaires at different occasions. Final selection of the similar questions in different questionnaires is based on the mentioned criteria above. If no question respected these criteria, a new question was formulated based on the existing ones, but respecting the criteria mentioned. Questions for the PIF are put in the first person form (I-form), as was the case in certain questionnaires found during the search. As the PIF may also have health educational aims, questions put in the first person will stay closer to the patients.

A final questionnaire, PIF or HSS should be evaluated and validated in the context of a PHE with the patients at a GP practice within Austria.

### **Health Summary Sheets and Patient Information forms**

The commissioner of this project suggested to take the Australian Health Summary Sheet as a possible reference for the development of new forms.

The following organisations were contacted by email, requesting copies of possible existing forms of HSS and PIF:

- the American Academy of Family Physicians,
- the American Board of Family Practice,
- the Royal Australian College of General Practitioners,
- the North American Primary Care Research Group,
- the Royal College of General Practitioners (UK),
- the Royal New Zealand College of General Practitioners

We contacted the WONCA contact persons of each organization and the main office and research boards of the different organisations.

(<http://www.globalfamilydoctor.com/>)

The North American Primary Care Research Group kindly forwarded our request on their listserver to all their members and networks.

These contacts resulted only in a copy of the Health Summary Sheet used in Australia for the Periodic Health Examination, and one used by the Occupational Health department of the Medical School in Marburg, Germany.

## Tasks for NIVEL and domains to be included

An original task-list was developed by the commissioner of the contract (Appendix A). During the development of the project the following domains received first priority in agreement with the commissioner:

- Cardiovascular risk profile and risk determinants: screening of riskgroups
  - Diabetes Mellitus (risk factor screening):
    - Anamnesis for familiar history
    - Hypertension
    - BMI  $\geq 30$
  - Anamnesis for familiar history of cardiovascular diseases in close male relatives  $\leq 50$  years and female relatives  $\leq 60$  years
  - Anamnesis for history of familiar hyperlipidaemia
  - Multifactorial risk profile:
    - Gender
    - Age
    - Smoking
    - Hypertension
    - Hyperlipidaemia
    - Diabetes mellitus
    - Familiar history of cardiovascular diseases
- Hearing impairment
- Vision impairment
- Glaucoma (risk factor screening)
  - Familiar glaucoma
  - Severe myopia
  - Diabetes Mellitus
  - Caucasian  $\geq 65$  years
  - African origin (Black)  $\geq 40$  years
- Use of sedatives and analgetics
- Mamma-carcinoma: anamnesis for familiar history

## Presentation of results

The results of the steps of research mentioned above are presented at follows:

- In chapter three:
  - General results are given about the search for questionnaires, general and specific,
  - Results about general questionnaires on health are presented,
  - Per domain an overview is given of the keywords used for different sources of information,
  - Per domain an overview is given of the results of the literature and website search, with URL and/or description of the result. Copies of the

questionnaires found during the search are put together in appendices presented per domain.

- Sources of the final selected questions
  
- Chapter four presents:
  - The questions selected or developed for all the included domains
  - Part of the Patient Information Form based on the selected questions
  
- In chapter five:
  - are copies given of the collected HSS and commented in the light of the development of new forms for the Austrian PHE
  - recommendations are given how to use the information from the PIF on the HSS, as well as information collected through further examinations.

### 3 Results literature search

During further contacts with the commissioner of the project, Hauptverband der Österreichischen Sozialversicherungsträger, the following domains were selected as priorities for further research: cardiovascular risk factors including obesity, hearing and vision impairment, glaucoma, use of sedatives and analgetics, and breast cancer risk factors.

#### General Results

While information on Guidelines in the context of Prevention are widely available, specific information on Health Information Sheets and Questionnaires is quite limited. While the need to use HSS is often mentioned in guidelines, the forms themselves are not on the net, excepted some questionnaires on specific topics in the format of a list of questions.

When some Questionnaires about the specific topics for a PHE are mentioned, they are rarely evaluated or evaluations are mentioned without showing the form itself. Databases of scientific literature may mention forms used during research or health care, but seldom give a copy of these forms or sheets. The majority of the forms found during our search for evidence, were found on the internet web-sites of specific organisations at primary and secondary health care level. Summarizing one may conclude that information about screening questionnaires for certain topics is available but no really evidence about validity, reliability or usefulness.

On the other hand, many evaluations were found about well-known standardized questionnaires on physical condition, social health and psychological health (König-Zahn, Essink-Bot), but few were useful for screening purposes in a general population at GP-level. Most of these questionnaires have a lot of questions and are designed for the purpose of research. As some of the specific questions used in these extended questionnaires may be used in a questionnaire for a PHE, we screened these general health questionnaires for this purpose (see Validated Generic Questionnaires).

As mentioned earlier, although attempts were made to contact several GP and Primary Care organisations in the US, UK, Canada, New-Zealand and Australia, to get copies from HSS and PIF used by their organisations and countries, only few organisations reacted. This resulted in copies of HSS forms used by two organisations.

## **Validated Generic Questionnaires**

König-Zahn (1994) and Essink-Bot (1991) discussed among others the following well-known questionnaires for physical or social health: Cornell Medical Index, OECD long-term disability indicator list, RAND Functional Limitations and Physical Abilities Batteries, COOP/WONCA cards, Duke-University Health Profile, McMaster Health Index, Medical Outcome Study Short-form questionnaire, Quality of Well-Being Scale, Nottingham Health Profile, Sickness Impact Profile and some Dutch questionnaires: Questionnaire Work and Health, Questionnaire Periodic Occupational Health Examination and the List of Chronic Diseases.

As mentioned before these questionnaires are in the first place developed for research purposes, but still some questions in a few more general questionnaires may be used in the context of PHE. We screened all questionnaires and present here the ones we thought might be the most appropriate for the aim of this research.

### **CORNELL MEDICAL INDEX**

The questions used in the CMI are simple and easy to use. The validity of the answers for specific diseases and diagnoses is low, but acceptable for an indicator of general health. It is efficient to get rapid information from the patient self, which can be deepened in communication with the doctor. Unfortunately the archivist of the Cornell Medical Index Archive in the US informed us that the CMI no longer could be used for studies of human subjects or in Periodic Health Examination Sheets. The questions are no longer valid for these purposes. So, although some of the questions in the questionnaire might have been useful, we may not use them anymore.

### **DUTCH QUESTIONNAIRE WORK AND HEALTH**

The complete questionnaire consists of 200 questions, from which 36 are about experienced health and health attitudes. The questionnaire is easy to fill in by the patients. The questions about experienced health are internally consistent and valid (Cronbach's alpha 0.85). A translation of these questions will be given in the Appendix B.

### **DUTCH PERIODIC OCCUPATIONAL HEALTH QUESTIONNAIRE**

Besides questions related to work and working conditions, employees are asked questions about health for a screening by the occupational health physician. The questions related to health are almost as consistent as those in the Dutch Questionnaire Work and Health (Cronbach's alpha 0.70). A translation of these questions will also be given in the Appendix B.

## **Specific questionnaires per domain**

Per priority domain mentioned in the methodology section we will give an overview of the keywords used and the URL links to the relevant results found per search. Copies of the relevant questionnaires can be found in an appendix per domain.

### **I Overview cardiovascular diseases and risk factors**

#### ***Keywords used in searches***

Hereafter we present the keywords used during the searches in different databases

#### *1 Search for relevant internet sites of health sheets, guidelines and questionnaires*

Keywords used: periodical health examination/ screening/ cardiovascular diseases/ hypercholesterolemia/ questionnaires/ health check/ summary health sheet/ primary care

#### *2 Search for relevant articles with health summary sheets and questionnaires in Pubmed*

Keywords used: family practice/ physician, family/prevention and control/ preventive medicine/ Medical history/ Medical audit/screening/ primary care/ hypercholesterolemia/ summary health sheets/ questionnaires/ health check/ periodical health examination

#### *3 Search for relevant articles in Psychinfo*

Keywords used: health check/ periodical health examine/ general practitioners/ family-medicine/health summary sheet/screening/primary health care/ health screening/ questionnaires/ cardiovascular diseases

#### *4 Search for articles in catalogue library NIVEL*

Keywords: measuring instruments/ cardiovascular diseases

#### *5 Search for questions in HIS/ HES database (no specific keywords used)*

#### ***Results relevant literature/ websites***

- Questionnaires and questions (see Appendix C)

1 Klungel OH, de Boer A, Paes AHP, Seidell JC, Bakker A. Cardiovascular diseases and risk factors in the population-based study in The Netherlands: agreement between questionnaire information and medical records. *Nether J Med* 1999;55:177-183.

Includes simple questions on cardiovascular diseases and risk factors. (Appendix C, reference 1).

2 Fullard E, Fowler G, Gray M. Promoting prevention in primary care: controlled trial of low technology, low cost approach. *BMJ* 1978;294:1080-1082.

Includes a health summary card used for this study (Appendix C, reference 2).

3 NIVEL. Questions used in the Second Dutch National Survey of General Practice

Contains among others a list of questions related to chronic diseases, smoking, obesity. (Appendix C, reference 3)

4 National Heart, Lung, and Blood Institute. National Institute of health. USA, 1995. Recommendations regarding public screening for measuring blood cholesterol. [http://www.nhlbi.nih.gov/guidelines/cholesterol/chol\\_scr.pdf](http://www.nhlbi.nih.gov/guidelines/cholesterol/chol_scr.pdf)

Includes recommendations on cholesterol screening and a risk factor questionnaire. The risk factor questionnaire is a kind of checklist about conditions and risks. (Appendix C, reference 4)

5 The Affairs of Heart Committee. Columbia University Medical Center, USA. [http://www.columbiasurgery.org/outreach/aoh\\_woman\\_risk.html](http://www.columbiasurgery.org/outreach/aoh_woman_risk.html)

An online questionnaire for women to assess their own risk for heart disease and gives health educational advice per risk factor. It works also as a score list. (Appendix C, reference 5)

6 Hutchison B, Birch S, Evans E, Goldsmith LJ, Markham BA, Frank J, Paterson M. Screening for hypercholesterolaemia in primary care: randomised controlled trial of postal questionnaire appraising risk of coronary heart disease. *BMJ* 1998;316:1208-1213  
<http://bmj.bmjournals.com/cgi/content/full/316/7139/1208>.

Validates a self administered postal questionnaire appraising risk of coronary heart disease and determines whether use of this questionnaire increases the percentage of people at high risk of coronary heart disease and decreases the percentage of people at low risk who have their cholesterol concentration measured. Although the questionnaire appraising coronary risk increased the percentage of people at high risk who obtained cholesterol testing, the effect was small. Most patients at risk who received the questionnaire did not respond by having a test.

The article includes the questionnaire used for this study. The questionnaire is validated and has the format of a score list giving advice on risk scores obtained.

It uses also a weight and height chart to measure BMI and a cut-off point for overweight. (Appendix C, reference 6)

7 Wood D. Joint British recommendations on prevention of coronary heart disease in clinical practice. *Heart* 1998;80:1-29.

<http://www.landlaeknir.is/Uploads/FileGallery/Kliniskarleidbeiningar/klinhjenteng.pdf>

Shows a screening pro forma suitable for use in cholesterol screening examinations. (Appendix C, reference 7)

8 The European Health Risk Monitoring Project.

<http://www.ktl.fi/publications/ehrm/product1/title.htm>

Shows questions on questionnaires that were used in national population risk factor surveys about hypercholesterolaemia, smoking, blood glucose measurement, hypertension. The following questionnaires are presented: WHO MONICA project, Risk factor monitoring project in the Netherlands, Germany and Norway, UK National Health Surveys, National Health and Nutrition Examination Survey (NHANES III) US, the Italian OEC project, FINBALT (Finland and Baltic States), German Federal Health Survey, Norwegian Age-40 programme. (Appendix C, reference 8)

9 Questions related to CVD in the HIS/ HES Database.

<https://www.iph.fgov.be/hishes>

Questions are selected related to cholesterol, blood pressure, obesity and smoking. (Appendix C, reference 9)

- Scientific literature (without questionnaires) :

10 Nigel Unwin. Implications of applying widely accepted cholesterol screening and management guidelines to a British adult population: cross sectional study of cardiovascular disease and risk factors. *BMJ* 1998;317:1125-1130.

<http://bmj.bmjournals.com/cgi/content/full/317/7166/1125>

The paper compares the implications of four widely used cholesterol screening and treatment guidelines by applying them to a population in the United Kingdom. Concludes that without evidence-based guidelines, there are problems of variation. A consistent approach needs to be developed and agreed across the United Kingdom.

11 Wilson S, Johnston A, Robson J, Poulter N, Collier D, Feder G, Caulfield MJ. Comparison of methods to identify individuals at increased risk of coronary disease from the general population. *BMJ* 2003;326:1436-1445.

<http://bmj.bmjournals.com/cgi/content/full/326/7404/1436>

Evaluates guidelines on measurement of cholesterol in the national service framework for coronary heart disease and compares alternative strategies for identifying people at high risk of coronary disease in the general population. Concludes that measuring the cholesterol concentration of everyone aged 50 years and over is a simple and efficient method of identifying people at high risk of coronary disease in the general population.

12 Hutchison B, Birch S, Evans EC, Goldsmith LJ, Markham BA, Frank J, Paterson M. Selective opportunistic screening for hypercholesterolemia in primary care practice. *J Clin Epidemiol* ; 51:817-825.  
[http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list\\_uids=9762874&dopt=Abstract](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9762874&dopt=Abstract)

Assesses the performance of selective opportunistic screening in a primary care group practice. The authors bring into question the effectiveness of opportunistic approaches to preventive care.

13 Lee GH, Su DHW, Su DHC, Fong ACY, Chow YH. Screening for hypercholesterolaemia in patients with other risk factors for coronary Singapore *Med J* 1999;40. <http://www.sma.org.sg/smj/4006/articles/4006a4.html>

Objective of the study is to determine the prevalence of hypercholesterolaemia in individuals with major risk factors of coronary heart disease and markers of hypercholesterolaemia.

They recommend screening for serum cholesterol only in those with at least 2 major risk factors of coronary heart disease in the general population between 35 and 69 years of age.

14 Walma EP, Thomas S, Prins A, Grundmeyer HGLM, Van der Laan JR, Wiersma Tj. *Huisarts en Wet* 2003; 46(8):435-49. NHG-Standaard Hypertensie (derde herziening) [Dutch: Dutch College of GP Guidelines for Hypertension, 3rd revision].

The third revision follows as much as possible the Consensus Hypertension of the Dutch Institute of Health Care and is adapted as much as possible to the situation in general practice. Changes in comparison with former versions: hypertension cut-off points decreased from 160 to 140 mm Hg systolic and from 95 to 90 mm Hg diastolic; a group of people with hypertension are not considered for treatment: only if the absolute risk for the development of cardiovascular diseases is 20% or more they will be treated. Patients older than 60 years without diabetes or familiar hypercholesterolemia will only be considered for treatment if systolic blood pressure is above 160 mm Hg. The absolute risk can be derived from a table where the cut-off for treatment of hypertension is indicated. The table presents 4 groups of patients with different colours: green, no treatment of blood

pressure or cholesterol; yellow, treatment of blood pressure if other risk factors are present; orange, treat blood pressure; red, treat blood pressure as well as cholesterol, so far as blood pressure is above 140 mm Hg (or above 160 mm Hg for people above 60 years). (see also figure 8, p.63)

See also NHG Practice guidelines: <http://www.nhg.artsennet.nl/> : Dutch guidelines for management of cholesterol and high blood pressure in primary care (prevention, identification and treatment of high blood cholesterol/ high blood pressure). English translation of guidelines is in process.

- Websites (guidelines and reports, no questionnaires):

15 National Heart foundation Australia. The cardiac society of Australia and New Zealand. Lipid Management guidelines 2001.

[http://www.heartfoundation.com.au/downloads/lipid\\_guide\\_2001.pdf](http://www.heartfoundation.com.au/downloads/lipid_guide_2001.pdf)

Summarises current evidence to serve as a prompt for practitioners for best clinical practice and encourages consistency of care in managing plasma lipid levels to prevent CHD.

16 Canadian Task Force on Preventive Health Care.

<http://www.ctfphc.org/Abstracts/Ch54abs.htm>

Recommendations for routine cholesterol screening, drug treatments, and dietary advice on fats for asymptomatic Canadian adults.

17 The seventh report of the joint national Committee on prevention, detection, evaluation, and treatment of high blood pressure 2003, USA.

<http://www.nhlbi.nih.gov/guidelines/hypertension/express.pdf>

Guidelines for hypertension prevention and management.

18 National Institutes of Health, USA.

<http://www.nhlbi.nih.gov/health/public/heart/cho/wyntk.htm>

National Cholesterol education program from the National Institutes of Health. Gives information about cholesterol. Includes tables for men and women with points and scores to assess risk of developing heart disease or a heart attack.

19 Computerized prescription record.

<http://www.cpr.net/diseases/endocrine/hypercholesterolemia/>

Contains a lot of topics on hypercholesterolemia and 10 years risk for heart disease calculators. The website provides links to several American organisations and programmes with checklists, risk assessments, health education and software

to calculate risks and others. One link refers to a questionnaire by the National Lipid Education Council to help patients to evaluate their risk factors for heart disease.

[http://www.lipidhealth.org/content/newsletter/vol6no3/newsletter\\_1a.pdf](http://www.lipidhealth.org/content/newsletter/vol6no3/newsletter_1a.pdf)

20 Institute for Algorithmic Medicine (<http://www.medal.org/ans.html> - Q4)

The Medical Algorithms Project produces Excel tables about different domains. The Chapter “Predicting Risk of Coronary Heart Disease and Prevention” gives a list of Excel tables to use:

- the Framingham Heart Study Coronary Heart Disease Risk Prediction Chart ([http://www.medal.org/sheets/ch6/Framingham\\_risk\\_prediction.xls](http://www.medal.org/sheets/ch6/Framingham_risk_prediction.xls)),
- the New 2000 Sheffield Tables for Primary Prevention of Cardiovascular Disease in Adults ([http://www.medal.org/sheets/ch6/risk\\_prediction New Zealand.xls](http://www.medal.org/sheets/ch6/risk_prediction_New_Zealand.xls)),
- the Updated New Zealand Cardiovascular Risk Prediction Charts ([http://www.medal.org/sheets/ch6/risk\\_prediction New Zealand.xls](http://www.medal.org/sheets/ch6/risk_prediction_New_Zealand.xls)) or
- the Joint British Societies Coronary Risk Prediction Charts for Primary Prevention of Coronary Artery Disease ([http://www.medal.org/sheets/ch6/risk\\_prediction joint British.xls](http://www.medal.org/sheets/ch6/risk_prediction_joint_British.xls))

### **Summary and Questions selected for development of questionnaire to cover domain Cardiovascular Diseases**

Most patient questionnaires mentioned above cover the different risk factors for the development of heart diseases. Some combine the different questions into a score list to create awareness with the patient about her/his own risk (search results 5, 6). A few explain more extensively the different risk factors and what can be done about it (search result 5). Another few are more Health Summary Sheets about cardiovascular risk profiles to be used by physicians (search results 2, 7).

For the development of the Patient Information Form questions about the risk factors smoking, familiar anamnesis for heart disease, hypertension, heart disease and overweight are reformulated or combined from the questions mentioned in the search results 5 and 12. Questions about diabetes mellitus are taken from NHANES III (search result 8). (See further under chapter 4 PHE Patient Information Form.)

All questions are transposed into the first person.(see figure 3, p.46)

Reference 20 produced a number of Excel files based on various published Risk Prediction Charts for Cardio Vascular Diseases. The charts may be used to calculate the individual risk for the patient according his or her individual risk factors. The risk score can be copied to the Health Summary Sheet. An

alternative is to limit the prediction to a category risk percentage as is used in several Risk Tables as the one used by the Dutch College of General Practitioners (see reference 14; see also pages 56-57 and figure 8, page 58). This last table indicates simultaneously the risk for Coronary Heart Disease and gives indications for treatment of hypertension and hypercholesterolemia.

## **II Overview Obesity**

### ***Keywords used in searches***

Only searches for articles in Pubmed resulted in relevant results.

Keywords used: obesity/body mass index/reproducibility of results/ health check/ periodical health examination/ identification/ diagnosis/ detection/ identification

### ***Results relevant literature/ websites***

- Scientific literature (without questionnaires) :

1 Spencer EA, Appleby PN, Davey GK, Key TJ. Validity of self-reported height and weight in 4808 EPIC-Oxford participants. *Public Health Nutr* 2002 Aug; 5(4):561-565.

To assess the validity of self-reported height and weight by comparison with measured height and weight in a sample of middle-aged men and women, and to determine the extent of misclassification of body mass index (BMI) arising from differences between self-reported and measured values. Self-reported height and weight data are valid for identifying relationships in epidemiological studies. In analyses where anthropometric factors are the primary variables of interest, measurements in a representative sample of the study population can be used to improve the accuracy of estimates of height, weight and BMI.

2 Deurenberg P, Andreoli A, Borg P, Kukkonen-Harjula K, de Lorenzo A, Marken Lichtenbelt WD, Testolin G, Vigano R, Vollaard N. The validity of predicted body fat percentage from body mass index and from impedance in samples of five European populations. *Eur J Clin Nutr* 2001 Nov; 55(11):973-979.

To test and compare the validity of a body mass index (BMI)-based prediction equation and an impedance-based prediction equation for body fat percentage among various European population groups. The prediction formulas give generally good estimates of BF% on a group level in the five population samples, except for the males from Tampere. More comparative studies should be conducted to get better insight in the generalisation of prediction methods and

formulas. Individual results and classifications have to be interpreted with caution.

3 Ben Noun L, Sohar E, Laor A. Neck circumference as a simple screening measure for identifying overweight and obese patients. *Obes Res* 2001 Aug; 9(8):470-477.

There are numerous methods of assessing overweight and obesity. We undertook an observational study to test a method of identifying overweight or obese patients solely by measuring the circumference of the neck. NC measurement is a simple and time-saving screening measure that can be used to identify overweight and obese patients. Men with NC <37 cm and women with NC <34 cm are not to be considered overweight. Patients with NC > or =37 cm for men and > or =34 cm for women require additional evaluation of overweight or obesity status.

4 Nawaz H, Chan W, Abdulrahman M, Larson D, Katz DL. Self-reported weight and height: implications for obesity research. *Am J Prev Med* 2001 May; 20(4):294-298.

Self-reported weight and height are under- and over-reported, respectively, in epidemiologic studies. This tendency, which may adversely affect study operations, has not been evaluated among subjects being enrolled into a weight-loss program. Obese women who seek weight-loss assistance tend to under-report their weight and over-report their height, suggesting that self-reported data are likely to be inaccurate. Misreporting is apparently influenced by employment and disability and has the potential to complicate recruitment of subjects for research studies.

5 Deurenberg P. Universal cut-off BMI points for obesity are not appropriate. *Br J Nutr* 2001 Feb; 85(2):135-136. (see reference 6)

6 Deurenberg P, Yap M. The assessment of obesity: methods for measuring body fat and global prevalence of obesity. *Baillieres Best Pract Res Clin Endocrinol Metab* 1999 Apr; 13(1):1-11.

Fat is a normal component of the human body that is stored in adipose tissue. Obesity can be defined as a condition of excessive fat accumulation to the extent that health and well-being are affected. Body fat can be determined in vivo in different ways, using rather accurate laboratory techniques or using simple estimation techniques that can also be applied in field conditions. For population studies, the World Health Organization defines cut-off values for obesity based on the body mass index (BMI): weight/height squared (kg/m<sup>2</sup>). Generally, for adults, if the BMI exceeds 25 kg/m<sup>2</sup>, a subject is considered to be overweight, and if the BMI exceeds the value of 30 kg/m<sup>2</sup>, a subject is considered obese. However, the relationship between body fat percentage and BMI differs between ethnic groups, and, as a consequence, cut-off points for overweight and obesity

based on BMI will have to be ethnicity specific. This means that, in some populations, the cut-off points could be lower or higher than the recommended figures. Adapting cut-off point values will have important consequences for prevalence data in some countries as the prevalence of obesity will dramatically increase or decrease. The prevalence of obesity, in children as well as in adults, is high in many countries all over the world and is rising. Given the impact of obesity on health, this is a public health issue that needs to be addressed seriously.

7 Niedhammer I, Bugel I, Bonenfant S, Goldberg M, Leclerc A. Validity of self-reported weight and height in the French GAZEL cohort. *Int J Obes Relat Metab Disord* 2000 Sep; 24(9):1111-1118.

To examine the validity of self-reported weight and height and the resulting body mass index (BMI), and to explore the associations between demographic, socioeconomic, and health-related factors on the one hand and bias in self-reported weight and height on the other, in order to determine the groups most likely to exhibit bias. These findings suggest that self-reported weight and height should be treated with caution, because of biases leading to misclassification for overweight and obesity, especially in certain segments of the population.

8 Flood V, Webb K, Lazarus R, Pang G. Use of self-report to monitor overweight and obesity in populations: some issues for consideration. *Aust N Z J Public Health* 2000 Feb; 24(1):96-99.

To examine the validity of self-reported height and weight data reported over the telephone in the 1997 NSW Health Survey, and to determine its accuracy to monitor overweight and obesity in population surveys. Caution should be used when interpreting SR height and weight data from surveys, because BMI derived from these is likely to underestimate the true prevalence of overweight and obesity. SR data have a place in nutrition monitoring because they are relatively inexpensive and easy to collect. However, classifying people into weight categories on the basis of accepted cut-points, using SR heights and weights, yields inaccurate prevalence estimates. Periodic sub-studies of the validity of SR heights and weights are needed to indicate the extent to which the validity of SR is changing.

9 Bolton-Smith C, Woodward M, Tunstall-Pedoe H, Morrison C. Accuracy of the estimated prevalence of obesity from self reported height and weight in an adult Scottish population. *J Epidemiol Community Health* 2000 Feb; 54(2):143-148.

To determine whether self reported heights and weights from Scottish adults can provide an accurate assessment of obesity prevalence in the population. This Scottish population was unique in the under-reporting of height as well as weight, which resulted in BMI estimates with low error. These data suggest that self

reported weights and heights would be satisfactory for the monitoring of obesity prevalence in Scotland.

10 Voss S, Kroke A, Klipstein-Grobusch K, Boeing H. Obesity as a major determinant of underreporting in a self-administered food frequency questionnaire: results from the EPIC-Potsdam Study. *Z Ernahrungswiss* 1997 Sept; 36(3):229-236.

The phenomenon of underreporting of dietary intake has been observed previously in many epidemiologic studies. In this study it was investigated whether dependencies exist between energy intake obtained by a semi-quantitative, self-administered food frequency questionnaire and lifestyle or anthropometric factors, particularly obesity. It is concluded that obesity is a major determinant of under-reporting. Energy adjusted dietary variables were found to be largely independent of such methodological influences.

11 Rosen JC, Jones A, Ramirez E, Waxman S. Body Shape Questionnaire: studies of validity and reliability. *Int J Eat Disord* 1996 Nov; 20(3):315-319.

The Body Shape Questionnaire (BSQ) is a useful measure of weight and shape concern. The purpose of this study is to contribute new psychometric information on the BSQ in order to assist clinicians and researchers who intend to use this measure. The BSQ demonstrated good test-retest reliability, concurrent validity with other measures of body image, and criterion validity for clinical status.

12 Roberts RJ. Can self-reported data accurately describe the prevalence of overweight? *Public Health* 1995 Jul; 109(4):275-284.

Overweight is an important public health problem affecting around 50% of the population of Wales, resulting in increased risk of illness, premature disability and premature death. The aim of this study was to examine critically the accuracy of self-reported data in describing the prevalence of overweight in Wales. The calculation of body mass index resulted in amplification of bias and underestimation of the prevalence of overweight and obesity in the study sample of 4.5% in men and 6.7% in women. The results have important implications for the use of self-reported data for the scientific measurement of the prevalence of overweight, especially in longitudinal studies, and suggest that further research should be conducted into the stability of reporting bias over time.

- Other literature found on websites:

13 Douketis JD, Feightner JW, Attia J, Feldman WF, with the Canadian Task Force on Preventive Health Care. Periodic health examination, 1999 update: Detection, prevention and treatment of obesity. <http://www.cmaj.ca/cgi/reprint/160/4/513.pdf>

Suggests that a) for people without obesity-related diseases, there is insufficient evidence to recommend the inclusion or exclusion of BMI-measurement as part of a periodic health examination and therefore BMI-measurement is left to the discretion of individual health care providers, b) for people with obesity-related diseases, BMI measurement is recommended because weight reduction should be considered with a BMI of more than 27.

14 National Institutes of Health. National Heart, Lung and Blood Institute:  
[http://www.nhlbi.nih.gov/guidelines/obesity/ob\\_xsum.htm](http://www.nhlbi.nih.gov/guidelines/obesity/ob_xsum.htm)

Summarises the clinical guidelines on the identification, evaluation and treatment of overweight and obesity in adults.

15 National Institutes of Health. National Heart, Lung and Blood Institute  
[http://www.nhlbi.nih.gov/guidelines/obesity/ob\\_home.htm](http://www.nhlbi.nih.gov/guidelines/obesity/ob_home.htm)

Contains a lot of topics regarding obesity.

### ***Summary and Questions selected for development of questionnaire to cover domain obesity***

In general obesity is seen as a risk factor for the development of heart disease, as it is an indicator for hypercholesterolaemia. There are many doubts about the validity of BMI values based on self-reported weight and height. Especially patients at risk seem to show a tendency of underestimation. The self-reported weight and height is included in the Patient Information/Anamnesis Form as a risk factor for heart disease, as it may have some value for the purpose of health education. It seems from the literature that both measurements have to be taken for people with obesity-related diseases.

To register weight and height the questionnaire number 6, mentioned in the CVD section, was used as an example. The Patient Information Form may give a table to indicate patients if their BMI goes over the chosen cut-off point for Austria. Patients start to look at the column with their height and the corresponding weight resulting in the BMI cut-off point. (See Appendix C, reference 6 and further under Chapter 4 and Figure 1, p.46.)

## **III Overview Hearing Impairment**

### ***Keywords used in searches***

Hereafter we present the keywords used during the searches in different databases:

*1 Search for relevant internet sites*  
hearing impairment/ screening/ elderly

2 Search for relevant articles in pubmed  
aged/ hearing test/ screening

3 Search for questions in the HIS/ HES Database  
(no keywords used)

### **Results relevant literature/ websites**

- Questionnaires and questions (see Appendix D)

1 the Hearing Handicap Inventory in the Elderly – Screening Questionnaire found on most of the resulted websites and in articles. (Appendix D, reference 1)

2 National Institute of Aging, USA: Women’s Health and Aging Study  
<http://www.nia.nih.gov/health/pubs/whasbook/chap14/chap14.htm>  
Includes a hearing questionnaire which is used in the Women’s Health and Aging Study. (Appendix D, reference 2)

3 Questions related to hearing impairment in the HIS/ HES Database.  
<https://www.iph.fgov.be/hishes> (Appendix D, reference 3)

- Scientific literature (without questionnaires) :

4 Yueh B, Shapiro N, MacLean CH, Shekelle PG. Screening and management of adult hearing loss in primary care: scientific review. JAMA 2003;289:1976-1985.

Conclusion on screening tests:

Whispered Voice test: No reliable way to control loudness of the whispers and robust description of interobserver variability and test-retest reliability are lacking.

Tuning fork/ Rubbing fingers: intrinsically subject nature of these tests is a serious limitation

HHIE-S Questionnaire: excellent accuracy in detecting hearing loss.

Audioscope: recommended by the Canadian Task Force on Preventive Health Care

The HHIE-S (functional loss) and the audioscope (physiological loss) screen different aspects of hearing loss. It is unclear whether the HHIE-S or the audioscope is likely to be more successful in detecting hearing loss.

5 Eekhof JA, de Bock GH, de Laat JA, Dap R, Schaapveld K, Springer MP. The whispered voice: the best test for screening for hearing impairment in general practice? Br J Gen Pract. 1996 Aug; 46(409):473-4.

In this study the diagnostic value of four simple test for screening for hearing loss in the elderly in general practice was examined. Conclusion: The whispered voice test can be a valuable test to identify people with hearing loss in general practice when paying attention to the loudness of the whispering.

6 Gates GA, Murphy M, Rees TS, Fraher A. Screening for handicapping hearing loss in the elderly. *J Fam Pract.* 2003 Jan; 52(1):56-62.

The HHIE-S questionnaire was compared with 1 global question (“ Do you have a hearing problem now?”) for screening for unrecognized handicapping hearing loss in the elderly. Conclusion: The global measure of hearing loss was more effective than the detailed questionnaire in identifying older individuals with unrecognized handicapping hearing loss.

7 Lichtenstein MJ, Bess FH, Logan SA. Validation of screening tools for identifying hearing-impaired elderly in primary care. *JAMA* 1988; 258:2875-2878.

The audioscope and HHIE-S are valid, reliable, inexpensive tools for detecting hearing impairment in the elderly.

8 Pirozzo S, Papinczak T, Glasziou P, Whispered voice test for screening for hearing impairment in adults and children: systematic review *BMJ* 2003;327:967.  
<http://bmj.bmjournals.com/cgi/content/abridged/327/7421/967>

Concludes that whispered voice test is a simple and accurate test for detecting hearing impairment.

9 Macphee GJ, Crowther JA, McAlpine CH. A simple screening test for hearing impairment in elderly patients. *Age Ageing* 1988;17:347-351.  
<http://ageing.oupjournals.org/cgi/content/abstract/17/5/347>

Concludes that Free-field voice testing appears a simple, reliable and reproducible test for detecting hearing impairment in elderly patients.

10 Eekhof JAH, De Bock GH, Schaapveld K, Springer MP. Screening for hearing and visual loss among elderly with questionnaires and test: which method is the most convincing for action. *Scan J Prim Health Care* 2000;18:203-207.

Hearing loss according to the whispered voice test compared to two questions (problems with hearing conversation with 1 person/ conversation with 3 persons or more). Concludes that when in a screening program with simple instruments for hearing loss the choice has to be made between questionnaire and test, the test will be the best choice.

- Websites (guidelines and reports, no questionnaires):

#### 11 Pharmaceutical Pfizer

[http://www.pfizer.com/download/health/pubs\\_acove\\_new\\_hearing.pdf](http://www.pfizer.com/download/health/pubs_acove_new_hearing.pdf)

Facts about hearing impairment in older adults.

The portable Audioscope appears to be the best objective screening tool for hearing loss among elderly. Hearing loss can also be quickly and easily detected with the HHIE-S questionnaire. This information is an interim result of a funded three-year collaboration between Pfizer and RAND to measure and improve the quality of care provided for older Americans (February 2000).

#### 12 Virtual Naval Hospital: Put Prevention Into Practice: Clinician's Handbook of Preventive Services, 2nd Edition: Adults and Older Adults -- Screening

<http://www.vnh.org/PreventionPractice/ch35.html>

Includes recommendations of major authorities and basics of hearing screening.

#### ***Summary and Questions selected for development of questionnaire to cover domain hearing impairment***

Simple tests in the literature that detect hearing loss:

- audioscope
- self-administered questionnaire, the Hearing Handicap Inventory for the Elderly screening version (HHIE-S): a 10-item 5-minute questionnaire that measures the degree of social and emotional handicap from hearing loss
- global question of hearing loss
- free-field voice testing/ whispered voice test
- rubbing fingers near the ear
- using a tuning fork

One 'scientific' review discusses the reliability of the Whispered Voice Test. That study cannot make any distinction between the test and the audioscope for screening purposes (reference 4). A systematic review on the other hand concludes that the test is simple and accurate in adults and children (reference 8).

Following reference 10, we decided to include one question about hearing impairment, as screening instrument to select patients for the Whispered Voice Test. The question selected comes from the UK National Household Survey 2002 (combination of 2 questions) (reference 3).

## IV Overview vision impairment

### *Keywords used in searches*

Hereafter we present the keywords used during the searches in different databases:

*1 Search for relevant internet sites*

visual impairment/ vision loss/ screening/ questionnaire

*2 Search for relevant articles in pubmed*

Aged/ vision screening/ questionnaires

*3 Search for relevant articles in psychmed*

questionnaires/ vision/ vision disorders/ visual acuity

*4 Search for articles in catalogues library NIVEL*

measure instruments/ vision

*5 Search for questions in HIS/ HES database*

(no keywords)

### *Results relevant literature/ websites*

- Questionnaires and questions (see Appendix E)

*1 National Institute of Aging, USA: Women's Health and Aging Study*

<http://www.nia.nih.gov/health/pubs/whasbook/chap14/chap14.htm>

(Appendix E, reference 1)

Includes a vision questionnaire used in the Women's Health and Aging Study.

*2 Snellingen T, Shrestha BR, Gharti MP, Shrestha JK, Upadhyay MP, Pokhrel RP. Socioeconomic barriers to cataract surgery in Nepal: the south Asian cataract management study Br J Ophthalmol 1998;82:1424-1428 (December).*

<http://bjo.bmjournals.com/cgi/content/full/82/12/1424> (Appendix E, reference 2)

Includes a visual function questionnaire. These questions were asked to non-acceptors of cataract surgery 1 year after an offer to undergo surgery.

*3 Lighthouse International, USA*

[http://www.lighthouse.org/aging\\_vision/summer2002/serious\\_vision\\_impairment.htm](http://www.lighthouse.org/aging_vision/summer2002/serious_vision_impairment.htm) (Appendix E, reference 3)

A self administered questionnaire that identifies functional changes in the individual's sight.

4 Lighthouse International, USA  
[http://www.lighthouse.org/bigtype/functional\\_vision.htm](http://www.lighthouse.org/bigtype/functional_vision.htm)  
(Appendix E, reference 4)

A functional vision screening questionnaire for older people from Lighthouse international.

5 Virtual Naval Hospital <http://www.vnh.org/PreventionPractice/ch45.html>  
(Appendix E, reference 5)

Includes recommendations of major authorities, basics of vision screening and a visual impairment questionnaire. The questionnaire is a standardized, self-administered questionnaire that can help identify individuals needing evaluation of their vision.

6 The Medical Algorithms Project: <http://www.medal.org/ch19.html>  
(Appendix E, reference 6)

Includes the VF-14 questionnaire to measure functional impairment on patients due to cataracts.

7 Questions related to visual impairment in the HIS/ HES Database.  
<https://www.iph.fgov.be/hishes> (Appendix E, reference 7)

- Scientific literature (without questionnaires) :

8 Eekhof JAH, De Bock GH, Schaapveld K, Springer MP. Screening for hearing and visual loss among elderly with questionnaires and test: which method is the most convincing for action. *Scan J Prim Health Care* 2000;18:203-207.

Visual loss according to the Snellen and low vision charts compared to two questions (difficulty recognizing a face/ difficulty reading letters). Concludes that when in a screening program with simple instruments for visual loss the choice has to be made between questionnaire and test, the test will be the best choice.

- Websites (guidelines and reports, no questionnaires):

9 Lighthouse International, USA  
[http://www.lighthouse.org/research\\_screening.htm](http://www.lighthouse.org/research_screening.htm)

Validation of the functional vision screening questionnaire for older people from Lighthouse international. Questionnaire was administered to the patient population of an ophthalmologist whose practice includes low vision. At a cut-off

score of 9 (reporting problems in at least 9 of 15 items), sensitivity was 0.72 and specificity was 0.94.

U.S. Preventive Service Task Force recommends routine vision screening with Snellen acuity testing for elderly persons and suggests that selected questions about vision may also be helpful in detecting vision problems in elderly persons, but they do not appear as sensitive or specific as the direct assessment of acuity.

Canadian Task Force on the Periodic Health Examination recommends screening with Snellen visual acuity chart for elderly persons but cannot determine whether any simple question has a high sensitivity for detecting eye disease.

### ***Summary and Questions selected for development of questionnaire to cover domain vision impairment***

Also for vision impairment, the literature suggests that a test – usually the Snellen acuity testing chart – is needed during a PHE, questions may be helpful for a first selection. The question in the Patient information Form was selected from the Australian or US National Household Survey 2001 (reference 7).

## **V Overview glaucoma**

### ***Keywords used in searches***

Hereafter we present the keywords used during the searches in different databases:

#### *1 Search for relevant internet sites*

glaucoma/ risk assessment/ risk identification/ risk factors/ screening/ questionnaire/ periodical health examination

#### *2 Search for relevant articles in pubmed*

glaucoma/ questionnaires/ risk assessment/ risk factors

#### *3 Search for relevant articles in psychmed*

questionnaire(s)/ glaucoma

#### *4 Search for articles in catalogues library NIVEL*

glaucoma

#### *5 Search for questions in HIS/ HES database*

(no results)

### ***Results relevant literature/ websites***

- Questionnaires and questions (see Appendix F)

#### 1 Prevent Blindness America

[http://www.preventblindness.org/eye\\_tests/glaucoma.html](http://www.preventblindness.org/eye_tests/glaucoma.html)

(Appendix F, reference 1)

A questionnaire to assess if someone is at higher risk for glaucoma.

#### 2 Institute for Algorithmic Medicine, USA: The Medical Algorithms project

<http://www.medal.org/ch19.html> (Appendix F, reference 2)

Includes a glaucoma symptom scale and a risk factor count of glaucoma in a patient with ocular hypertension.

- Websites (guidelines and reports, no questionnaires):

#### 3 Glaucoma foundation

<http://www.glaucomafoundation.org/docs/PatientGuide.pdf>

A patient guide from the glaucoma foundation.

#### 4 U.S. Preventive Services Task Force.

<http://cpmcnet.columbia.edu/texts/gcps/gcps0044.html>

Screening for glaucoma: recommendations from the U.S. Preventive Services Task Force.

### ***Summary and Questions selected for development of questionnaire to cover domain glaucoma***

The US Prevent Blindness America Programme (reference 1) has 9 screening questions to screen risk profiles for the development of glaucoma.

Diabetes, gender, age and probably ethnicity are questions or information that will be included elsewhere in the PIF. We included one additional question from this list of screening questions about familiar risk anamnesis and one question asking about a risk factor – severe myopia -mentioned in the manual for the PHE developed by the commissioner of this project.

## VI Overview use of analgetics, sleeping drugs

### *Searches*

As it was not feasible to limit the literature search to specific scientific literature about this domain focusing on screening questions and questionnaires, we limited the search to the websites.

1 European Health Risk Monitoring project

<http://www.ktl.fi/publications/ehrm/product1/title.htm>

(Appendix G, reference 1)

Gives an overview of questions used in national population risk factor surveys.

2. Health Information and Examination Surveys mentioned in the HIS/HES database (<https://www.iph.fgov.be/hishes>) (Appendix G, reference 2).

3 Face to face interview, Netherlands

<http://www.iph.fgov.be/epidemiologie/epien/crospen/hisen/his97en/his12.pdf>

(Appendix G, reference 3)

Questions about the use of medicines used in health interview survey.

### *Summary and Questions selected for the development of questionnaire to cover domain analgetics and sleeping drugs*

We selected questions mentioned in the Canadian Community Health Survey cycle 2000 mentioned in reference 2.

## VII Overview breast cancer

### *Keywords used in searches*

Hereafter we present the keywords used during the searches in different databases:

1 *Search for relevant internet sites*

cancer/ questionnaire/ family risk/ screening/ periodical health examination/ breast cancer

2 *Search for relevant articles in pubmed*

questionnaires/ mass screening/ screening/ family risk/ family history/ cancer

3 *Search for relevant articles in psychmed*

questionnaire/ cancerscreening

4 Search for articles in catalogues library NIVEL  
measure instruments/ cancer

5 Search for questions in HIS/ HES database  
(no results)

**Results relevant literature/ websites**

- Questionnaires and questions (see Appendix H)

*Questions/ literature related to family history of cancer in general*

1 Scottsdale Healthcare  
<http://www.shc.org/hi/pdf/GeneticRiskAssess703141003.pdf>  
(Appendix H, reference 1)

A questionnaire from the Scottsdale Healthcare to consider genetic counselling.

2 Emory Clinics  
[http://www.emoryhealthcare.org/departments/genetics/patient\\_info/Cancer\\_History\\_Form-.pdf](http://www.emoryhealthcare.org/departments/genetics/patient_info/Cancer_History_Form-.pdf)  
(Appendix H, reference 2)

A cancer genetic screening questionnaire used by Emory Clinics for genetic consultation.

3 The M.D. Anderson Cancer Center Risk Assessment Clinic.  
<http://www3.mdanderson.org/prevention/BROV3.pdf>  
(Appendix H, reference 3)

A questionnaire to assess family history of cancer used by The M.D. Anderson Cancer Center Risk Assessment Clinic.

4 New York State Department of Health.  
<http://www.health.state.ny.us/nysdoh/cancer/obcancer/append11.htm>  
(Appendix H, reference 4)

A cancer family history questionnaire used by New York State Department of Health.

5 Bio Analogics  
<http://www.bioanalogics.com/download/pdf/HRA-Q.pdf>  
(Appendix H, reference 5)

A lifestyle questionnaire from Bio Analogics with non-controllable risk factors, cancer warnings and tobacco-consumption.

6 Pinsky PF, Kramer BS, Reding D, Buys S. Reported family history of cancer in the prostate, lung, colorectal and ovarian cancer screening trial. *Am J Epidemiol* 2003;157:792-799. (Appendix H, reference 6)

Contains questions on the baseline questionnaire of the prostate, lung, colorectal and ovarian cancer screening trial that were related to family history of cancer.

*Questions to assess risk for developing breast cancer*

7 FOX CHASE Cancer Center

[http://www.fccc.edu/clinical/cancer\\_risk.html](http://www.fccc.edu/clinical/cancer_risk.html)

(Appendix H, reference 7)

A questionnaire from the FOX CHASE Cancer Center to assess your cancer risks. Includes questions to identify persons at increased risk of developing breast cancer.

8 Women's Cancer network

<http://www.wcn.org/interior.cfm?diseaseid=13&featureid=3>

(Appendix H, reference 8)

A questionnaire from the Women's Cancer network to assess risk level for developing breast cancer, ovarian cancer, endometrial cancer, cervical cancer, vulvar cancer and vaginal cancer.

9 National Breast Cancer Centre

[http://www.nbcc.org.au/resources/documents/BFT\\_familyhistory.pdf](http://www.nbcc.org.au/resources/documents/BFT_familyhistory.pdf)

(Appendix H, reference 9)

A questionnaire from the National Breast Cancer Centre to assess risk for developing breast cancer.

10 Group Health Cooperative's Center for Health Studies

<http://www.centerforhealthstudies.org/surveillanceproject/data-collection-instruments/bsrr/bsrr-in-clinic.pdf>

(Appendix H, reference 10)

A questionnaire from the Group Health Cooperative's Center for Health Studies to assess risk of getting breast cancer.

11 University of Virginia Cancer Center for breast and ovarian cancer.

<http://www.healthsystem.virginia.edu/internet/cancer/breastquestionnaire.cfm>

(Appendix H, reference 11)

A genetics questionnaire from the UVA Cancer Center for breast and ovarian cancer.

12 Breast Cancer Surveillance Consortium.  
<http://breastscreening.cancer.gov/ptlong5.pdf>  
(Appendix H, reference 12)

A questionnaire given to women when they come for a mammogram at the Breast Cancer Surveillance Consortium.

- Scientific literature (without questionnaires) :

13 Leggatt V, Mackay J, Yates JRW. Evaluation of questionnaire on cancer family history in identifying patients at increased risk in general practice. *BMJ* 1999;319:757-758.  
[http://bmj.bmjournals.com/cgi/content/full/319/7212/757?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=1&author1=leggatt,+V&title=cancer&andorexacttitle=and&andorexacttitleabs=and&andorexactfulltext=and&searchid=1074092269420\\_8525&stored\\_search=&FIRSTIN](http://bmj.bmjournals.com/cgi/content/full/319/7212/757?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=1&author1=leggatt,+V&title=cancer&andorexacttitle=and&andorexacttitleabs=and&andorexactfulltext=and&searchid=1074092269420_8525&stored_search=&FIRSTIN)

- Websites (guidelines and reports, no questionnaires):

However these questionnaires were not included because they measure general health and were thus too general.

14 [http://www.inglewoodhospital.com/BreastCenter/Risk\\_Assesment.html](http://www.inglewoodhospital.com/BreastCenter/Risk_Assesment.html)

Includes a Health Risk Assessment Questionnaire consisting in a Part I-Patient information and a Part II-Family medical history.

15 [http://www.covhealth.org/stellent/groups/public/documents/www/cov\\_014095.hcsp](http://www.covhealth.org/stellent/groups/public/documents/www/cov_014095.hcsp)

A questionnaire for CT screening Center participants

16 <http://www.ama-assn.org/ama/pub/article/2380-2844.html>

Includes a questionnaire to rule out a condition that may have developed later in life, which may or may not have been inherited.

***Summary and Questions selected for development of questionnaire to cover domain***

All sites mention questionnaires and the required questions are present in one or other format in all questionnaires.

Questions from questionnaires 7 – US FOX CHASE Cancer Center - and 9 - National Breast Cancer Centre in the US - were selected and combined for the screening of familiar history of breast cancer.



## 4 PHE Patient Information Form: Overview of Selected Questions

In chapter 3 the results of the literature search for the different tasks were presented and summarized. In this chapter the selected questions from the questionnaires and literature mentioned in the previous chapter will be used to develop a Patient Information Form. The Patient Information Form will guide the physician in evaluating the individual risk for the patient to have or to develop a certain illness. The PIF is intended to give feedback to the patient on several individual risks and give recommendations for prevention.

The present Austrian PHE-programme for adults uses various types of forms: the Anamneseblatt for adults of both gender and one specific form for women concerning gynaecological problems. Results of clinical and blood examinations as well as risk factors for several diseases are recorded on the Befundblatt (see chapter 5), one for both gender and again one specific form for women. The Anamneseblatt gives space for three successive examinations (Figure 1 and 2). The Anamneseblatt will be replaced by a new to be developed Patient Information Form (figure 3), that will combine two functions: the collection of anamnestic and risk profile information and feedback of different risk profiles to the patient.

### Remarks regarding the development of the Patient Information Form

- The form should be designed as practical as possible to be filled in by patients self at an education level of 12 years old so that all adult patients from all education levels and socio-economical levels may use the form without difficulties.
- Questions on emotional or sensitive issues should stay at the end of the questionnaire: e.g. questions about drug use and family history of cancer.
- Start the questionnaire with the least sensitive questions: e.g. hearing and vision questions.
- Client will keep one duplicate of the questionnaire for the purpose of health education and feed-back tot the client. The new to be designed form will provide the patient with information on her/his risk profile for cardiovascular diseases.
- Some questions give the patient the possibility to indicate that she/he does not know the answer to that question. This avoids discussion if the patient might have forgotton to tick the right box when no box is ticked on the PIF. It gives the GP the possibility to prone for information, or to decide to still go for testing or not.
- If the PIF could be developed electronically, it might be connected to the Health Summary Sheet by providing patient risk profiles to urge the physician to the right action to be undertaken based on the patient characteristics and the patient information provided on the PIF.



**Figure 2 - Austrian HSS: Anamneseblatt, adults (rear view)**

BELASTUNG AM ARBEITSPLATZ DURCH:	1. Untersuchung	2. Untersuchung	3. Untersuchung
schwere körperliche Arbeit, Nacht-, Schicht-, Akkordarbeit			
a) Witterung, b) Hitze, c) Zug			
Lärm			
a) Staub, b) Gase, c) Geruch, d) Chemikalien			
dauerndes a) Stehen, b) Gehen			
a) Konzentration, b) Gefahr, c) Verantwortung			

**ANAMNESEBLATT**

Üben Sie einen Nebenberuf aus

**SUBJEKTIVE ERSCHEINUNGEN:**

Sind Sie nervös, ängstlich, überlastet, überfordert

Haben Sie Schlafstörungen

Haben Sie Atemnot bei körperlicher Belastung (Stiegensteigen)

Wachen Sie wegen Atemnot auf

Haben Sie nächtlichen Harndrang

Sind Ihre Beine abends geschwollen

Haben Sie Schmerzen in den Waden, die sich beim Gehen verstärken

Beschwerden in der Herzgegend, Herzjagen, Herzstolpern, Herzschmerzen

Haben Sie Gelenks- oder Muskelschmerzen

Bronchialasthma, ständig wiederkehrender Auswurf

Heiserkeit

Hat sich in der letzten Zeit der Hustencharakter geändert

Schluckbeschwerden

Appetitlosigkeit

Haben Sie in letzter Zeit ungewollt abgenommen

Beschwerden in der Magengegend, nüchtern/nach dem Essen

Widerwillen gegen Speisen, Völlegefühl, Ekel

Besteht eine Verstopfung

Haben Sie häufig Durchfall

Haben sich die Stuhlgewohnheiten geändert

Haben Sie am Stuhl Blut oder Schwarzfärbung (Teerstuhl) bemerkt

Beschwerden beim Urinieren, trüber, übelriechender Harn

Haben Sie im Urin Blut bemerkt

Haben Sie ein Muttermal, das sehr dunkel ist, wächst oder blutet

Bestehen sonstige Hautveränderungen

Bestehen andere Beschwerden, nach denen nicht gefragt wurde

Anmerkungen:

Dieses Blatt kann nach Bedarf als Checkliste verwendet oder probandenbezogen ausgefertigt werden. Die Archivierung bei der Untersuchungsstelle oder die Weitergabe an den behandelnden Arzt oder den Probanden bleibt der Untersuchungsstelle überlassen.

**Questions developed by NIVEL according the Austrian manual for the PHE**

*1. Questions to select for screening Total Cholesterol and HDL-cholesterol for the age-group 20 to 40 years, develop risk profile for CHD or select for screening Blood glucose*

*1.1 Smoking:*

- I smoke:

- Yes (1 POINT)       No

*1.2 Diabetes mellitus:*

- I have been told I have diabetes or sugar diabetes (not including pregnancy)

- Yes (1 POINT)       No       I do not know

- For women: during pregnancy I have been told I have diabetes or sugar diabetes:

- Yes       No       I do not know

- I am now taking

- insulin (injections)       Yes       No
  - oral pills to lower blood sugar       Yes       No
- (also called oral agents or oral hypoglycaemic agents)

- I have a blood relative with diabetes mellitus

- Yes       No       I do not know

*1.3 Familiar anamnesis for heart disease (male family members  $\leq$  50 yrs; female family members  $\leq$  60 yrs):*

- I have/ had a father/brother 50 years or younger or a mother/sister 60 years or younger with heart disease (not including heart valve problems) or who died from it

- Yes       No       I do not know

- I have/ had a blood relative with high blood cholesterol

Yes  No  I do not know

If one of both answers is yes: (1 POINT)

1.4 Hypertension:

- I have hypertension (blood pressure > 140/90 or currently taking medication for hypertension):

Yes (1 POINT)  No  I do not know

1.5 Heart disease:

- I had a heart attack or I have been told that I have coronary heart disease or angina (pectoris):

Yes (1 POINT)  No  I do not know

1.6 Overweight: BMI  $\geq$  30:

- My length = ..... cm      - My weight = ..... kg

See chart according your length: if my weight is minimal the weight mentioned on the chart, my Body Mass Index (BMI) is 30 or higher :

Yes (1 POINT)  No

Please add your points: ..... points.

If you score is 2 or more your cholesterol should be checked.

The higher your score the more risk for a high bloodcholesterol level and the more risk to develop a heart attack within the next ten years .

A score of one or none means you are at low risk of having a heart attack within the next ten years . Here are some tips to help you can maintain you low risk status:

- Eat a healthy well balanced diet, low in fat and cholesterol
- Exercise regularly
- Maintain a health weight

## 2. Questions for Hearing Impairment

- I have difficulties with my hearing (even when using my hearing aid if needed):

Yes                       No

## 3. Questions for Vision Impairment

- I have difficulties with my sight (even when wearing my glasses or contact lenses, if needed):

Yes                       No

## 4. Questions for Glaucoma

- I need strong glasses or contact lenses to be able to correct my vision at a distance

Yes                       No                       I do not know

- I have/ had a blood relative with glaucoma

Yes                       No                       I do not know

## 5. Questions about use of sedatives / analgetics

- In the past 2 weeks I took:

- A pain reliever (such as aspirin, [other used in Austria])     Yes     No
- A tranquilizer (such as Valium, [other used in Austria])     Yes     No
- A sleeping tablet (such as [common used in Austria])     Yes     No

## 6. Questions for screening family history of Mammary carcinoma

- I have/ had a female blood relative who has/had breast cancer:

Yes                       No                       I do not know

- I have/ had at least one first-degree relative (mother, sister or daughter) who has/ had breast cancer:

Yes                       No                       I do not know

7. *Question for screening family history of melanoma*

- I have/ had at least one first-degree relative (parent, brother, sister or child) who has/ had skin cancer (melanoma):

Yes                       No                       I do not know

8. *Question for screening family history of any type of other cancers*

- I have/ had at least one first-degree relative (parent, brother, sister or child) who has/had any type of other cancers (lung, intestines, blood, gynaecological,..):

Yes                       No                       I do not know

If yes, please specify:

First-degree relative (parent, brother, sister or child)	Type of cancer
<hr/>	

9. *General questions about acute and chronic diseases*

- during the last 2 months I had the following acute disease(s) [please cercle the correct answer]: cold, influenza, acute bronchitis, pneumonia, infection of kidneys or urine tract, diarrhoea, vomiting, gastric ulcer or other [specify]:

- I have/had the following chronic disease(s) [please cercle the correct answer]: cerebral attack or bleeding, heart attack or other heart disease, cancer, depression, migraine or regularly severe headache, asthma, chronic bronchitis, emphysema, CARA, chronic eczema, dizziness with falls, severe illnesses of intestines, incontinence, severe backache, attrition of the joints, chronic infection of the joints, chronic illness of the extremities or other chronic disease [please specify]:

Hereafter the above selected questions are put in the format of a designed questionnaire in figure 1, limited to those questions. Patient basic characteristics (name, date of birth or age, gender, and maybe ethnicity) and possible other questions can be added. Other specific designs for paper or electronic PIF can be seen in the various appendices. The most efficient way to work with the PIF would be an electronic link between PIF and HSS, whereby a patient risk profile would be automatically generated based on the patient characteristics and answers from the patient to the questions in the PIF.

**Figure 3- Patient Information Form (limited form) developed by NIVEL**

1. I smoke:  
 Yes (1 POINT)  
 No

2. I have been told I have diabetes or sugar diabetes (not including pregnancy):  
 Yes (1 POINT)  
 No  
 I do not know

3. For women: during pregnancy I have been told I have diabetes or sugar diabetes:  
 Yes  
 No  
 I do not know

4. I am now taking :  

- insulin (injections):  
 Yes  
 No
- oral pills to lower blood sugar:  
(also called oral agents or oral hypoglycaemic agents)  
 Yes  
 No

5. I have a blood relative with diabetes mellitus  
 Yes [*DIABETES RISK I*]  
 No  
 I do not know

6. I have or had a father/brother 50 years or younger or a mother/sister 60 years or younger with heart disease (not including heart valve problems) or who died from it:  
 Yes  
 No  
 I do not know

7. I have or had a blood relative with high blood cholesterol  
 Yes  
 No  
 I do not know

If answer 6 or 7 is yes: (1 POINT)

8. I have hypertension (blood pressure > 140/90 or currently taking medication for hypertension):

- Yes (1 POINT) [*DIABETES RISK 2*]
- No
- I do not know

9. I had a heart attack or I have been told that I have coronary heart disease or angina (pectoris):

- Yes (1 POINT)
- No
- I do not know

10. My length = ..... cm

11. My weight = ..... kg

See chart according your length: if my weight is minimal the weight mentioned on the chart, my Body Mass Index (BMI) is 30 or higher :

- Yes (1 POINT) [*DIABETES RISK 3*]
- No
- I do not know

Please add your points: ..... points.

If you score is 2 or more your cholesterol should be checked.

The higher your score the more risk for a high blood cholesterol level and the more risk to develop a heart attack within the next ten years .

A score of one or none means you are at low risk of having a heart attack within the next ten years . Here are some tips to help you can maintain you low risk status:

- Eat a healthy well balanced diet, low in fat and cholesterol
- Exercise regularly
- Maintain a health weight

Please add your *DIABETES RISKS* (QUESTIONS 5,8,11): ..... risk points.

Your physician will assess your risk to develop diabetes.

12. I have difficulties with my hearing (even when using my hearing aid if needed):

- Yes
- No

13. I have difficulties with my sight (even when wearing my glasses or contact lenses, if needed):
- Yes
  - No
14. I need strong glasses or contact lenses to be able to correct my vision at a distance
- Yes
  - No
  - I do not know
15. I have a blood relative with glaucoma
- Yes
  - No
  - I do not know
16. In the past 2 weeks I took:
- A pain reliever (such as aspirin, [other used in Austria])
    - Yes
    - No
  - A tranquilizer (such as Valium, [other used in Austria])
    - Yes
    - No
  - A sleeping tablet (such as [common used in Austria])
    - Yes
    - No
17. I have a female blood relative who had/has breast cancer:
- Yes
  - No
  - I do not know
18. I have at least one first-degree relative (mother, sister or daughter) who had/has breast cancer:
- Yes
  - No
  - I do not know
19. I have/ had at least one first-degree relative (parent, brother, sister or child) who has/ had skin cancer (melanoma):
- Yes
  - No
  - I do not know

20. I have/ had at least one first-degree relative (parent, brother, sister or child) who has/had any type of other cancer (lung, intestines, blood, gynaecological,...):

If yes, please specify:

First-degree relative (parent, brother, sister or child)	Type of cancer
_____	_____
_____	_____
_____	_____

21. During the last 2 months I had the following acute disease(s) [please encircle the correct answer(s)]:

cold,  
influenza,  
acute bronchitis,  
pneumonia,  
infection of kidneys or urine tract,  
diarrhoea,  
vomiting,  
gastric ulcer or  
other [specify]:  
\_\_\_\_\_

22. I have/had the following chronic disease(s) [please encircle the correct answer(s)]:

cerebral attack or bleeding,  
heart attack or other heart disease,  
cancer,  
depression,  
migraine or regularly severe headache,  
asthma,  
chronic bronchitis,  
emphysema,  
CARA,  
chronic eczema,

dizziness with falls,  
severe illnesses of intestines,  
incontinence,  
severe backache,  
attrition of the joints,  
chronic infection of the joints,  
chronic illness of the extremities or  
other chronic disease [please specify]:

---

## 5 Health Summary Sheets

In chapter 4 the Patient Information Form was developed based on the questions and questionnaires found in the literature and on various websites in different countries. In this chapter recommendations will be given for the development of the Health Summary Sheet by using the information and risk scores given by the PIF.

The present Austrian PHE-programme records results of clinical and blood examinations as well as risk factors for several diseases on the Befundblatt, one for both gender and one specific form for women. The Anamneseblatt gives space for three successive examinations (Figure 1 and 2). The Befundblatt (Figure 4) has three copies, one for the physician, one for the health insurance company and one for the patient.

The new to be set up evidence-based system of PHE wants the forms to be based on evidence-based guidelines following international PHE and screening policies, and to use newly designed forms that would reflect this approach. To set up a more efficient system – to save time and money – and to simultaneously provide health education to the patients, the new forms should be divided in a Patient Information Form (Chapter 4) and a Health Summary Sheet (HSS).

The Health Summary Sheet should be designed based on new evidence-based guidelines for the new PHE programme that will be developed by the other partners in the Austrian project. As mentioned before in Chapter 4, the HSS should also reflect the risk profile of the patient based on the PIF.

The search and request for Health Summary Sheets for Periodic Health Examinations among the various Colleges of General Practitioners and Research Groups of the same practitioners in various countries resulted finally only in two different HSS used by the GP's in Australia (Figure 5 and 6), and in Marburg, Germany (Figure 7).

The Australian HSS, developed during the evidence-based development of the PHE programme in Australia, uses rather open fields to record information on family history, lifestyle risks, screening data, current problems and current policy. There is neither a clear link with the guidelines for the PHE, nor a clear guide for the physician's policy according the risk profile of the patient. According Australian researchers who were interviewed for this project and who contributed to the evidence-based developed Periodic Health Examination programme, it became clear that the development of the Health Summary Sheet itself was only partly evidence-based.

The Marburg HSS seems to try to give partly insight in the risk profile of the patient by dividing certain information in predefined categories for instance for age, blood pressure, total cholesterol. It links personal risk factors with family history, and links (possible) diagnoses with actions to be undertaken.

**Figure 4 - Austrian HSS: Befundblatt, adults**

<b>VORSORGEUNTERSUCHUNG DER ÖSTERREICHISCHEN SOZIALVERSICHERUNG</b> <span style="float: right; font-size: 2em; font-weight: bold;">A</span>																															
PROGRAMM FÜR MÄNNER UND FRAUEN AB DEM VOLLENDETEN 19. LEBENSJAHR																															
Name und Anschrift des Probanden:	männl. <input type="checkbox"/> Versicherungsnummer: <table border="1" style="display: inline-table; border-collapse: collapse; text-align: center;"> <tr><td style="width: 10px;"> </td><td style="width: 10px;"> </td></tr> <tr><td colspan="10" style="font-size: 8px;">Geburtsdatum</td></tr> <tr><td colspan="3" style="font-size: 8px;">Tag</td><td colspan="3" style="font-size: 8px;">Mon.</td><td colspan="4" style="font-size: 8px;">Jahr</td></tr> </table>											Geburtsdatum										Tag			Mon.			Jahr			
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weibl. <input type="checkbox"/>	Zuständige Krankenkasse:																														
Vom Probanden zu bestätigen: 1. In den letzten 12 Monaten vor dieser Untersuchung habe ich keine Vorsorgeuntersuchung der österreichischen Sozialversicherung in Anspruch genommen. 2. Ich war im letzten Quartal <input type="radio"/> nicht in Behandlung <input type="radio"/> in Behandlung wegen ..... ..... (Hauptdiagnose) <span style="float: right;">Datum, Unterschrift des Probanden</span>																															
BEFUNDBLATT																															
Ausfertigung für	PROBAND																														
<b>KLINISCHE UNTERSUCHUNG</b> Gewicht in kg <table border="1" style="display: inline-table; border-collapse: collapse; text-align: center;"> <tr><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td></tr> </table> Größe in cm <table border="1" style="display: inline-table; border-collapse: collapse; text-align: center;"> <tr><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td></tr> </table> Blutdruck syst. <table border="1" style="display: inline-table; border-collapse: collapse; text-align: center;"> <tr><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td></tr> </table> diast. <table border="1" style="display: inline-table; border-collapse: collapse; text-align: center;"> <tr><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td></tr> </table> Puls/min. <table border="1" style="display: inline-table; border-collapse: collapse; text-align: center;"> <tr><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td></tr> </table>																															
Kopf	Mammae																														
Hals	Gefäße (Tastbefunde)																														
Herz, Lunge	A Leber <span style="float: right;">Qf</span>																														
WS/Gelenke	B D O Milz <span style="float: right;">Qf</span>																														
Rektal-digital	M E N Resistenzen																														
Prostata	Sonstige Auffälligkeiten (z. B. tastbare Lymphknoten)																														
<b>HARNUNTERSUCHUNG (Teststreifen)</b>																															
Leukozyten	Glucose																														
Nitrit	Keton																														
pH	Urobilinogen																														
Eiweiß	Bilirubin																														
<b>BLUTUNTERSUCHUNG</b>																															
Cholesterin	<table border="1" style="display: inline-table; border-collapse: collapse; text-align: center;"> <tr><td style="width: 15px;"> </td><td style="width: 15px;"> </td><td style="width: 15px;"> </td></tr> </table> mg/dl																														
Blutsenkung (n. W.)	Harnsäure (muß bei Frauen erst ab dem 50. Lebensjahr durchgeführt werden)																														
Blut im Stuhl (bei Probanden ab dem 40. Lebensjahr mittels 3-fach-Testbrief)	Blutzucker (nüchtern)																														
	Gamma-GT																														
	Triglyceride																														
Erkrankung der Atmungsorgane	Gicht																														
Lebererkrankung	Fettstoffwechselstörungen																														
Verdacht auf:																															
Diagnosen der neuentdeckten Krankheiten:																															
Abschlußgespräch am: ..... über Gesundheitszustand, Risikofaktoren, Lebens- und Ernährungsgewohnheiten usw. <input type="checkbox"/>																															
Weitere Maßnahmen, die sich aus der Vorsorgeuntersuchung ergeben:																															
Begründung für Vorsorgeuntersuchung, wenn erforderlich:																															
Datum, Stampiglie und Unterschrift der Untersuchungsstelle																															

The newly to be developed HSS form for the Austrian PHE may follow the Marburg approach, but still should more reflect the new PHE evidence-based guidelines and risk profiles of the patient. An electronic link between the PIF and the HSS might guide the physician in the screening examinations to be undertaken. For instance, the risk profile score based on the information about risk factors for hypercholesterolemia and cardiovascular diseases on the PIF may directly provide the information needed for the physician to take the decision to check the cholesterol level of the patient or not. Information collected on the PIF about risk factors for diabetes or glaucoma will also guide the screening actions to be undertaken or not. The BMI may be calculated straight away by linking the information about weight and height to the electronic HSS through a spreadsheet or algorithm programme.

Once the data from the laboratory tests is also copied on the HSS, a risk percentage for developing cardiovascular diseases can be calculated using the Medical Algorithms spreadsheet programmes developed by the Institute of Medical Algorithms (see p.22). It has to be decided to follow the risk profile according the British, Sheffield, New Zealand (the algorithms) or Dutch definitions (see figure 8), or to develop a local Austrian risk profile. An automatic link between the electronic HSS and the algorithm will provide immediately the individual risk percentage for the development of a cardiovascular disease within ten years of time or an individual risk profile. Other examples of computerized decision support are presented in the Oxford textbook of Primary Medical Care (Emery 2004) and by Hingorani and Vallance (1999).

An electronic link between PIF ad HSS would smooth and facilitate the process of PHE. For the practical design of a paper or electronic format of the new HSS for the Austrian PHE, based on the newly developed guidelines decisions have to be taken about all information that should be registered on the form. The new form has to be tested and piloted in a representative sample of patients coming for a Periodic Health Examination.

### ***Specific recommendations for the HSS***

*Diabetes risk profile:* copy the risk score 0 to 3 for the development of diabetes mellitus from the PIF to decide if blood glucose should be measured. If so, record level of glucose.

*Blood pressure:* note the results of two or three measurements of systolic and diastolic blood pressure to decide about the presence of hypertension based on cut-off point that will be decided.

*Cardiovascular risk profile:*

- ▶ Copy the risk score for the development of hypercholesterolemia from the PIF: if the score is 2 or more total cholesterol and HDL will be measured.
- ▶ Total cholesterol/ HDL ratio will be calculated.





Figure 7 - Marburg HSS

## Berichtsvordruck Gesundheitsuntersuchung

**Teil b** (Durchschrift für den Arzt)

Beleg-Nr. 91468669

### Krankenkasse

AOK  BKK  IKK   
 Landwirtsch. Krankenkasse  Bundesknappschaft   
 VdAK  AEV

### Alter

unter 35  50-54  70-74   
 35-39  55-59  75-79   
 40-44  60-64  80 u. älter   
 45-49  65-69

### Geschlecht

weiblich  männlich

Es wird gleichzeitig eine Krebsfrüherkennungsuntersuchung durchgeführt? ja

### Anamnese

Es wurde bereits eine Gesundheitsuntersuchung nach den Richtlinien durchgeführt? ja

### Vorbestehende Krankheiten

	in der Eigenanamnese	in der Familienanamnese
Hypertonie	<input type="checkbox"/>	<input type="checkbox"/>
koronare Herzkrankheit	<input type="checkbox"/>	<input type="checkbox"/>
sonst. arter. Verschlusskrankheit	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes mellitus	<input type="checkbox"/>	<input type="checkbox"/>
Hyperlipidämie	<input type="checkbox"/>	<input type="checkbox"/>
Nierenkrankheiten	<input type="checkbox"/>	<input type="checkbox"/>
Lungenerkrankung	<input type="checkbox"/>	<input type="checkbox"/>

### Persönliche Risikofaktoren

Nikotinabusus  Adipositas   
 dauerhafte emotionale Belastungsfaktoren  Alkoholabusus   
 Bewegungsmangel

### Befunde

krankhafte Veränderungen (ohne interkurrente Befunde)

Brustkorb (Inspektion)  Bewegungsapparat   
 Herzauskultation  Haut   
 Lungenauskultation  Sinnesorgane   
 Abdomenpalpation (einschl. Nierenlager)  Nervensystem   
 Fußpulse  Psyche   
 Karotisauskultation

### Blutdruck

bis 140/90 mmHg  bis 180/105 mmHg   
 bis 160/95 mmHg  über 180/105 mmHg

Der relativ höhere Wert (systolisch oder diastolisch) bestimmt die Klassenzugehörigkeit (z.B.: 150/100 mmHg= bis 180/105 mmHg). Bei Werten über 140/90 mmHg ist eine zweite Messung durchzuführen und der Mittelwert aus beiden Messungen für die Klassen-zuordnung zugrunde zu legen.

### Labor

#### Blut

Gesamtcholesterin: bis 200 mg/dl   
 201 bis 220 mg/dl   
 221 bis 250 mg/dl   
 251 bis 300 mg/dl   
 über 300 mg/dl

Bestimmung des HDL/LDL-Cholesterins veranlaßt? ja

Glukosewert auffällig? ja

#### Harn

Eiweiß positiv  Ery/Hb positiv  Leukozyten positiv   
 Glukose positiv  Nitrit positiv

### Neue Diagnose / Verdachtsdiagnose

(ohne interkurrente Erkrankungen)

neu gestellte Diagnose	davon behandlungsbedürftig	Abklärungsdiagnostik bei Verdacht auf bisher unbekannte Erkrankung eingeleitet
Hypertonie	<input type="checkbox"/>	<input type="checkbox"/>
koronare Herzkrankheit	<input type="checkbox"/>	<input type="checkbox"/>
arterielle Verschlusskrankheit	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes mellitus	<input type="checkbox"/>	<input type="checkbox"/>
Hyperlipidämie	<input type="checkbox"/>	<input type="checkbox"/>
Nieren-erkrankung	<input type="checkbox"/>	<input type="checkbox"/>
Lungen-erkrankung	<input type="checkbox"/>	<input type="checkbox"/>
orthopädische Erkrankung	<input type="checkbox"/>	<input type="checkbox"/>
Haut-erkrankung	<input type="checkbox"/>	<input type="checkbox"/>
Erkrankung des Nervensystems	<input type="checkbox"/>	<input type="checkbox"/>
Erkrankung der Psyche	<input type="checkbox"/>	<input type="checkbox"/>
andere Krankheiten	<input type="checkbox"/>	<input type="checkbox"/>

### Folgende Maßnahmen wurden veranlaßt

Ernährungs-umstellg./Diätber.  neu verordnete medikamentöse Therapie   
 Nikotin-entwöhnung  sonstiges   
 Bewegungs-training  keine speziellen Maßnahmen   
 Entspannungs-techniken

Name

Geburtsdatum

- ▶ Cardiovascular risk factors gender, smoking, present diabetes will ticked off according the information on the PIF.
- ▶ Copy the risk percentage for the development of a cardiovascular disease and coronary heart disease from the risk tables for males of women depending of the risk factors diabetes, blood pressure, smoking and the total cholesterol / HDL ratio. Different tables and models are published (see reference 20, page 22). The risk table developed for the Dutch College of General Practitioners differs from other risk tables in the way it combines absolute risk with guidelines for treatment of hypertension and cholesterol. (see figure 8, p 58: Risicotabel NHG-Standaard M17 copied from Huisarts en Wetenschap, 2003; 46:439)

The table presents 4 groups of patients with different colours: green, no treatment of blood pressure or cholesterol; yellow, treatment of blood pressure if other risk factors are present; orange, treat blood pressure; red, treat blood pressure as well as cholesterol, so far as blood pressure is above 140 mm Hg (or above 160 mm Hg for people above 60 years).

The parallel curves are iso-risk curves for the development of cardiovascular diseases. The percentages are the 10 years risk percentages for the development of CVD. The curves bordering the red area's are iso-risk curves indicating the age-dependent 10 years risk for the development of coronary heart disease.

Translation of Dutch terms: mannen = men, vrouwen = women; niet-roker = non-smoker, roker = smoker; SBD = systolic blood pressure.

### *Hearing*

Copy the result of the Whispered Voice Test for patients with difficulties with their hearing.

### *Vision*

- ▶ *Impairment*  
Copy the result of the Snellen acuity chart for patients with their vision.
- ▶ *Glaucoma*  
Copy the risk score for glaucoma and result of further ophtalmological examination when necessary.

### *Use of sedatives*

Tick off use of sedatives and write down reason for it.

### *Cancer risk*

- ▶ *Breast*  
Tick of breast cancer risk. Mention result of further examination when necessary.
- ▶ *Melanoma*  
Tick of melanoma cancer risk. Mention result of further examination when necessary.
- ▶ *Intestines*  
Tick of intestines cancer risk. Mention result of further examination when necessary. Mention result of Haemocult
- ▶ *Other(familiar)*  
Tick of breast cancer risk. Mention result of further examination when necessary.

### *Suspicion of something being wrong*

General physicians have 'experience based knowledge' to construct a picture from all patient's complaints and (clinical) intuition telling them something is wrong (serious illnesses needing therapeutic intervention) or not (non-serious self-limiting illnesses) without knowing yet any specific diagnosis. (Van Leeuwen, 1998; Dinant 2004-1 and 2; Macnaughton 2004) On the HSS room must be given to tick off suspicion or not and to write down what the reasons are for the physician's suspicion.

**Figure 8 - Risk table for the development of Cardio Vascular Disease and Coronary Heart Disease of the Dutch College of General Practitioners 2003**

## Risicotabel

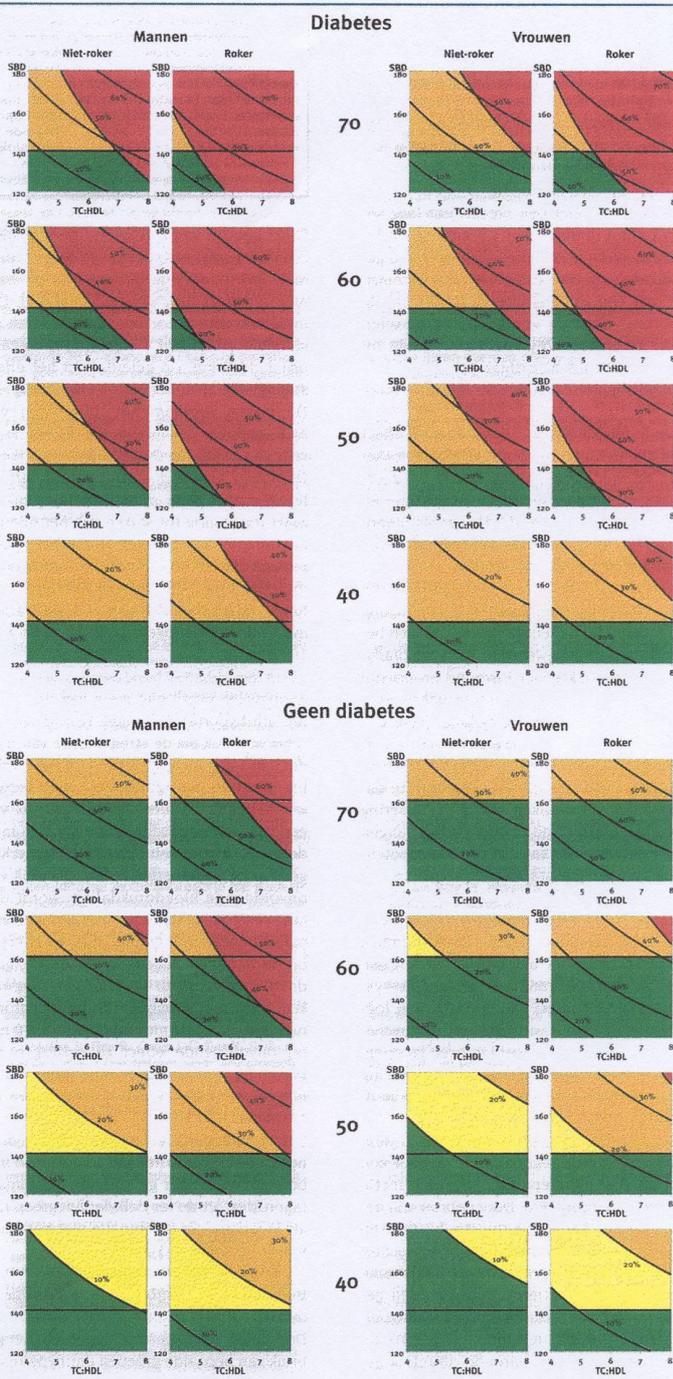
**Indicaties voor bloeddruk- en cholesterolverlagende therapie bij mensen zonder hart- en vaatziekten op basis van een gecombineerd risico-profiel**

Bepaal aan de hand van leeftijd, geslacht, aanwezigheid van diabetes en roken, bloeddruk en totaal cholesterol/HDL-cholesterol-ratio de plaats van de patiënt op de kleurenkaart. Voor patiënten ouder dan 70 jaar moet de tabel worden gebruikt die betrekking heeft op 70-jarigen.

Lees uit de kleur van het gebied af of medicamenteuze behandeling moet worden ingesteld

- behandeling van bloeddruk en cholesterol niet geïndiceerd
- behandel bloeddruk alleen bij bijkomende risicofactoren zoals familiale belasting
- behandel bloeddruk
- behandel zowel de bloeddruk als cholesterol, mits bloeddruk boven behandeldrempel van 140 mmHg (of bij 60-plussers boven 160 mmHg) ligt

\* De parallele krommen zijn iso-risicolijnen op hart- en vaatziekten. De daarbij vermelde percentages geven de tienjaarsrisico's aan. De krommen die de grens vormen van de rode gebieden zijn eveneens iso-risicolijnen. Deze geven het per leeftijdscategorie wisselende tienjaarsrisico op uitsluitend coronaire hartziekten aan.





## 6 Summary and conclusions

We will summarize the results and findings of this technical report in this chapter summarized and present conclusions based on our experience during this research project. But first we want to have a look at a higher level, namely the functionality and usefulness of the Periodic Health Examination in health and health care.

National Preventive Task Forces, Primary Care Research Groups and Colleges of General Practitioners from various countries develop evidence-based guidelines for preventive activities at various levels of the health care system including primary health care and Periodic Health Examinations. However, only little evidence is available about effectiveness and usefulness of Periodic Health Examinations, or satisfaction of patients attending Periodic Health Examinations executed by General Practitioners, public health nurses or by health personnel at the worksite. A quick search on the Pubmed database reveals about 385 publications with the words periodic health examination in title or abstract. But these publications usually do not focus on Periodic Health Examination as their subject of research. They may discuss e.g. the follow-up of specific diseases, specific screening activities within a periodic medical check-up or prenatal care with periodic visits.

Looking for effectiveness and efficiency of PHE's, Burton et al. (2002) also found very few studies by a literature search in Medline. Their own research at a worksite calculated a net return on investment in financial terms from medical claims and short-term disability days absent after three years of follow-up. A major American study – the Multiphasic Health Checkup Evaluation Study – published in 1985 found after a follow-up of 16 years a 30% reduction in deaths from pre-specified “potentially postponable” causes (mostly colorectal cancer and hypertension) in a cohort urged to have yearly medical check-ups. This reduction was more pronounced in the early years, while neither overall mortality nor self-reported disability were different compared to a control group not urged to have annual medical check-ups. (Friedman et al. 1985) Comparable, large prospective studies are to our knowledge not available for other countries and more recent years.

In several countries general practitioners are involved in preventive activities and national prevention programmes, such as influenza vaccination or cervical cancer screening. Apart from screening programmes general practitioners provide preventive services to indicated patients, visiting their practice on whatever occasion. Still, several studies found that the strongest determinant of receiving preventive services in the US and Canada is having a periodic health examination. (Sox et al 1997; Finkelstein 2002).

The Canadian Task Force on the Periodic Health Examination published several scientific papers about the evidence of including various screening tests in the PHE. They provided each topic with recommendations for inclusion, rating from A to C: C was given when insufficient evidence was available, B when inclusion was advocated under certain conditions or for a limited target group, A when there was enough evidence to include the activity into the PHE. In the light of the actual demographic changes and the increasing numbers of older people some emphasize the role of the PHE for older people within a community approach to population health. Including evidence-based activities in the PHE for older people may improve the quality of life and reduce the risk of premature death. (Patterson and Feightner, 1997). But where is the evidence for such an outcome in the long run? And where is the evidence that general practitioners actually follow those evidence based guidelines? There is evidence that physicians still order laboratory tests not recommended by practice guidelines at the PHE. (van Walraven et al. 2000). Moreover, the existence of different guidelines advocated by different national Working Groups and Task Forces do not facilitate a standardized policy in some countries as Canada and the USA. (MacLean et al. 1999; Beck 1999)

Besides the usefulness of the PHE in asking physicians to pay attention to prevention and health promotion, periodic health examinations running for many years may be used in monitoring the health of the general population or specific subgroups. Health policy needs information on trends in the health of the population. This information is currently extracted from different sources, such as national health interview surveys, primary care morbidity registration networks or hospital discharge diagnoses. In some countries periodic health examination surveys are organised in the framework of specific projects, such as the WHO MONICA project, monitoring trends and determinants of cardiovascular diseases. (Gutzwiler 1993) Nationwide PHE's at GP level could be a valuable source of public health monitoring information. A condition is that those attending PHE come from a random selection of the population or that the chance of attending is known, in order to be able to make statistical interference. Of course, standardized and computerized documentation of the findings during a periodic health examination would be a "conditio sine qua non".

Among the few studies looking at patient satisfaction, a study in Finland found that almost all their respondents attending a PHE executed by a public health nurse evaluated the periodic examination as beneficial for everyone. Access to PHE was demanded from the vantage point of individual rights and entitlement, or self-care (women). (Nupponen 1996) Also in Spain patients were satisfied with the PHE executed by the nursing staff. (Buitrago et al. 1991).

Periodic health examination requires instruments (questionnaires, forms, summary sheets) to record patient information about health and about individual risk factors for the development of several diseases. The collection of this information must guide the physician in the further process of the necessary

clinical examinations and screening tests in each individual case. The instruments should reflect the national policy of preventive activities within the framework of a periodic health examination.

But, while PHE programmes may be designed based on scientific evidence and may use developed guidelines and policies as reference, the information about the forms used in these programmes is poor.

Not only are there very few publications about the content of these forms, also evidence on the validity and reliability of specific questions on certain topics, let alone of complete questionnaires, remains scarce. Screening questions and questionnaires are sometimes discussed in scientific papers, but literature remains limited and when available it produces usually not the forms themselves. Information on validity and reliability is only available for a number of generic questionnaires used for research purposes as mentioned in Chapter 3.

We used the approach of a systematic review to collect all possible information on the chosen priority domains in scientific databases and on the internet. Most of the information on questions and questionnaires comes from different sites on the internet. The sites are from National Prevention Task Forces, universities and university hospitals, Colleges of General Physicians and Non-governmental Organisations aiming at disease prevention. All questionnaires found through this approach were screening tools and Patient Information Forms, on paper or electronic. To develop questions on the selected subjects for the Patient Information Form we screened the various forms found through the search, compared the different approaches and phrasings, and used the criteria for the development of questions and questionnaires as mentioned in Chapter 2. This resulted in Chapter 4 in a number of screening questions covering the priority domains as given in figure 3. The questions provide a risk profile for hypercholesterolemia / cardiovascular diseases, diabetes, glaucoma and cancer.

The up-to-date views about this kind of Patient Information Forms are that they should not only be used to collect information from the side of patients, but also to provide patients with information on their risk to develop certain diseases. Risk profiles can be used for this purpose. Calculation of diabetes risk profiles, calculation of BMI, calculation of individual risks for the development of cardiovascular diseases in the next future, all this would be easier once the registration of information would be computerised. The use of a computerized health risk appraisal with a counselling report, developed by the Centers of Disease Control in the USA, during the periodic health examination resulted a significant improvement in physical activity. (Gemson 1995) Computerisation will facilitate the link between the Patient Information Form and the Health Summary Sheet, and probably shorten the time of consultation with the physician.

Health Summary Sheets that can be used by the physicians have not been found in the literature nor through a search on the internet. Although we tried several

times and by several means to contact various Colleges of General Practitioners, the response was very meagre. The North-American Primary Care Research Group was so kind to put our request on their server list. This resulted after 4 weeks in 2 reactions. Our Australian colleagues of Family Medicine departments and research departments resulted finally after almost 2 months in hard copies of the HSS they are using. This low response to our requests for information might (either or both) indicate a lack of interest in these aspects of PHE's or the actual lack of evidence based forms. All these efforts resulted for this limited project in a comparison of the actual sheets used by the Austrian PHE and the Australian forms and the Marburg forms. The comparison and the information found through the search on the internet resulted in recommendations for the development of the new forms, with a strong advocacy for an electronic link between the PIF and the HSS. This link might automatically provide the physician with different risk profiles for different diseases, facilitating the screening and making the whole process more efficient. Some algorithms are already developed and freely available.

The technical report provides a start of a Patient Information Form with questions and risk profiles addressing the priority domains and the task list provided by the commissioner. Recommendations are given for the development of a Health Summary Sheet, the background information needed to calculate risk profiles and about some actions to be taken. The further final development of the questionnaires in paper and/or electronic format for the Austrian Periodic Health Examination will be based on the new evidence-based policies developed in Austria. They still need further development, testing and piloting in the reality of Austrian general practice. Once the new standardised policy will be implemented and the new standardized forms will be used, the Austrian authorities should think of a baseline measurement and an evaluation over time of the whole process of the Periodic Health Examination (data collection, counselling, implementation of preventive activities, implementation of guidelines by the physicians). One should also study the possibilities and usefulness to use the data collection of the Austrian PHE programme for epidemiological purposes, evaluation of preventive activities and development of health policy.

We thank the colleagues of the Royal Australian College of General Practitioners and the North American Primary Care Research Group for their help in our search for information. We thank also colleague dr. Franz Piribauer from the Hauptverband der Österreichischen Sozialversicherungsträger for his guidance through the major Austrian activities and information collected by the various working groups within this project and for his patience with our work. We hope that this technical report will contribute to a standardized, effective and efficient periodic health examination in Austria.

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## Appendix A Original Task list Hauptverband der Österreichischen Sozialversicherungsträger - NIVEL

<b>Item</b>	<b>Task Nivel</b>
<b>Bisherige Intervention Aktivität / ev..</b>	
<b>Neue Aktivität</b>	
Krankheits-symptome abfragen ; Kürzungen andenken.	Yes, reduce to very few
Regelmäßige Einnahme von Sedativa/ Analgetika	Yes, one valid question
Regelmäßige Einnahme sonstige	?? should this be included. ?? doctors' representative (Medical Chamber) wants it
Gesamte Hautoberfläche inspizieren	Yes, risk family question should be in the patient questionnaire, Very few standardised questions (Australian ones? )
(Vor)Erkrankungen / Operationen: Siehe Protokoll.	See above
<b>Sonstige auffällige Befunde aus der allgemeinen med.</b>	denoting special findings ( rest category, free text field)
Familien-Anamnese Diabetes	standard questions (Australia ?)
Familien-Anamnese KHK	Standard questions understandable by lay persons
Familien-Anamnese Krebs	?? specific vs. Generic ?: Australian = Generic ?
PAP - Abstrich	Classification system, propose answers to check by GP/Gyn
Arteriosklerose-Risiko festhalten	Advice to restrict HDL measurement to male target group
Arteriosklerose-Risiko festhalten	Advice to restrict HDL measurement to female target group
BMI errechnen	Advice how to do it ?; nothing to do ?:
Rauchen	One or two valid/ precise questions in patient questionnaires – validated German version necessary
Familien-Anamnese Malignes Melanom	First degree relative with MM (problem ask lay people about melanoma, or skin cancer in general
Kopfuntersuchen/ Augen untersuchen - Ophtalmoskopie	How to ask patients/ how to formulate written question, / how to document high risk
Krankheitssymptome Melanom abfragen	See above skin cancer
Beratung zur körperlichen Bewegung	Something like; counselling on daily

<b>Item</b>	<b>Task Nivel</b>
<b>Bisherige Intervention Aktivität / ev.. Neue Aktivität</b>	
	physical activity performed to achieve personal goal ... ??
Blutzucker messen/festhalten; , bei besonderer Zielgruppe auf Grund von Anamnese / Vorbefunden	Categories to tick off ... ;
Verdachtsmomente ?	Is this usual enclosed, doctors' delegates in Austria wanted it.
Zusammenfassung: Risikofaktoren	Categories to tick off
Arteriosklerose-Risiko festhalten	Class - Categories to tick off
Erhöhung Gemüse Zufuhr; Reduktion/ Ersatz der gesättigten Fette <b>für Personen mit erhöhter nachgewiesener KHK Risikoklasse</b>	How to report on dietary counselling?
Mammographie	Risk categories to tick off? : international classification system exists
Blutzucker messen/festhalten, bei besonderer Zielgruppe auf Grund von Anamnese / Vorbefunden	Categories to tick off ... ;
Arteriosklerose-Risiko festhalten	Class - Categories to tick off
Hämocult	How to report?
Sigmoidoskopie / Kolonoskopie	How to report?; Questionnaire on family risk?: 35% of cancer in group identifiable by history (family + personal)
Blutzucker messen/festhalten	Categories to tick off
Lärmbelastung abfragen/ Flüsterstest Durchführen	How to advice physician on simple test, how to report
Familien-Anamnese Glaucom	How to ask patients/ how to formulate written question, / how to document high risk
Kopf untersuchen/ Prüfung des Sehvermögens	How to ask best;

## **Appendix B. Dutch Questionnaires Work and Health, and Periodic Occupational Health**

## **A) English version of the Work and Health questionnaire (VAG)**

### *Internal organs*

Do you feel breathless or have shortness of breath now and again?

Do you suffer from heart problems now and again?

Do you suffer from stomach problems now and again?

Do you suffer from abdominal pain or cramps now and again?

### *Musculo-skeletal*

Do you have frequent complaints of the arms?

Do you have frequent complaints of the legs or feet?

Do you have frequent complaints of the shoulder or neck /neck pain?

### *Sensory*

Do your eyes often get watery, tired or painful?

Do you often have trouble seeing sharp (with glasses if you are wearing them)?

Do you often have difficulty with hearing?

### *Indefinite health problems*

Do you lately suffer from health problems?

Do you have trouble working because of not feeling well?

Do you feel dizzy now and again?

Do you often have difficulty remember things?

Do you have frequent headaches?

Do you often feel tense?

Do you often feel nervous?

Do you often feel edgy?

Do you often feel hurried?

Do you often feel despondent?

### *(Night's) rest*

When you get out of bed do you often still feel tired?

Do you usually sleep badly?

Do you loose frequent much sleep?

### *Disease behaviour*

Do you regularly take medicines?

During the past 6 months, have you visited a doctor because of medical complaints?

During the past 6 months, did you have to take time of work because of illness or an accident?

Are you now under treatment for:

High blood pressure?

Other cardiovascular diseases?

Lung disease?

Diseases/ disorders in one or more abdominal organs?

Hypersensitiveness (Allergy)?

Back problems?

Other muscle or joint disorders?

Others?

## **B) English version of the Periodic Occupational Health Questionnaire (POBG)**

### *Stress reactions*

- Do you often feel tired?
- Do you sleep badly?
- Do you often feel sleepy or drowsy?
- Do you constantly feel as though you cannot take it anymore?
- Do you suffer from tension?/Are you bothered a lot by nerves?

### *Eyes*

- Do you wear glasses or contact lenses?
- Do you have vision problems (even when wearing glasses or contact lenses)?

### *Eyes, nose and throat*

- Do you suffer from ear problems?
- Is your nose frequent stuffed-up?
- Are you often hoarse?

### *Lung*

- Do you have an persistent cough?
- Do you have shortness of breath now and again?

### *Heart*

- Do you often feel breathless at night?
- Do you experience pain or an oppressed feeling in the chest or heart area several times?
- Do you have to urinate more than usually during the night?
- Do you often have thick feet in the evening?

### *Stomach*

- Do you often have stomach problems?
- Do you often have abdominal pain?
- Do you often have stool problems?
- Do you have a rupture (inguinal hernia, navel rupture or other rupture)?
- Do you suffer from urinate problems?

### *Limbs*

- Do you often experience tightness or pain in your upper limbs?
- Do you often experience tightness or pain in your lower limbs?

### *Back/neck*

- Do you often experience tightness or pain in your neck?
- Do you often experience tightness or pain in your back?

### *Central Nervous system*

- Do you have frequent headaches?
- Do you often feel dizzy?

*Blood vessels*

Do you have varicose veins?

Do you experience pain in your calves while walking?

*Hypersensitiveness*

Do you have an allergy?

*Medical History*

Have you been treated for one of the conditions/ diseases mentioned below during the past 5 years?

-overstrain

-muscle or joint disorders

-long-term back or neck problems

**Appendix C . Questions related to Cardiovascular Diseases and Risk  
Factors**

## Questions related to Cardio Vascular Diseases Risk Factors

### 1. Questions from the self-reported questionnaire that was used in the survey of the Monitoring Project on Cardiovascular Disease risk factor, carried out by the Netherlands.

Source: Klungel OH et al. Cardiovascular diseases and risk factors in a population-based study in The Netherlands: agreement between questionnaire information and medical reports. Netherlands J Med 1999;55:177-183

Condition	Question
Myocardial infarction	Have you ever had a heart attack?
Cerebrovascular disease	Have you ever had a stroke ( brain haemorrhage, attack, half sided paralysis)?
Diabetes - including medication	Do you have diabetes? - Do you use a diet pill, injections or nothing for diabetes?
Myocardial infarction of father	Has your father ever had a heart attack?
Myocardial attack of mother	Has your mother ever had a heart attack?
History of hypertension - First diagnosed by GP	Have you ever had an elevated blood pressure? - Who determined this high blood pressure at that time?
History of hypercholesterolemia - First diagnosed by GP	Has an elevated cholesterol level ever been assessed? - Who determined this?
Invasive cardiac procedure	Have you had heart surgery?

**2. Health summary card used in health checks during the study of Fullard E, et al.**

Source: Fullard E, et al. Promoting prevention in primary care: controlled trial of low technology, low cost approach. BMJ 1987;294: 1080-1082

						Female		
Name <input style="width: 150px;" type="text"/>				D O B <input style="width: 100px;" type="text"/>				
		SMWD				No.		
Own occupation and Partner occupation		<input style="width: 100%; height: 20px;" type="text"/>						
		<input style="width: 100%; height: 20px;" type="text"/>						
							Notes:	
Date	<input style="width: 50px;" type="text"/>	Date	<input style="width: 50px;" type="text"/>	Date	<input style="width: 50px;" type="text"/>			
1 <sup>st</sup> BP	<input style="width: 50px;" type="text"/>	2 <sup>nd</sup> B/P	<input style="width: 50px;" type="text"/>	3 <sup>rd</sup> B/P	<input style="width: 50px;" type="text"/>	mean if applicable <input style="width: 50px;" type="text"/>		
Height	<input style="width: 50px;" type="text"/>	Weight	<input style="width: 50px;" type="text"/>	Ideal weight	<input style="width: 50px;" type="text"/>			
Nutritional advice			<input style="width: 100px;" type="text"/>		Exercise			<input style="width: 150px;" type="text"/>
Smoker		Cigarettes		pipe		Since 19		
Non-smoker		Never		Stopped 19				
Family history Of CVA or MI		<input style="width: 100%; height: 20px;" type="text"/>						
Diabetes		Yes		Insulin		Diet		
		No						
Oral conception years of use		Current		Past		Never		
Last cervical smear		Date		Result				
Rubella		Immune		Yes		No		
		Vaccination		No		No		
Date of tetanus		1 <sup>st</sup>		2 <sup>nd</sup>		3 <sup>rd</sup>		
		Booster						
Urine		Date		Protein		Sugar		
Alcohol		<input style="width: 100%; height: 20px;" type="text"/>						
Notes/ Advice given/ Further action								

---

**Continuation**

Date	B/P	Smokin g		Contr acp.					

SMWD=single, married, windowed, divorced; BP=blood pressure; CVA=cerebrovascular accident;  
MI=myocardial infarction; OHD=oral hypoglycaemic drug therapy.

### 3. NIVEL. Questions from the questionnaire used in the Second Dutch National Survey of General Practice.

Source:

#### *Questions related to chronic diseases*

##### **Gezv23a**

Do you suffer from diabetes?

- 1 Yes
- 2 No

##### **Gezv23b**

Has this been treated or checked by your general practitioner during the past 12 months?

- 1 Yes
- 2 No

##### **Gezv23c**

Has this been treated or checked by a specialist during the past 12 months?

- 1 Yes
- 2 No

##### **Gezv23d**

Do you use insulin for it at the moment?

- 1 Yes
- 2 No

##### **Gezv23e**

Did you start using insulin within 6 months after diabetes had been diagnosed?

- 1 Yes
- 2 No

##### **Gezv\_24a**

Have you ever had a stroke, cerebral haemorrhage or cerebral attack?

- 1 Yes
- 2 No

##### **Gezv\_24b**

Have you had this during the past 12 months?

- 1 Yes
- 2 No

##### **Gezv24c**

Has this been treated or checked by your general practitioner during the past 12 months?

- 1 Yes
- 2 No

**Gezv24d**

Has this been treated or checked by a specialist during the past 12 months?

- 1 Yes
- 2 No

**Gezv\_24e**

Do you still suffer from health problems or limitations because of this affliction?

- 1 Yes
- 2 No

**Gezv25a**

Have you ever had a heart attack?

- 1 Yes
- 2 No

**Gezv25b**

Have you had this during the past 12 months?

- 1 Yes
- 2 No

**Gezv25c**

Has this been treated or checked by your general practitioner during the past 12 months?

- 1 Yes
- 2 No

**Gezv25d**

Has this been treated or checked by a specialist during the past 12 months?

- 1 Yes
- 2 No

**Gezv26a**

Have you had a serious heart condition during the past 12 months ( like heart failures or angina pectoris)

- 1 Yes
- 2 No

**Gezv26b**

Has this been treated or checked by your general practitioner during the past 12 months?

- 1 Yes
- 2 No

**Gezv26c**

Has this been treated or checked by a specialist during the past 12 months?

- 1 Yes
- 2 No

**Gezv30b1**

Do you now or did you have an elevated blood pressure during the past 12 months?

- 1 Yes
- 2 No

**Gezv30b2**

Has this been treated or checked by your general practitioner during the past 12 months?

- 1 Yes
- 2 No

**Gezv30b3**

Has this been treated or checked by a specialist during the past 12 months?

- 1 Yes
- 2 No

**Gezv30c1**

And constriction of the blood vessels in stomach or legs (no varicose veins)?

- 1 Yes
- 2 No

**Gezv30c2**

Has this been treated or checked by your general practitioner during the past 12 months?

- 1 Yes
- 2 No

**Gezv30c3**

Has this been treated or checked by a specialist during the past 12 months?

- 1 Yes
- 2 No

***Questions related to smoking*****LRV1**

Do you smoke now and again?

- 1 Yes
- 2 No

**LRV2**

Do you smoke every day?

- 1 Yes, every day
- 2 Yes, once in a while
- 3 No

**LRV3a**

Do you smoke cigarettes now and again?

- 1 Yes
- 2 No

**LRV3b**

On average, how many cigarettes do you smoke a day or a week?

Unit:

- 1 a day

2 a week

**LRV3c**

Number?

**LRV4a**

Do you smoke cigars now and again?

1 Yes

2 No

**LRV4b**

On average, how many cigars do you smoke a day or a week?

Unit:

1 a day

2 a week

**LRV4c**

Number?

**LRV5a**

Do you smoke pipe now and again?

1 Ja

2 Nee

**LRV5b**

On average, How many packs of tobacco (of 50 gram) do you smoke a week or a month?

1 a week

2 a month

**LRV5c**

Number?

**LRV6**

Have you ever smoked in the past?

**LRV6b**

If you add up all cigarettes you smoked during your entire life, are that then more than 100?

1 Ja

2 Nee

**LRV7**

How old were you when you started to smoke?

I was then ..... years

**LRV8**

How old were you when you stopped smoking?

I was then ... years

**LRV9**

Why did you stopped smoking?

- 1 I got health problems
- 2 I wanted to prevent health problems
- 3 Because of too big dependency
- 4 Because it was too expensive
- 5 Because of my work
- 6 Because I got troubles with others
- 7 Other reason

**LRV10**

Have you been advised to stop smoking or was it on your own initiative?

- 1 own initiative
- 2 Request of partner
- 3 Advised to by family
- 4 Advised to by a doctor
- 5 Request of colleague
- 6 Advised to by others

**LRV11a**

Have you ever stopped smoking since you smoke?

- 1 Ja
- 2 Nee

**LRV11b1**

For how many years, months and weeks did you not smoke then?

How many years?

**LRV11b2**

How many months?

**LRV11b3**

How many weeks?

***Questions related to obesity*****Gezv14**

How tall are you (without shoes) in centimetres?

**Gezv15**

How much do you weight ( without clothes) in kilograms?

INT: pregnant women the weight before pregnant.

**4. Risk factor questionnaire from the National Heart, Lung, and Blood Institute and National Institutes of health. 1995: Recommendations regarding public screening for measuring blood cholesterol.**

Source: <http://www.cpr.net/diseases/endocrine/hypercholesterolemia/>

**RISK FACTOR QUESTIONNAIRE**

1. Have you ever had any of the following conditions?

(Check if yes)

- A. Been told by a doctor that you have coronary heart disease?
- B. Heart attack (myocardial infarction)
- C. Angina pectoris (chest pain due to insufficient blood flow to the heart)
- D. Coronary bypass surgery
- E. Coronary angioplasty (coronary “balloon” procedure)
- F. Abdominal aortic aneurysm
- G. Blockage of arteries to the legs
- H. Transient ischemic attacks (TIAs; transitory strokes)
- I. Blockage of a carotid artery

2. Which of the following pertain to you?

(Check if yes)

- A. Current cigarette smoker
- B. History of high blood pressure (or taking blood pressure medication)
- C. History of diabetes (high blood sugar)
- D. Heart attack in first-degree relative (mother, father, sisters, brothers, children)—if a male relative before age 55 or female relative before age 65
- E. Male 45 years or over
- F. Female 55 years or over

## 5. Woman's risk assessment for heart disease

Source: [http://www.columbiasurgery.org/outreach/aoh\\_woman\\_risk.html](http://www.columbiasurgery.org/outreach/aoh_woman_risk.html)

Printer-friendly Version



**A WOMAN'S RISK ASSESSMENT**  
REDUCE, CONTROL, PREVENT!

*The Affairs of the Heart™ Committee hopes to encourage women to take heart disease seriously. The Committee suggests that you determine your risk for heart disease with the following risk assessment, and then work with your doctor to reduce, control or prevent as many risk factors as possible.*

**DO YOU HAVE A BLOOD RELATIVE WITH HEART DISEASE?**

YES  NO

Your heredity can put you at risk for heart disease. If your mother/sister developed heart disease before age 65, or your father/brother developed heart disease before age 55, your risk for developing heart disease is increased. Please note: African Americans have a greater risk for developing heart disease.

**ARE YOU MENOPAUSAL OR ARE OVER 55 YEARS OF AGE?**

YES  NO

Estrogen protects a woman's heart. If you are menopausal your estrogen levels have dropped and you are at almost the same risk as the average man for developing heart disease. Be aware of your risks, and work with your doctor to determine if hormone replacement therapy is right for you.

**DO YOU SMOKE OR LIVE WITH SOMEONE WHO SMOKES?**

YES  NO

Smoking is a serious risk to your heart, and can also increase your risk for stroke. Smokers face a greater risk of developing heart disease than developing cancer.

**HAVE YOU EVER BEEN TOLD YOU HAVE HIGH BLOOD CHOLESTEROL LEVELS, OR IS YOUR HDL BELOW 45MGM/dl?**

YES  NO

Your risk for heart disease rises as blood cholesterol levels rise. When high cholesterol exists with high blood pressure and smoking, the risk increases even more.

**HAVE YOU EVER BEEN TOLD YOU HAVE HIGH BLOOD PRESSURE HIGHER THAN 140/90 MM HG?**

YES  NO

High blood pressure forces the heart to work harder, causing it to weaken over time. You can help take control of your blood pressure with lifestyle changes and/or medication.

**ARE YOU OVERWEIGHT BY 20 POUNDS OR MORE?  
DO YOU GET LESS THAN 30 MINUTES OF PHYSICAL ACTIVITY  
3 DAYS PER WEEK?**

YES  NO

If you are overweight and physically inactive your heart has to work harder. Excess weight can also increase your risk for high blood pressure.

**HAVE YOU BEEN DIAGNOSED WITH DIABETES?**

YES  NO

Research has shown that diabetes can be more harmful to a woman's heart than a man's. If not controlled or treated diabetes can cause hardening of the arteries and damage the heart.

**Know your medical history and see your doctor regularly. Although not all risk factors can be controlled, your life style choices can help keep your heart healthy longer.**

**If you answered "yes" to 3 or more questions, you may be at risk for heart disease. It is strongly recommended that you review the above heart-health risk assessment with your doctor. If you need an internist or cardiologist please call the Columbia University Medical Center Physician Referrals at 1.800.5.HEART.2 (1.800.543.2782).**

## 6. Questionnaire appraising risk of coronary heart disease

Source: Hutchison B. Screening for hypercholesterolaemia in primary care: randomised controlled trial of postal questionnaire appraising risk of coronary heart disease. *BMJ* 1998;316:1208-1213

<http://bmj.bmjournals.com/cgi/content/full/316/7139/1208>

**HEART CHECK**  
CHOLESTEROL QUESTIONNAIRE

<b>AGE/SEX</b>	Females age 20 - 69 years	Score 1	<b>SCORE</b> <input type="text"/>
	Males age 20 - 34 years	Score 1	
	Males age 35 - 59 years	Score 2	
	Males age 60 - 69 years	Score 1	
<b>SMOKING</b>	If you smoke	Score 1	<input type="text"/>
<b>HIGH BLOOD PRESSURE</b>	If you have high blood pressure even if it is controlled with medication	Score 1	<input type="text"/>
<b>HEART DISEASE</b>	If you have had a heart attack or been told you have coronary heart disease or angina	Score 3	<input type="text"/>
<b>FAMILY HISTORY</b>	If you have a parent, brother or sister who has high cholesterol or had a heart attack or died from coronary heart disease before age 60	Score 1	<input type="text"/>
<b>DIABETES</b>	If you have diabetes	Score 1	<input type="text"/>
<b>WEIGHT</b>	If your weight is too high (see other side of the page)	Score 1	<input type="text"/>
<b>TOTAL SCORE</b>			<input type="text"/>

✓ If your total score is 2 or less you do not need a cholesterol test.

✓ If your score is 3 or more, and you have not already had a cholesterol test, we advise you to have your cholesterol level checked.

✓ If you have any questions or concerns talk to your doctor.

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- ✔ Find your height in the first column below
- ✔ If your weight is the same as or greater than the weight in the second column **Score 1**

Height	Weight
5ft 0in	138lbs
1in	143lbs
2in	147lbs
3in	152lbs
4in	158lbs
5in	162lbs
5ft 6in	168lbs
7in	172lbs
8in	178lbs
9in	182lbs
10in	189lbs
11in	193lbs
6ft 0in	199lbs
1in	204lbs
2in	210lbs
3in	217lbs
4in	222lbs
5in	229lbs
6ft 6in	233lbs
7in	240lbs

\* Based on a Body Mass Index (BMI) of 27  
 BMI = Weight (kilos) / Height (metres)<sup>2</sup>

Sensitivity of questionnaire appraising coronary risk: 87,5%  
 Specificity of questionnaire appraising coronary risk: 91,7%

## 7. Screening pro forma suitable for use in screening examinations

Source: Wood D. Joint British recommendations on prevention of coronary heart disease in clinical practice. Heart 1998;80:1-29

[http://heart.bmjournals.com/cgi/content/full/80/suppl\\_2/S1?ijkey=88431f42e835cbe3feea69477d1a54f901665168&keytype2=tf\\_ipsecsha](http://heart.bmjournals.com/cgi/content/full/80/suppl_2/S1?ijkey=88431f42e835cbe3feea69477d1a54f901665168&keytype2=tf_ipsecsha)

**Table 2** Screening pro forma suitable for use in screening examinations

Name	<i>Telephone number</i>		
Gender	Age		
Personal history	Previous myocardial infarction/angina of effort/peripheral arterial disease/cerebral infarction		
Family history	Angina or heart attack in: mother/sister aged < 65 years father/brother aged < 55 years		
Smoking habit			
Current	Cigarettes	/day	
Past	Cigarettes	/day	
	Length of exposure		Years
	Other tobacco		
Diabetes mellitus	Yes/no		
Age at menopause	Years		
Body weight	kg	Height	cm
Blood pressure	Systolic	mm Hg	
(treated hypertension yes/no)	Diastolic	mm Hg	
Xanthelasmata	Yes/no		
Other xanthomata (eg, tendon)	Yes/no		
Corneal arcus in patient aged < 50 years	Yes/no		
Cholesterol	mmol/l		
HDL cholesterol	mmol/l		
Date of last tetanus booster			
Date of last cervical smear			

---

NB If angina is diagnosed for the first time the screening nurse should refer the patient to the doctor. Referral to a cardiologist for full evaluation may be important because further investigation may be indicated on prognostic grounds even if symptoms are not severe. Of more immediate concern is lifestyle advice, control of blood pressure, blood cholesterol, and diabetes mellitus, and therapy with low dose aspirin.

## 8. Questions used in national population risk factor surveys.

Source: The European Health Risk Monitoring project

<http://www.ktl.fi/publications/ehrm/product1/title.htm>

### Awareness and treatment of high cholesterol

#### Questions

Agreement between data for awareness and treatment of high cholesterol collected by questionnaire and data obtained from medical records is over 75%. The agreement is better for women and for younger age groups. (1)

#### *WHO MONICA Project*

The MONICA Manual (2) has four questions about the awareness and treatment of high cholesterol.

1. "Have you ever been told by a doctor or other health worker that you have high blood cholesterol?"   
1 = yes  
2 = no (if no, record 8 in *Question 2* and *Question 3*)  
9 = insufficient data
2. "Are you on special diet prescribed by a doctor or other health worker to lower your blood cholesterol level?"   
1 = yes  
2 = no  
3 = uncertain  
8 if *Question 1* = 2  
9 = insufficient data
3. "Are you taking (in the last two weeks) pills or other medicine prescribed by a doctor to lower your blood cholesterol level?"   
1 = yes  
2 = no  
3 = uncertain  
8 if *Question 1* = 2  
9 = insufficient data
4. "Have you had your blood cholesterol measured in the last year?"   
1 = yes  
2 = no  
9 = insufficient data

For the *Question 2*, the MONICA Manual (2) gives the additional instructions:

Code 1 if yes

Code 2 if no

Code 3 if the person is following a special diet but he/she is not sure whether the diet is for cholesterol lowering purposes.

Code 8 if the person has never been told by a doctor or other health worker that he/she has high blood cholesterol (*Question 1* = 2).

Code 9 if insufficient information is available to use the other codes.

For the *Question 3* the additional instructions are:

Code 1 if yes

Code 2 if no.

Code 3 if the use of cholesterol lowering drugs is reported but the person in question is not sure whether these have been used during the last two weeks or he/she is not sure whether the drugs used were for lowering cholesterol.

Code 8 if the person has never been told that he/she has high blood cholesterol (*Question 1 = 2*).

Code 9 if insufficient information is available to use the other codes.

### ***Risk factor monitoring in the Netherlands***

In the *Monitoring Project on Cardiovascular Disease Risk Factors* in the Netherlands, the questions on high cholesterol used during the period 1987 to 1991 (3, 4) were:

1. Have you ever been diagnosed with hypercholesterolemia?
1. Yes  
2. No
- If yes:
- 2a. When was the first time (year)?
- 2b. Who made the diagnosis?
1. General practitioner  
2. Specialist  
3. Company doctor  
...
- 2c. Do you have a diet for this at present?
1. Yes  
2. No
- 2d. If yes, what kind of diet?
1. Fat reduced  
2. Cholesterol reduced  
...
- 2e. If yes, who provided the dietary advice?
1. Doctor  
2. Dietician  
3. Own initiative  
...
- 2f. Do you use antihypercholesterolemia medication?
1. Yes  
2. No

In the *MORGEN*-project the following questions were used for awareness and treatment of high cholesterol (4):

1. Have you ever been diagnosed with hypercholesterolemia?
1. Yes  
2. No  
3. Don't know
2. If yes, do you use medication at present?

1. Yes
2. No

In the *REGENBOOG* project the following questions about the awareness and treatment of high cholesterol were included to the questionnaire (5):

1. Is your cholesterol elevated at the moment? 
  1. Yes
  2. No
  3. I don't know
2. Do you use drugs to lower your cholesterol? 
  1. Yes
  2. No
3. Are you on a diet to lower your blood cholesterol? 
  1. Yes
  2. No

### ***Risk factor monitoring in Germany***

The questionnaire for the German *Federal Health Survey 1998* (6) included high cholesterol among a long list of possible answers to the question

Which one of the following diseases did you ever have:

	Yes	No	Don't know
High blood lipids, elevated cholesterol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The informant's response was further clarified in a subsequent physician interview, when information on the use of pharmacological agents was collected. These were then grouped into 34 categories depending on their indication (7). The question asked whether, during the past 12 months, medications of a particular drug category were used :

daily, or several times per week, or 1-2 times per week, or less than once a week, or 1-3 times per month, or seldom, or never.

One of the drug category was "for lowering of blood lipids".

### ***UK National Health Surveys***

Question used in 1998 *Health Survey for England* (8):

1. Have you ever had your blood cholesterol level measured by a doctor or nurse? 
  1. Yes (Go to *Question 2*)
  2. No
2. When was the last time your blood cholesterol level was measured by a doctor or nurse? 
  1. During the last 12 months
  2. At least a year but less than 3 years ago
  3. At least 3 years but less than 5 years ago
  4. Five years ago or more

3. Last time your blood cholesterol was measured, were you told it was
1. Normal (alright/fine)
  2. Higher than normal
  3. Lower than normal
  4. Were you not told anything

***National Health and Nutrition Examination Survey (NHANES III), US***

The following questions about the awareness and treatment of high cholesterol were asked during the home visit from adults (9):

1. Have you ever had your blood cholesterol checked?
1. Yes
  2. No
2. Have you ever been told by a doctor or other health professional that your blood cholesterol level was high?
1. Yes
  2. No
3. Because of your high blood cholesterol, have you ever been told by a doctor or other health professional to
- 1=Yes, 2=No
- a. eat fewer high fat or high cholesterol foods?
  - b. control your weight or lose weight?
  - c. exercise?
  - d. take prescribed medicine?
4. To lower your blood cholesterol, are you now following this advice to
- 1=Yes, 2=No
- a. eat fewer high fat or high cholesterol foods?
  - d. take prescribed medicine?
5. To lower your blood cholesterol, have you made any lasting and major changes on your own? Specifically
- 1=Yes, 2=No
- b. have you controlled your weight or lost weight?
  - c. do you exercise more?

More detailed instruction for above questions are:

*Question 1.* Enter Code 1 (YES) if respondent has ever had his/her blood cholesterol checked by anyone.

For Code 2 (NO) skip questions concerning the SP's efforts to lower his or her blood cholesterol on his/her own (Question 5).

*Question 3.* Enter Code 1 (YES) if the respondent has ever been advised by a doctor or other health professional to follow one or more of the treatments listed. Enter Code 2 (NO) if the respondent has not been advised to follow one or more of the above treatments or if s/he has been advised to do so for any condition other than high cholesterol.

Note that "prescribed medication" may include pills, powders, or liquids, and must be purchased by prescription.

*Question 4.* Mark Code 1 (YES) if the person is currently following the treatment either on a regular or irregular basis.

Question 5. In this question you will only ask about those treatments that were not recommended by a doctor to lower the SP's cholesterol in Question 3. Therefore if a doctor has advised the SP to make all four changes in Question 3, this question will be skipped.

### ***The Italian OEC Project***

The questionnaire section on awareness of high cholesterol preceded the section on diabetes.

1. Has a doctor or other health professional ever told you that you have high cholesterol?   
1. Yes  
2. No (go to section on diabetes)  
3. Insufficient data (go to section on diabetes)
2. Do you eat a special diet, prescribed by a physician or other health professional, to lower cholesterol?   
1. Yes  
2. No  
3. Uncertain
3. During the past two weeks, have you taken medication, prescribed by a physician, to lower cholesterol?   
1. Yes  
2. No (go to section on diabetes)  
3. Uncertain (go to section on diabetes)
4. How many types of medications have you taken?

#### Medication 1

5. Name of medication
6. Do you take it daily? Yes No
7. Number of pills per day   
Number of pills per week

#### Medication 2

8. Name of medication
9. Do you take it daily? Yes No
10. Number of pills per day   
Number of pills per week

#### Medication 3

11. Name of medication
12. Do you take it daily? Yes No
13. Number of pills per day   
Number of pills per week

### ***Risk factor monitoring in Norway***

The questions used in the National Cardiovascular Screening for high cholesterol were (10):

1. Do you use medication for treatment of high cholesterol at present?

1. Yes
2. No

Questionnaire also has other questions about the age when person has started to use these medications, the reason for treatment and the name and dose of the drug.

## **11.2 Quality assurance**

### ***11.2.1 Retrospective quality assessment report***

#### *WHO MONICA Project*

The detailed description about the availability and quality of the data on awareness and treatment of high cholesterol is given in the Quality Assessment of Data on Awareness and Treatment of High Cholesterol in the *WHO MONICA Project* (11).

#### *Awareness of high cholesterol*

In many populations which included the question about the awareness of the high cholesterol the expression "*told by a doctor or other health worker*" was omitted (11). This omission will bias the response to the actual question asked in MONICA.

#### *Dietary treatment of high cholesterol*

There were a few centres where the local question about the dietary treatment of the high cholesterol could bias the response to the actual MONICA question. In these centres, the expression "*prescribed by a doctor or other health worker*" was omitted and some centres did not ask the question if the person was complying with the prescribed diet. (11)

#### *Drug treatment of high cholesterol*

There were a few centres where the local question about the drug treatment of the high cholesterol could bias response to the actual MONICA question. In these centres, the expression "*prescribed by a doctor or other health worker*" was omitted or the question asked in general terms about the treatment for high cholesterol without defining whether it is drug or dietary treatment. There were also discrepancies between MONICA and local questions on the time period when the medication was taken. The MONICA question asked about the use during the "*last two weeks*". The local questionnaires varied in their specification of the period from "*preceding week*" to "*few months*". (11)

#### *Cholesterol measurement within the last year*

The questions on cholesterol measurement within the last year were in most centres as suggested by the MONICA manual. Some had the questions formulated differently but the exact MONICA data could still be extracted from them. (11)

No information is available on retrospective quality assessment of the cholesterol questions for *Risk factor monitoring in the Netherlands, Risk factor monitoring in Germany, UK National Health Surveys, and NHANES III*.

## **11.3 Indicators used for reporting the results**

Indicators where the measured cholesterol level and treatment status for the high cholesterol are combined were discussed in [Chapter 5](#). Here, we will list other indicators used in different studies to describe the awareness and treatment of high cholesterol in populations.

#### *WHO MONICA Project*

In the *WHO MONICA Project* the results about the awareness and treatment of high cholesterol are reported using proportions of persons told about the high cholesterol, and four categories of treatment to lower blood cholesterol (12). These four categories are proportion of the persons aware of their high cholesterol status:

- I. Taking pills or other medication to lower blood cholesterol level.
- II. Having a special diet prescribed by a doctor or other health worker to lower blood cholesterol level.
- III. Taking pills or other medication and having a special diet prescribed by a doctor or other health worker to lower blood cholesterol level.
- IV. No drug or diet treatment.

*Risk factor monitoring in Germany*

The German Federal Health Survey 1998 reported prevalence of medication use by drug categories and ranked them by prevalence for men and women and for the old and new states (7).

No information on treatment indicators are available for *Risk factor monitoring in the Netherlands*, *UK National Health Surveys*, and *NHANES III*.

## 11.4 Discussion and conclusions

Most surveys considered here have asked if a person has ever had his/her blood cholesterol measured or whether it was measured within the past year by a health professional. The exception is the German Federal Health Survey 1998 where a less specific question was used.

---

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## 7. Smoking

Smoking is a strong risk factor for cardiovascular diseases, cancer and several other chronic diseases. This report focuses on tobacco smoking, leaving out smokeless tobacco use.

### 7.1 Definitions

The WHO has published standardized guidelines for measurement of smoking (1). Based on these guidelines, people can be classified as smokers or non-smokers; and these two main categories can be divided into number of sub-categories.

A **smoker** is a person who, at the time of the survey, smokes any tobacco product either daily or occasionally. i.e. smokers can be either daily or occasional smokers. A **daily smoker** is a person, who smokes any tobacco product at least once a day (except that people who smoke every day, but not on days of religious fasting, are still classified as daily smokers). An **occasional smoker** is a person, who smokes, but not every day. Occasional smokers can be reducers, continuing occasional smokers or experimenters. A **reducer** is a person, who used to smoke daily but now does no longer smoke every day. A **continuing occasional smoker** is a person who has never smoked daily, but who has smoked 100 or more cigarettes (or the equivalent amount of tobacco) and now smokes occasionally. An **experimenter** is a person who has smoked fewer than 100 cigarettes (or the equivalent amount of tobacco) and now smokes occasionally.

A **non-smoker** is a person who, at the time of the survey, does not smoke at all. Non-smokers can be ex-smokers, never-smokers or ex-occasional smokers. An **ex-smoker** is a person who was formerly a daily smoker but currently does not smoke at all. A **never-smoker** is a person who either has never smoked at all or has never been a daily smoker and has smoked less than 100 cigarettes (or the equivalent amount of tobacco) in his/her lifetime. An **ex-occasional smoker** is a person who was formerly an occasional, but never a daily smoker and who has smoked 100 or more cigarettes (or the equivalent amount of tobacco) in his/her lifetime.

In addition to smokers and non-smokers we can define ever smokers. An **ever smoker** is a person who has smoked at least 100 cigarettes (or the equivalent amount of tobacco) in his/her lifetime. For **ever smokers** there is a sub-category ever daily smokers. Ever daily smoker can be a currently daily smoker, reducer or ex-smoker.

### 7.2 Questionnaires

In this subsection we review the smoking questionnaires used in the surveys considered in this report. We include in the review also other recent international recommendations for smoking questionnaires.

#### *7.2.1 WHO MONICA Project*

The smoking questionnaire in the *WHO MONICA Project* represents a compromise among different proposals and was derived from the WHO Cardiovascular Survey Methods questionnaire (2). According to the MONICA instructions, it can be self administered if it is sent to the home of the invited persons together with the invitation to

the examination; or it can be administered by a technician or nurse at the screening site. The same procedure, however, should be applied throughout the study in the same centre.

Following is the *WHO MONICA Project* protocol for recording the smoking history (3):

SMOKING QUESTIONNAIRE (March 1992)

1. Do you smoke cigarettes now?   
1 = yes, regularly Go to 2.  
2 = no Go to 5.  
3 = occasionally Go to 3.
2. On average, how many cigarettes do you smoke a day? Go to 8.   
Number:
3. On how many days a week do you smoke cigarettes?   
1 = usually on one day or less  
2 = usually on 2 to 4 days  
3 = almost every day
4. On average, how many cigarettes do you smoke a day?   
Number:
5. Did you ever smoke cigarettes regularly in the past?   
1 = yes Go to 6.  
2 = no Go to 10.
6. When did you stop smoking cigarettes regularly? Year, 19--
7. If in the last 12 months   
1 = less than 1 month ago  
2 = 1-6 months ago  
3 = 6-12 months ago
8. What is the highest average daily number of cigarettes you have ever smoked for as long as a year?   
Number:
9. How old were you when you began to smoke cigarettes regularly?   
Age:
10. Have you ever smoked cigars/cigarillos?   
1 = now smoke regularly Go to 11.  
2 = no Go to 12.  
3 = now smoke occasionally (less than one/day) Go to 11.  
4 = used to, but not now Go to 12.
11. How many do you smoke per week? Number:
12. Have you ever smoked a pipe?   
1 = now smoke regularly Go to 13.  
2 = no Go to 14.  
3 = now smoke occasionally (less than once a day) Go to 13.  
4 = used to, but not now Go to 14.
13. About how many grams of tobacco do you smoke per week?   
Grams:

14. To be completed by occasional and non-smokers only (i.e. when item 1 is coded 2 or 3): |\_|\_|  
For how many hours, on average each day, are you closely subjected to other people's tobacco smoke?

The MONICA Manual (3) gives the following additional instructions for the above questionnaire:

*Question 1.* Do you smoke cigarettes now?

Code 1 if a regular cigarette smoker. Include subjects who smoke hand-rolled cigarettes regularly.

Code 2 if a non-smoker, i.e. if a person does not smoke cigarettes at all (Go to 5)

Code 3 is used when the person smokes cigarettes but usually less than one cigarette per day (Go to 3).

*Question 2.* On average, how many cigarettes do you smoke a day?

Code the average number of cigarettes smoked daily. Include subjects who smoke hand-rolled cigarettes regularly (Go to 8). If the answer to Question 2 is irrelevant, i.e. the answer to Question 1 = 2 or 3, draw a horizontal line through the boxes.

*Question 3.* On how many days a week do you smoke cigarettes?

Code 1 if usually on one day or less a week. Include "holiday smokers" who smoke fairly regularly for a few weeks a year but only one day a week or less for most of the year.

Code 2 if usually on 2-4 days a week.

Code 3 if almost every day.

*Question 4.* On average, how many cigarettes do you smoke a day?

Code the average number of cigarettes smoked per day. In many cases the answer is obtained by dividing the number of cigarettes smoked per week by 7 and rounding to the nearest whole number, i.e. if the subject usually smokes 3 cigarettes at most per week, code 000; if the subject smokes on average from 4 to 10 cigarettes per week, code 001; and if 20 cigarettes at the weekend, code 003.

This should only be answered by those who have answered 3 to Question 1, otherwise skip the question.

Draw a horizontal line through the boxes if this question is skipped.

NOTE: This question is the same as Question 2 but is not asked for the same subject. If either one of the questions has been asked, the answer should be entered for Question 2 in the data transfer format.

*Question 5.* Did you ever smoke cigarettes regularly in the past?

Code 1 if yes.

Code 2 if No (Go to 10).

This should only be completed for Non-smokers, i.e. Question 1 = 2 and for occasional smokers Question 1 = 3.

Draw a horizontal line through the box if this question is skipped.

*Question 6.* When did you stop smoking cigarettes regularly?

Enter the year of smoking cessation (if the subject cannot be sure of the exact year, please give an estimate).

*Question 7.* If in the last 12 months

Code 1 if less than 1 month ago

Code 2 if 1-6 months ago

Code 3 if 6-12 months ago.

This should only be answered for those who replied Yes to Question 5.

Draw a horizontal line through the boxes if this question is skipped.

*Question 8.* What is the highest average daily number of cigarettes you have ever smoked for as long as a year?

Code the number of cigarettes smoked per day. The purpose of this question is to get a round idea of how heavily the subject has smoked in the past.

Draw a horizontal line through the boxes if this question is skipped.

*Question 9.* How old were you when you began to smoke cigarettes regularly?

Code age in years.

Draw a horizontal line through the boxes if this question is skipped.

*Question 10.* Have you ever smoked cigars or cigarillos?

Code 1 if now smoke regularly

Code 2 if No (Go to 12)

Code 3 if now smoke occasionally (less than one/day)

Code 4 if used to, but not now (Go to 12).

*Question 11.* How many do you smoke per week?

Enter the actual number of cigars or cigarillos smoked per week.

Draw a horizontal line through the boxes if this question is skipped.

*Question 12.* Have you every smoked a pipe?

Code 1 if now smoke regularly

Code 2 if No (Go to 14)

Code 3 if now smoke occasionally (less than once a day)

Code 4 if used to, but not now (Go to 14)

*Question 13.* About how many grams of pipe tobacco do you smoke per week?

Enter the number of grams (1 ounce = 30 grams).

Draw a horizontal line through the boxes if this question is skipped.

*Question 14.* For how many hours, on average each day, are you closely subjected to other people's tobacco smoke?

To be completed for occasional and non-smokers only.

"Closely subjected" in this context implies that the subject is aware of seeing and smelling, or inhaling the tobacco smoke.

Try to estimate an average for the number of hours each day over the seven days of the week, as exposure to other people's tobacco smoke may vary throughout the week.

It does not matter that the answer for many subjects will be 00 or 01, as this question aims to determine the proportion of occasional and non-smoking subjects who are exposed to other people's tobacco smoke to a substantial degree.

### 7.2.2 Risk factor monitoring in the Netherlands

In the *Monitoring Project on Cardiovascular Disease Risk Factors* in the Netherlands the following questions were used in the period from 1987 until 1991 (4).

Subjects were classified as current, former and non-smokers.

Current cigarette smoking was estimated from the questions.

Q1: Do you smoke?

Q2: How many cigarettes do you smoke per day?

Former cigarette smoking was estimated from the following question:

Q3: Have you ever smoked cigarette regularly?

Q4: At what age did you start cigarette smoking?

Q5: How many years did you smoke cigarettes?

Q6: How many cigarettes did you smoke on average per day?

Additional questions were about smoking cigar or pipe.

In the *MORGEN*-project following smoking questions were used (5):

Current cigarette smoking was estimated from the questions:

Q1: Do you smoke? (If not, but did in the past -> Q2)

Q2: How many cigarettes do you smoke on average per day?

Former cigarette smoking was estimated from the following questions:

Q1: Do you smoke (if not, but did in the past -> Q4)

Q4: At what age did you start cigarette smoking?

Q5: Did you ever stop smoking for a period, after which you started again?

Q6: How many cigarettes did you smoke on average per day?

Z7: At what age did you stop smoking?

Additional questions were about smoking cigar or pipe and the use of filtered or non-filtered cigarettes.

### 7.2.3 Risk factor monitoring in Germany

The German *Federal Health Survey 1998* used questions that incorporated the ones from the WHO guidelines and in addition addressed the issues of passive smoking and quitting of smoking (6).

1. Have you previously smoked or are you presently smoking?

a) Have never smoked Go to  
(except for a few rare experiments) 6.

b) Smoke at present |\_|\_| Go to  
1. yes, daily 2.  
2. yes, occasionally

c) Smoked previously, but not for at least a year  
Stopped at age: |\_|\_|\_|

d) Stopped in the past twelve months  
How much did you previously smoke?  
cigarettes: |\_|\_|\_|  
cigars, cigarillos: |\_|\_|\_|  
pipes: |\_|\_|\_|

2. How old were you when you started smoking regularly, even in small

quantities?   
Started to smoke at age:

**Only to be answered by smokers**

3. During the past 12 months, have you stopped smoking for a day or longer, because you wanted to quit smoking?   
1. Yes  
2. No
4. How much on average do you smoke per day? Quantity  
Cigarettes   
Cigars, cigarillos   
Pipes

**Only to be answered by former smokers**

5. Which were your most important reasons for quitting smoking: Indicate three:   
Did not want to smell like a smoker   
Pregnancy   
Request of partner, parents, etc.   
Partner/colleague/friend has quit   
Wanted to get rid of addiction   
Spend money more reasonably   
Better role model for children   
Worried about own health   
Improved air quality at home/work site   
Get fit again   
Other reasons, specify

**To be answered by all**

6. During the day or in the evening, do you often stay in room where people smoke
- |                 | Does it bother you?      |                          |                          |                          |
|-----------------|--------------------------|--------------------------|--------------------------|--------------------------|
|                 | no                       | yes                      | no                       | yes                      |
| At work         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| At home         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| At other places | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7. How many persons smoke in your household, you included:

**7.2.4 UK National Health Surveys**

Question used in 1998 *Health Survey for England* (7):

1. Have you ever smoked a cigarette, a cigar or a pipe?   
1. yes  
2. no
2. Do you smoke cigarettes at all nowadays?   
1. yes

2. no
3. About how many cigarettes a day do you usually smoke on weekdays?
4. Do you mainly smoke
1. filter-tipped cigarettes
  2. plain or untipped cigarettes
  3. hand-rolled cigarettes
5. Which brand of cigarettes do you usually smoke?
6. Have you ever smoked cigarettes?
1. yes
  2. no
7. Did you smoke cigarettes regularly, that is at least one cigarette a day, or did you smoke them only occasionally?
1. smoked cigarettes regularly, at least 1 per day
  2. smoked them only occasionally
  3. spontaneous: never really smoked cigarettes, just tried them once or twice
8. About how many cigarettes did you smoke in a day?
9. And for approximately how many years did you smoke cigarettes regularly?
10. How long ago did you stop smoking cigarettes?
- 10a. How many months ago was that?
1. Less than six months ago
  2. Six months, but less than one year
11. Did you use any nicotine products, such as nicotine patches, chewing gum, lozenges or other similar products at all to help you give up?
1. yes
  2. no
12. How old were you when you started to smoke cigarettes regularly?
13. Do you smoke cigars at all nowadays?
1. yes
  2. no
14. Do you smoke cigars regularly, that is at least one cigar a month, or do you smoke them only occasionally?
1. Smoke at least one cigar a month
  2. Smoke them only occasionally
15. Do you smoke a pipe at all nowadays?
1. yes
  2. no
16. Now, in most weeks, how many hours a week are you exposed to other people's tobacco smoke?

Following coding instructions are given:

Question 2. If Question 1 = "Yes" then ask this question.

Question 3. If Question 2 = "Yes" then ask this question. If less than one a day, enter 0. If range given and can't estimate, enter mid point. If respondent smokes roll ups and cannot give number of cigarettes, code 97.

Question 5. If Question 4 = "filter-tipped cigarettes" or "plain" or "untipped cigarettes" then ask this question. Assign 2-digit code from coding card C. If not on list, code as 997.

Question 6. If Question 2 = "No" then ask this question.

Question 7. If Question 6 = "Yes" then ask this question.

Question 8. If Question 7 = "Smoked cigarettes regularly" then ask this question. If less than one a day, enter 0. If range given and can't estimate, enter mid point. If respondent smokes roll ups and cannot give number of cigarettes, code 97.

Question 9. If less than one year, code 0.

Question 10. If Question 7 = "Smoked cigarettes regularly" or "smoked them only occasionally" then ask this question. If less than one year age, code 0. If Question 10 = 0 then ask Question 10a.

Question 11. If Question 10 <> Empty and Question 10 < 2 then ask this question. If respondent has given up more than once, ask about most recent occasion.

Question 12. If Question 2 = "Yes" or Question 7 = "Smoked cigarettes regularly" then ask this question. If never smoked regularly code 97.

Question 14. If Question 13 = "Yes" then ask this question.

Question 15. If Sex = "Male" than ask this question.

Question 16. If Age of respondent is 13 years or over then ask this question.

Additional to these questions there is a group of questions asked only from female. These questions ask about the smoking during the pregnancy. Also from all smokers the brand of the cigarettes they smoked were asked.

### **7.2.5 National Health and Nutrition Examination Survey (NHANES III), USA**

The following smoking questionnaire was used in *NHANES III* during the interview at subject home (8):

1. Have you smoked at least 100 cigarettes during your entire life?   
1. yes  
2. no
2. How old were you when you first started smoking cigarettes fairly regularly?   
\_\_ age
3. Do you smoke cigarettes now?   
1. yes  
2. no
4. About how many cigarettes do you smoke per day?   
\_\_ number
5. For approximately how many years have you smoked this amount?   
\_\_ years
6. Was there ever a period of a year or more when you smoked more than 2   
packs of cigarettes per day?  
1. yes

2. no
7. During the period when you were smoking the most, about how many cigarettes per day did you usually smoke?       
 \_\_\_ number
8. For how many years did you smoke that amount?     
 \_\_\_ years
9. Have you ever quit smoking for a period of one year or longer?   
 1. yes  
 2. no
10. Since you first started smoking: how many years altogether have you stayed off cigarettes?     
 \_\_\_ years
11. About how old were you when you last smoked cigarettes fairly regularly?     
 \_\_\_ age
12. About how many cigarettes per day did you usually smoke at that time?       
 \_\_\_ number
13. Did you quit smoking because you had a health problem that was caused or made worse by smoking?   
 1. yes  
 2. no
14. Have you ever smoked at least 20 cigars in your entire life?   
 1. yes  
 2. no
15. Do you now smoke cigars?   
 1. yes  
 2. no
16. How many cigars do you smoke per day?       
 \_\_\_ number
17. Have you ever smoked at least 20 pipefuls of tobacco in your entire life?   
 1. yes  
 2. no
18. Do you now smoke a pipe?   
 1. yes  
 2. no
19. How many pipefuls of tobacco do you smoke per day?       
 \_\_\_ pipefuls

Following coding instructions were given:

*Question 1.* If No go to question about non-smoked tobacco use (Have you ever used chewing tobacco or snuff?)

*Question 2.* This can be difficult to answer since it depends on the SP's interpretation of 'fairly regularly'. We want to know the SP's age when smoking became routine or became an established habit for them rather than the time when they may have first experimented with cigarettes. Record the respondent's best estimate. Enter code 000 if never smoked regularly.

*Question 3.* By 'now' we mean the current month or so and not necessarily whether the SP has had a cigarette today. Even the use of a very small number of cigarettes at the present time would qualify as a 'Yes' response. Enter code 1 (Yes) for respondents who indicate they have stopped smoking temporarily, for example, due to illness, but expect to begin again.

*Question 4.* We are interested in the current 'usual' habit, the average number smoked on a typical day. Enter a number in the first field and the appropriate code to indicate whether the answer reflects cigarettes or packs. If the SP's answer is 'it varies', probe for a more specific answer. If after probing the answer is still 'varies' enter '666'. This should only be done for those whose habit is so irregular and variable that no 'average' value can accurately reflect the SP's habit.

*Question 5.* Record the total duration of the amount of cigarettes specified in Question 4. We are interested in total years of smoking rather than the length of any one period of smoking.

*Question 7.* An approximate number is acceptable here. Enter a number in the first field and the appropriate code to indicate cigarettes per day/packs per day. Enter code 666 (varies) only after probing and only for those whose habit is so irregular and variable that no 'average' value can accurately reflect the SP's peak habit.

*Question 8.* The phrase 'that amount' refers to the amount smoked in Question 7. See specifications for Question 5.

*Question 9.* By 'one year or longer' we mean at least one year continuously off cigarettes.

*Question 10.* Count all of the time of cigarettes, summing up not only the long intervals of six months or more but the shorter intervals as well.

*Question 11.* We are looking for the point in time when the person generally quit, even if s/he had a couple of cigarettes after that point.

*Question 12.* See Question 4 for general guidelines. We want the person's main pattern prior to quitting. Ignore very brief aberrations in their usual habit due to their efforts to quit.

*Question 13.* The major distinctions important to make are whether the person had a medical problem that caused or was made worse by smoking and inspired him/her to quit, e.g. a cough, an allergy, a heart attack, ect., or whether they were influenced or motivated by other factors. If the SP quit because of an existing health problem, enter code 1 (Yes) but if s/he did not quit because of a health problem, enter code 2 (No).

*Question 15.* By 'now' we mean the current month or so and not necessarily whether the SP has had a cigar today. Even the use of a very small number of cigars at the present time would qualify as a code 1 (yes). Enter code 1 (yes) for respondents who indicate they have stopped smoking temporarily, for example, due to illness, but expect to begin again.

*Question 16.* We want the current 'usual' habit, the average number smoked on a typical day.

*Question 17-19.* See specifications for Questions 14-16.

### **7.2.6 FINBALT**

*FINBALT* (9) is a collaborative study for monitoring health behavior and related factors in Estonia, Finland, Latvia and Lithuania.

FINBALT questions for smoking in their next surveys are:

1. Do you or any family members smoker at home? 
  1. No, nobody smokes
  2. Yes, somebody smokes
2. How many hours a day do you spend at your workplace where somebody smokes?

1. more than 5 hours
  2. between 1 and 5 hours
  3. less than one hour a day
  4. almost never
  5. I do not work outside the home
3. Have you ever smoked in your life?
1. no
  2. yes
4. Have you ever smoked at least 100 cigarettes, cigars or pipefuls in your lifetime?
1. no (end smoking questionnaire)
  2. yes
5. Have you ever smoked daily (=almost every day for at least one year)? If so, how many years altogether?
1. no
  2. yes, I have smoked daily for a total of || years
6. Do you smoke at the present time (cigarettes, cigars, pipe?)
1. yes, daily
  2. occasionally
  3. not at all
7. When did you last smoke? If you smoke currently, please circle alternative 1.
1. yesterday or today
  2. 2 days - 1 month ago
  3. 1 month - half a year ago
  4. half a year to one year ago
  5. 1-5 years ago
  6. 5-10 years ago
  7. more than ten years ago
8. How much do you smoke, or did you smoke before you stopped, on average per day?  
Please give an answer to each item. ||
- manufactured cigarettes \_\_\_\_\_ cigarettes per day ||
- self-rolled cigarettes \_\_\_\_\_ cigarettes per day ||
- pipe \_\_\_\_\_ pipefuls a day ||
- cigars \_\_\_\_\_ cigars a day ||
9. Would you like to stop smoking?
1. no
  2. yes
  3. I am not sure
  4. I do not smoke at present
10. Have you ever tried seriously to stop smoking and been without smoking for at least 24 hours? If so, when was the last time?
1. during the last month
  2. a month to half a year ago
  3. half a year to one year ago
  4. more than one year ago
  5. never

11. Are you concerned about the harmful consequences that smoking can have on your health?
1. very concerned
  2. somewhat concerned
  3. not much concerned
  4. not at all concerned
12. During the last year (12 months) have you been advised to stop smoking by any of the following: 1= yes, 2=no;
- a doctor
  - a dentist
  - other health care personnel
  - a family member
  - others

The above questionnaire has been adopted by CINDI Programme to be used in the CINDI Health Monitor, an interview survey system in the CINDI countries (10).

### **7.2.7 EUROHIS**

For the needs of the WHO strategy of Health for All, the European Office of WHO has a project on international harmonization of methods and instruments for health interview surveys (EUROHIS). The EUROHIS questions for smoking are (11):

1. Do you smoke?
- Yes, daily
  - Yes, occasionally (go to question 3)
  - No (go to question 4)
2. How many cigarettes do you usually smoke on average each day?
- Do not smoke cigarettes
  - Fewer than 20
  - 20 or more (heavy smoker)
3. Compared with two years ago would you say you now have reduced smoking?
- Yes (end)
  - No (end)
4. Have you ever smoked?
- Yes, daily
  - Yes, occasionally
  - No (end)
5. How long ago did you stop smoking?
- Less than two years ago
  - Two years ago or more

It is not known which studies have used this questionnaire or what the experience was.

### **7.2.8 WHO recommendation**

The WHO recommendations were prepared by an international expert group and published in the WHO book 'Guidelines for controlling and monitoring the tobacco epidemic' (1). The recommended questions are:

1. Have you ever smoked? |\_|  
 1 = Yes  
 2 = No  
 If no, stop interview/questionnaire here.
2. Have you ever smoked at least 100 cigarettes or the equivalent amount of tobacco in your lifetime? |\_|  
 1 = Yes  
 2 = No
3. Have you ever smoked daily? |\_|  
 1 = Yes  
 2 = No
4. Do you now smoke |\_|  
 1 = daily  
 2 = occasionally  
 3 = not at all?
5. On average, what number of the following items do/did you smoke per day?  
 Manufactured cigarettes |\_|\_|\_|\_|  
 Hand-rolled cigarettes |\_|\_|\_|\_|  
*Bidis* |\_|\_|\_|\_|  
 Pipefuls of tobacco |\_|\_|\_|\_|  
 Cigars/cheroots/cigarillos |\_|\_|\_|\_|  
 Goza/hookah |\_|\_|\_|\_|
6. How many years have you smoked/did you smoke daily? |\_|\_|\_|\_|  
 (To be asked only of ever-daily smokers.)
7. How long has it been since you last smoked daily? |\_|  
 (To be asked only of ex-daily smokers.)  
 1 = Less than one month  
 2 = One month or longer but less than six months  
 3 = Six months or longer but less than one year  
 4 = One year or longer but less than five years  
 5 = Five years or longer but less than 10 years  
 6 = 10 years or longer

There are following clarifications and instructions are provided for coding and for modifying the above questions, respectively:

*Question 1.* Those who have smoked very few (even one) cigarette(s) in their lifetime should still answer "yes" to this questions.

*Question 2.* Smoking 100 cigarettes is approximately the same as smoking one cigarette per day for three or four months, or occasional smoking for about one year.

*Question 3.* If desired, the qualification "for at least six months" could be added to preserve comparability with previous WHO definitions.

*Question 4.* This refers to current smoking status at the time of the survey.

*Question 5.* This list of items should be adapted to suit local tobacco use patterns. Some of these items may not be used and therefore should be excluded, but others not listed might be common and therefore should be

included. If some items are smoked, but the average is less than one per day, use the number zero. For former daily smokers, the average should refer to the time when they were daily smokers.

*Questions 6. and 7.* The actual daily amount smoked should be recorded. Pre-coded categories such as 1-10 per day, 11-20 per day etc. should be avoided. This question should be asked only of ever daily smokers (i.e. those who answer "yes" to question 3 and/or who answer "daily" to question 4). Enter number of years. If less than one year, code as zero. Do not count time periods when the person was not smoking.

*Question 7.* This question should be asked only of ex-daily smokers (i.e. those who answer "yes" to question 3 and "occasional" or "not at all" to question 4). Enter number of years. If less than one month, code as zero. Do not count time periods when the person was not smoking. Respondents who have stopped smoking as recently as one day prior to the survey should still be classified as ex-smokers (with a duration of less than one month).

It is not known which studies have used this questionnaire or what the experience was.

### 7.2.9 Norwegian Age-40 Programme

The Norwegian *Age-40 Programme* questionnaire had questions in 15 areas of inquiry, starting with health history and ending with womens' health. Questions about smoking appeared in ninth position of this order.

1. How many hours daily are you exposed to indoor smoke? |\_|\_| hrs  
(Enter 0 if not exposed)
2. Do you smoke yourself
 

	Yes	No
Daily cigarettes?	_	_
Daily cigars/cigarillos?	_	_
Daily pipes?	_	_
Never smoked daily?	_	
3. If you have previously been a daily smoker, how many years has it been since you stopped? |\_|\_| years
4. If you have been or are now a daily smoker
 

How many cigarettes did you or do you smoke daily?	_ _ _  Number of cigarettes
How old were you when you started smoking daily?	_ _  Age in years
How many years altogether have you been smoking daily?	_ _ _  Number of years

### 7.2.10 The Italian OEC Project

The questionnaire section on smoking followed sections dealing with demographic, socio-economic, and physical activity and preceded the section on awareness and treatment of hypertension.

1. Do you now smoke cigarettes? |\_|
  1. Yes, daily (complete section A)
  2. No (complete section B)
  3. Occasionally (less than one cigarette per day, complete section C)
  4. Insufficient data

**Section A: For regular smokers**

2. How many cigarettes on average do you smoke each day?
3. Do you inhale the smoke? Yes No
4. Do you smoke filter cigarettes? Yes No
5. What brand of cigarettes do you usually smoke?
6. How much of the tobacco section of your cigarette remains when you throw it a way?
1. 0.5 cm  
2. 1 cm  
3. 2 cm  
4. 3 cm
7. What is the maximal number of cigarettes you smoked daily for at least a year?
8. At what age did you start smoking regularly?
9. For how long has it been at the current level?   years
10. Do you want to quit smoking? Yes No
11. Have you ever tried to quit smoking? Yes No  
If yes, for how long a period maximally have you not been smoking?   years   months
12. How many years in total have you abstained from smoking before you started again? Sum all periods   years
- Go to section D

**Section B: Presently non smoker**

13. Have you regularly smoked cigarettes in the past?
1. Yes (complete this section)  
2. No (go to section D)
14. What is the maximal number of cigarettes you smoked daily for at least a year?
15. At what age did you start smoking regularly?
16. In what year did you quit smoking regularly? 19
17. If in 1998 specify:
1. less than 1 month ago  
2. 1-6 months  
3. 6-12 months  
4. > 1 year
18. Before you quit smoking regularly, did you periodically abstain from smoking? Yes No
19. For how many years in total did you abstain from smoking? Sum partial periods   years
- Go to section D

**Section C: For occasional smokers**

20. For how many days per week do you smoke cigarettes? If less than 1 day per week, code 1
21. On days when you smoke, how many cigarettes do you smoke on average?
22. Have you smoked cigarettes regularly in the past?   
1. Yes (complete rest of this section=  
2. No (go to section C2)
23. What is the maximal number of cigarettes you smoked daily for at least a year?
24. At what age did you start smoking regularly?
25. In what year did you quit smoking regularly? 19
26. If in 1998 specify:   
1. less than 1 month ago  
2. 1-6 months  
3. 6-12 months  
4. > 1 year
27. Before you quit smoking regularly, did you abstain from smoking for some periods? Yes No
28. For how many years in total did you abstain from smoking? Sum partial periods.  years  
Go to section D

**Section C1: For occasional smokers with more than 28 cigarettes per week**

29. Do you inhale the smoke? Yes No
30. Do you smoke filter cigarettes? Yes No
31. What brand of cigarettes do you usually smoke?
32. How much of the tobacco section of your cigarette remains when you throw it a way?   
1. 0.5 cm  
2. 1 cm  
3. 2 cm  
4. 3 cm
33. What is the maximal number of cigarettes you smoked daily for at least a year?
34. At what age did you start smoking regularly?
35. For how long has it been at the current level?  years
36. Do you want to quit smoking? Yes No
37. Had you quit smoking in the past? Yes No  
If yes, for how long a period maximally have you not been smoking?  years  months
38. How many years in total have you abstained from  years

smoking before you started again? Sum all periods

Go to section D

**Section C2: For those who always smoked occasionally**

39. Do you inhale the smoke? Yes No
40. Do you smoke filter cigarettes? Yes No
41. What brand of cigarettes do you usually smoke? \_\_\_\_\_
42. How much of the tobacco section of your cigarette remains when you throw it a way?
- 1. 0.5 cm
  - 2. 1 cm
  - 3. 2 cm
  - 4. 3 cm
43. At what age did you start smoking regularly? \_\_\_\_|\_\_\_\_
44. How many years in total have you abstained from smoking before you started again? Sum all periods \_\_\_\_|\_\_\_\_| years

Go to section D

**Section D: For cigar or cigarillo smokers**

45. Have you smoked cigars or cigarillos?
- 1. Yes, regularly at the moment
  - 2. No, never (go to section E)
  - 3. Occasionally, less than one per day
  - 4. Yes, only in the past (go to section E)
  - 5. Insufficient data (go to section E)

**Section E: For pipe smokers**

46. Have you smoked pipe?
- 1. Yes, regularly at the moment
  - 2. No, never (go to section F)
  - 3. Occasionally, less than one pipe per day
  - 4. Yes, only in the past (go to section F)
  - 5. Insufficient data (go to section F)
47. How many grams of tobacco do you smoke per week? \_\_\_\_|\_\_\_\_|\_\_\_\_|  
One pouch contains 50 g of tobacco

**Section F: Passive smoking**

**This section should only be completed for present non-smoker or occasional smokers**

48. For how many hours per day are you on average exposed to second hand smoke in closed space? \_\_\_\_|\_\_\_\_| hrs exposed to passive smoking  
(99 for insufficient data)

**7.3 Biochemical markers for exposure to tobacco smoke**

Biochemical markers like thiocyanate, cotinine and expired air carbon monoxide can be used to validate smoking data collected by questionnaires. Markers can also be used to indicate smoking status or exposure to environmental tobacco smoke.

When assessing the reported smoking status by biochemical markers one has to consider the time between filling in questionnaire and sample collection for biochemical validation. If a person fills in the questionnaire at home a few weeks before coming to the clinical examination where a blood/saliva/urine sample is collected he/she may have stopped or started smoking during that time. Also, the exposure to environmental tobacco smoke has to be assessed and taken into account when analysing the results.

Biochemical markers alone can be used as indicators for smoking status.

Exposure to the environmental tobacco smoke may depend on several factors, including the number of smokers in an enclosed area, the size and nature of the area, and the degree of ventilation. The development of new biochemical methods enables one to obtain measurements of exposure to environmental tobacco smoke by determining the uptake of specific agents in body fluids and calculating the risk relative to that of the exposure of active smokers. The uptake of individual agents from environmental tobacco smoke can be determined by biochemical measures that have been developed for assessment of active smoking behavior, as long as these measures are sensitive and specific enough for quantifying exposure to such agents by nonsmokers.

In this chapter we will briefly describe three biochemical markers: thiocyanate, cotinine and expired air carbon monoxide. Also, the use of biochemical markers in different studies will be discussed.

### ***7.3.1 Types of biochemical markers***

Thiocyanate is the chief metabolite of hydrogen cyanide, which occurs in tobacco smoke, and can be used as a marker for smoking status. Thiocyanate can be measured in blood, saliva or urine (12). The major problem with thiocyanate is that it is not specific to tobacco smoking. Its advantage is longer half life than in cotinine or carbon monoxide.

The most commonly used cutoff point for blood serum/plasma thiocyanate level for current smoking is 100  $\mu\text{mol/l}$ . Depending on the study, this cutoff point yields specificity of 75%-100% and sensitivity of 76%-99%. In these studies the error rate varies from 9% up to 36%. In most studies the error rate was below 30%. (13, 14)

Cotinine is the principal metabolite of nicotine and has a half-life of about 17 hours (15). It can be measured either in saliva (16), blood (17), urine (18) or hair (19). Cotinine is very specific and sensitive, but expensive to measure (20). However, in many countries the use of nicotine replacement therapy may cause problems, because it also increases cotinine.

There is no commonly agreed cutoff point for cotinine level in current smokers. In published studies the cutoff points range from 3ng/ml up to 50 ng/ml. The sensitivity of the cotinine ranges between 87%-99% and the specificity between 79%-100%. In these studies the error rate varies from 7% up to 22%. In most studies the error rate was below 20%. (12, 13, 15, 21)

Exhaled carbon monoxide (CO) measurement is cheap and gives an instant readout, but CO has a comparatively short half-life, shows diurnal variation in smokers and is confounded to some extent by environmental or occupational exposure (12).

A commonly used cutoff point for expired air CO for current smokers is 9 ppm. The sensitivity varied between 88%-100% and specificity from 84% up to 99%. The error rate in these studies was between 3%-23%. In most studies the error rate was below 20%. (12, 13)

#### *WHO MONICA Project*

In the WHO MONICA Project it was recommended that smoking questionnaire data should be validated using expired air carbon monoxide, serum cotinine or serum thiocyanate for all (100%) subjects. If the centre is not able to do validation for all subject it should do it for at least 10% of subject, irrespective of their smoking history (3). In the initial MONICA survey, thiocyanate was measured by most centres (22). However, after it was found that there was a very large variation in the distribution of thiocyanate between the non-smoking populations, the usefulness of thiocyanate was questioned (unpublished result). As a consequence, only few centres measured thiocyanate in the final survey. Serum cotinine and expired air carbon monoxide were recommended for the middle and final survey, but they were measured in very few centres only (22).

MONICA did not use biochemical markers to assess the exposure to environmental tobacco smoke.

#### *UK National Health Survey*

In the *UK National Health Survey* saliva cotinine was used to assess the smoking status (7).

Cigarette smoking prevalence is measured in two ways in the *Health Survey for England*. Informants are asked directly whether they smoke cigarettes nowadays, and cotinine levels in saliva are measured for those providing a saliva sample at the nurse interview. A saliva cotinine level of  $\geq 15$  ng/ml is taken as an indication that the informant currently smokes (those who use other nicotine products are excluded). (7)

In women the cotinine based estimates of prevalence of smoking were the same as prevalence based on questionnaire, but in men cotinine estimates were 4% higher than questionnaire based estimates. This difference can be explained by cigar and pipe smoking. (7) The UK Health Survey smoking questionnaire does not ask about the current cigar or pipe smoking (see [section 7.2.4](#)).

### *NHANES III*

In *NHANES III* a biochemical determination of tobacco exposure was used to assess both passive smoking and tobacco use through measurement of blood cotinine levels from specimens obtained by venipuncture in the Mobile Examination Centre from examinees aged 4 years and over. Cotinine was detected using an isotope dilution, liquid chromatography, tandem mass spectrometry method developed by the National Center for Environmental Health, CDC, which conducted the analyses. This was a newly developed method designed to detect levels as low as 0.030 nanograms per milliliter.

### *Other surveys*

No information about biochemical markers for exposure to tobacco smoke were found for *Risk factor monitoring in the Netherlands* and *Risk factor monitoring in Germany*.

## **7.4 Quality assurance**

### ***7.4.1 Retrospective quality assessment report***

#### *WHO MONICA Project*

The detailed description about the availability and quality of smoking questions in MONICA is given in the Quality Assessment of Data on Smoking Behavior in the WHO MONICA Project (22).

In the final survey, 33% of the centres included in their questionnaires at least 10 out of 13 questions identical to the MONICA format. Although many centres had changed their questions for the final survey according to the MONICA model, there were still deviations between MONICA question and questions used locally. Most common deviations were:

- CIGS and EVERCIG inquire not only about cigarette smoking but also include pipe and cigar smoking in the same questions.
- CIGS and EVERCIG allow only yes/no options, so that regular and occasional smokers cannot be separated.
- EVERCIG precedes CIGS, changing the whole structure of the questionnaire.
- NUMCIGS excluded occasional smokers.
- NUMCIGS was also asked of past smokers.
- STOP inquired how many years ago the subject stopped smoking.
- STOP and IFLYEAR were combined asking the month besides the year of quitting.
- MAXCIGS excluded current smokers.
- CIGARSM, CIGAR, PIPESM and PIPE were combined, permitting only partial extraction of CIGARSM and PIPESM and preventing distinction between current and past cigar/pipe smokers.
- DAYCIGS asked the number of smoking days per week.

## 7.5 Indicators used for reporting the results

The WHO recommends several prevalence figures that can be used when reporting the smoking results (1). **Prevalence of smokers** is the percentage of smokers among "smokers + non-smokers". **Prevalence of daily smokers** is percentage of daily smokers among "daily smokers + plus occasional smokers + non-smokers". **Prevalence of ex-smokers** is percentage of ex-smokers among "ever smokers + never-smokers". **Prevalence of cessation**, also known as quit rate, is percentage of ex-smokers among "ever daily smokers".

### *WHO MONICA Project*

In the *WHO MONICA Project* the most commonly used indicators for smoking are prevalence of daily cigarette smoking, and prevalence of ex-smokers. The daily cigarette smoker is a person who reported smoking cigarettes regularly at the time of the survey. The ex-smoker is a person who reported having smoked cigarettes regularly in the past but was not a current smoker at the time of the survey. (23, 24)

### *Risk factor monitoring in the Netherlands*

In the *Monitoring Project on Cardiovascular Disease Risk Factors* and the *MORGEN*-project the percentage of smokers, ex-smokers and never-smokers were reported as well as average number of cigarettes smoked by smokers (5).

### *Risk factor monitoring in Germany*

The German *Federal Health Survey 1998* reported the prevalence of never-smoker, ex-smokers, and smokers (unknown whether this includes daily and occasional smokers). In addition, the average cigarette consumption per daily-smoker and the percentage of smokers who had started smoking at age 20 or earlier. All data are reported by sex and age group. (25)

### *UK National Health Surveys*

In the *UK National Health Survey* several indicators are used to report smoking prevalence in the population. From self-reported data the following indicators are derived (7): current cigarette smoker, ex-regular cigarette smoker and never regular cigarette smoker. Also the average number of cigarettes smoked per day by smokers is reported.

### *NHANES III*

In *NHANES III* the prevalence of current cigarette smokers was used for reporting of smoking data. The self-reported smoking status was validated by serum cotinine levels (cutpoint > 13 mg/ml). (26)

## 7.6 Discussion and conclusions

All of the reviewed questionnaires ask about the person's current and past smoking status, but there are differences in the structure, the order, and the wording of the questions. Surveys collected a variable amount of other related information, such as amount of smoking, brand of cigarettes and exposure to environmental tobacco smoke.

Prevalence of daily smoking is probably the most important indicator that all surveys intend to measure. In this respect the questionnaires fell into two categories. In one category were those which focused primarily on cigarette smoking, and took pipe and cigar smoking separately at the end of the questionnaire (MONICA, Netherlands, UK, NHANES). In the other category were the questionnaires which measured directly any type of smoking, and possibly asked about the different forms of smoking at the end of the questionnaire (FINBALT, EUROHIS, WHO). The focus on cigarette smoking in many of the questionnaires presumably comes from the fact that it is by far the most common form of smoking in Europe, and in many countries practically the only form of smoking. However, all forms of smoking carry a similar risk. In some countries pipe and cigar smoking are common. Furthermore, as a result of intensive antismoking activities, some cigarette smokers tend to switch to cigar or pipe smoking. This justifies the general smoking approach in the relatively new FINBALT and WHO questionnaires for international use. All of the questionnaires also provided information on ex-daily smoking, but many collected this information for cigarette smoking only.

Very little has been published about the validation of the different questionnaires, although biochemical validation of self-reported smoking status was part of many studies. The quality assessment of the data on smoking behavior in the MONICA Project is largely based on assessment of the data, without knowing the true smoking status of the participants.

The importance, or even the usefulness of biochemical markers of smoking in population surveys is not obvious. The problem with thiocyanate and carbon monoxide is their non-specificity. Therefore, more literature exists about the validation of these markers as indicators of smoking than about the validation of questionnaire data using these biomarkers. Cotinine is very specific and sensitive to smoking or use of other nicotine containing products, such as nicotine replacement therapy or smokeless tobacco. If cheaper techniques for its measurement will be developed, it may be an important indicator of exposure to environmental tobacco smoke in the future, because the measurement of environmental tobacco smoke using only a questionnaire is not easy.

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<b>8. Blood glucose measurement</b>
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Glucose is the major carbohydrate present in blood. Glucose derived from dietary sources is either oxidized to provide energy or converted to glycogen or fatty acids for storage in the liver and other tissues. Blood glucose level is chiefly controlled by the hormones insulin and glucagon, but other hormones play also a role. A defect in insulin secretion, insulin action, or both results initially in impaired glucose tolerance (IGT) and causes hyperglycemia. Eventually, most cases of IGT will progress toward overt diabetes mellitus, a condition where the blood glucose level exceeds the reabsorption threshold of the kidneys and glucose is excreted in the urine. Hyperglycemia causes microvascular and macrovascular damage in several organs and is a powerful risk predictor for cardiovascular disease morbidity and mortality (1-4). While IGT is unquestionably a risk factor for

diabetes, there is still some debate whether it alone is also a direct risk factor for cardiovascular disease or whether it only becomes one through the development of diabetes.

Since the prevalence of diabetes appears to be increasing in most western societies, it seems advisable to incorporate into population surveys some measurements that can serve as markers for this metabolic disorder. This is especially so since the molecular mechanisms that connect obesity with IGT appear to become clarified (5), making IGT a modifiable risk factor.

Two of the surveys included in this review have incorporated in their protocol measurements related to diabetes and these two surveys, *NHANES III* and the *German Federal Health Survey 1998*, will serve as the source for most of the information covered in this section. The *Health Survey for England 1999* (6) also measured fasting glucose and glycated hemoglobin in a sub-sample of their survey participants.

## 8.1 Methods

Information related to abnormal glucose metabolism has been collected through questionnaires, blood and urine measurements. Urine measurements will not be covered in this report, since they become useful only in the later stages of IGT.

### 8.1.1 Questionnaire assessment

#### *NHANES III*

For participants older than 17 years, *NHANES III* (7) had included in its household questionnaire a number of questions related to diabetes.

1. Have you ever been told by a doctor that you have diabetes or sugar diabetes?   
1. Yes  
2. No
2. Where you pregnant when you were told that you had diabetes?   
1. Yes  
2. No
3. Other than during pregnancy, has a doctor ever told you that you had diabetes or sugar diabetes?   
1. Yes  
2. No
4. How old were you when a doctor first told you that you had diabetes (not including during pregnancy)? Age
5. Are you now taking insulin?   
1. Yes  
2. No
6. About how often do you take insulin?  times per day (week)
7. On average, how many units per day do you take?  units per day
8. For how long have you been taking insulin?  
a) less than 1 month  
b)  number of months (years)
9. Are you now taking diabetes pills to lower blood sugar? These are sometimes called oral agents or oral hypoglycemic agents.

1. Yes
  2. No
10. On your own, how often do you check yourself for
    - a) glucose or sugar in your urine
      - a) |\_\_||\_\_| times per day, week, month
      - b) never
    - b) glucose or sugar in your blood
      - a) |\_\_||\_\_| times per day, week, month
      - b) never
  12. How long ago was the last time you had your eyes examined by a doctor?
    - a) |\_\_||\_\_| days, weeks, months, years
    - b) never
    - c) don't know
  13. How long ago has it been since you had an eye exam in which your pupils were dilated? (This would have made you temporarily sensitive to bright light.)
    - a) |\_\_||\_\_| days, weeks, months, years
    - b) never
    - c) don't know
  14. Have you ever had a photograph taken of the retina in your eyes?
    1. Yes
    2. No
    3. Don't know
  15. Has a doctor ever told you that diabetes has affected your eyes or that you had retinopathy?
    1. Yes
    2. No
    3. Don't know

German *Federal Health Survey 1998*

The questionnaire of the German *Federal Health Survey 1998* (8) included the question

- | 1. Did you ever have diabetes | Yes | No | Don't know |
|-------------------------------|-----|----|------------|
| a) treated with insulin       | _   | _  | _          |
| b) treated without insulin    | _   | _  | _          |

During the subsequent physician interview, the participant's response was further clarified, and corrected if deemed necessary, by questions about the type of medication and diet prescription. Not all of the self-reported cases of diabetes could be confirmed by the physician. The difference between prevalence of diabetes calculated by the raw responses and after correction by the physician was 0.3% in men and 0.1% in women (8).

The Italian *OEC Project* had the following questions about diabetes in its questionnaire (they preceded the section on use of aspirin).

1. Has a physician or other health professional ever told you that you have diabetes?
  1. Yes
  2. No (go to section on aspirin)
  3. Insufficient data (go to section on aspirin)

2. Do you eat a special diet, prescribed by a physician or other health professional, for diabetes?
1. Yes
  2. No
  3. Uncertain

3. During the past two weeks, have you taken medication, to control diabetes?
1. Yes
  2. No (go to section on aspirin)
  3. Uncertain (go to section on aspirin)

4. How many types of medication have you taken?

Medication 1

5. Name of medication

6. Do you take it daily? Yes No

7. Number of pills per day
- Number of pills per week

Medication 2

8. Name of medication

9. Do you take it daily? Yes No

10. Number of pills per day
- Number of pills per week

**8.1.2 Blood glucose level**

Although blood glucose level is hormonally controlled, external factors still cause it to fluctuate over the short time, rising as a result of food intake and declining as a result of metabolic demand such as muscle activity. In order to obtain measurements that are predictable of disturbed glucose metabolism, blood glucose levels are measured under two different conditions:

1. Fasting blood glucose is determined from samples taken when the subject did not have any caloric intake for several hours, usually 8 to 12.
2. Post-challenge glucose is determined from samples taken 2 hours after the fasting subject received a glucose load of the equivalent of 75-g anhydrous glucose dissolved in water.

A number of factors have to be observed to obtain valid measurements.

**8.1.2.1 Pre-analytic stage**

**a) Circadian and seasonal variation**

It has been found that in patients with type 2 diabetes, the sensitivity to insulin varies throughout the day, decreasing during the night and increasing during the day (9). There is also some evidence that glucose concentration varies with ambient temperature. Difference in 2-hour glucose concentration is on average 1.03 mmol/l when moved from 5-14 °C to 25-31 °C. (10)

## ***b) Length of fasting***

The WHO recommends an 8 to 14 hour fast before a glucose tolerance test is performed (11). The recommendations of the American Diabetes Association define fasting as "no caloric intake for at least 8 hours" (12).

## ***c) Exercise***

Physical activity increases glucose uptake by muscle through an insulin-independent pathway (13). Exercise can increase glucose uptake by muscle up to two hours post-exercise, but insulin sensitivity may be increased by up to 16 hours for healthy and type 2 diabetes subjects (14). How this translates into blood glucose levels depends on several factors, such as food consumption prior to exercise, exercise duration, exercise intensity, and whether IGT is present. A moderate bout of exercise caused no significant post-exercise decline of blood glucose in diabetic patients, but an increase in healthy persons (15).

## ***8.1.2.2 Collection and preparation stage***

### ***a) Specimen type***

Several studies have shown that there are differences in glucose concentration between whole blood and plasma as well as between venous or capillary specimen. (16, 17)

In the fasting stage there is no difference between venous and capillary specimen but after 2-hour glucose load the difference is around 8%. (17)

#### *NHANES III*

In *NHANES III* plasma was used. (18)

#### *German Federal health Survey 1998*

The German *Federal health Survey 1998* determined blood glucose from serum.

#### *Risk factor monitoring in the Netherlands*

In the *MORGEN*-project and *REGENBOOG* project the blood glucose was determined from plasma (19, 20).

### ***b) Collection of specimen***

#### *NHANES III*

In *NHANES III* all adults aged 40 to 74 who provide a "fasting" blood sample and who did not take insulin were asked to participate in the glucose tolerance test (GTT). Adults taking oral medications other than insulin to control diabetes were eligible for the GTT. Subjects taking pills for diabetes were instructed to bring their pills to the mobile examination centre on the day of their exam and to take them after the GTT was finished. If the 2-hour draw could not be completed before the end of the session, no Trutol (Trutol® used as the standard beverage in Glucose Tolerance Testing) was administered. The second venipuncture for the GTT was done 2 hours after the Trutol was administered. (18)

### ***c) Preservatives***

#### *NHANES III*

In *NHANES III*, NaF was used as a preservative of glucose in blood at room temperature. It interferes with other tests to be made on the sample. It appears to be the most commonly used glucose preservative in recent studies. Another glucose preservative is D-mannose. The two preservatives differ in their ability to maintain blood glucose levels. A combination of the two was found to give the best stability (21).

#### *Risk factor monitoring in the Netherlands*

In the *MORGEN*-project and *REGENBOOG* project the Sodium Fluoride was used as a preservative for glucose (19, 20).

#### ***d) Centrifuging and storing before centrifuging***

Blood specimens for glucose determination should be processed immediately, but in practice this is impossible. The blood glucose concentration declines on average by 0.5 mmol/l over a 2-4 h period. The main decrease occurs during the first hour. (22)

*NHANES III*

In *NHANES III*, specimens were centrifuged immediately at 1500 G for 10 min. (18)

#### ***e) Storage after centrifuging***

*NHANES III*

In *NHANES III*, plasma was frozen at -70 °C until analysis. (18)

### ***8.1.2.3 Analytic stage***

#### ***a) Methods of blood glucose determination***

*NHANES III*

The criteria for unacceptable specimens were either a low volume (< 0.2 mL) or gross hemolysis (18). Specimens collected without NaF, or those that had thawed upon arrival, were also unacceptable.

Calculations (18):

1. The Cobas Mira glucose analysis was lineared up to plasma glucose concentrations of 600 mg/dL. Samples containing more than 600 mg/dL were reanalyzed by diluting the specimen two-fold (1+1) with distilled water.
2. Glucose values less than 50 mg/dL or greater than 200 mg/dL were considered abnormal and analysis must be repeated for confirmation.

Specimens were allowed to reach and maintain at 20-25 °C during analysis. Specimens were returned to storage at -70 °C as soon as the analyses were completed. (18)

*German Federal Health Survey 1998*

The *German Federal Health Survey 1998* used the GOD-PAP method (Merck, analysis system MEGA) for serum glucose analysis (8).

#### ***b) Calibration***

*NHANES III*

Glucose standard 100 mg/dL, 150 mg/dL, and 500 mg/dL. (18)

Calibration standard 150 mg/dL of Certified Glucose (D-glucose) Standard Solution purchased from Sigma Chemical Company and calibrated against the National Institute of Standards and Technology (NIST) standard reference material SRM 909. The standards were stored as 2 mL-aliquots in tightly capped polypropylene tubes at -20 °C until the day of assay. A thawed and well-mixed standard was placed at the cup position 1 in the calibration rack. A new calibration standard tube was used for each assay. (18)

The Cobas Mira glucose assay uses a single 150-mg/dL calibration point, which was analyzed at the beginning of each run as a sample. The glucose value for the calibrator should fall within limits of 148 to 152 mg/dL. The instrument requires recalibration if the value of the calibrator was outside the specified limits. (18)

### **8.1.3 Glycated hemoglobin**

Minor hemoglobin components of human erythrocytes are designated A1a, A1b, and A1c. Hemoglobin A1c is most important since its sugar moiety is glucose covalently bound to the terminal amino acid of the beta chain. Since normal glycohemoglobin concentrations exclude marked blood glucose fluctuations over the preceding three to four weeks, the concentration of glycated hemoglobin A is a more reliable index of the blood sugar average over a long period of time. Glycated hemoglobin is an index of average glucose levels over the previous 2 to 3 months and is now considered an important test for diagnosis of diabetes (23). Glycated hemoglobin concentration seems to explain most of the excess mortality risk of diabetes in men and to be a continuous risk factor throughout the whole population distribution for all-cause mortality, cardiovascular, and ischaemic heart disease mortality (24).

#### **8.1.3.1 Analysis method**

##### *NHANES III*

The specimen for HbA1c assay is whole blood collected with anticoagulant EDTA, refrigerated to 4-8 °C after collection and shipped on 4-8 °C refrigerant packaging.

The Bio-Rad Diamat automated HPLC system is used for analysis. This system uses the principle of ion exchange high-performance liquid chromatography.

For quality control, "batch control" samples are placed in each run. A 5% random sample of specimens is analysed in another run and the coefficient of variation between duplicate measurements has to be below 10%.

##### *German Federal Health Survey 1998*

The Bio-Rad Diamat automated HPLC system is used for analysis. This system uses the principle of ion exchange high-performance liquid chromatography.

##### *Health Survey of England 1999*

The *Health Survey of England 1999* used the Tosoh HLC-723 GHb V, A1c2.2 glycohemoglobin analyzer (6) that had been found to suffer less from interference compared with older equipment such as the Bio-Rad Diamat (25).

## **8.2 Quality assurance**

### **8.2.1 Training**

No information was found on training specifically for the blood glucose analysis. Presumably, all surveys employed professionals for this purpose.

### **8.2.2 Laboratory quality control**

##### *NHANES III*

In NHANES III, two types of quality control (QC) systems were used: 1) "sample QC" and 2) "batch QC" (18).

1. For sample QC (i.e., precision estimation), 5% of specimens were randomly selected and analyzed either within-assay or between-assay for quality assurance purposes. If the CV between duplicates was greater than 5%, the specimen was reanalyzed. If more than three paired replicate samples had CVs greater than 5%, the instrument was checked and the calibration process was performed.

2. Batch QC specimens were placed in the calibration rack at the beginning and the end of each sample rack and at the end of the entire run. The batch QC pools consisted of four levels of control pools, which covered the full range of plasma glucose concentrations for normal and diabetic populations. Two commercial lyophilized serum controls, BC1 and BC2, were purchased from Baxter Scientific Company. BC1 and BC2 were placed in the calibration rack and were identified to the instrument as the system controls. The bias limit was set at 1 SD or the 67% limit; the warning limit (WL) was the 2-SD or the 95% limit and the control limit (CL) was the 3-SD or the 99% limit.

Two types of QC charts were used in assessing the quality of an assay. The first chart plotted the mean of all the replicate determinations in a run and compared it with the established target mean, which was the overall mean established by the 20 characteristic runs. The NHANES guideline declared a system as "out-of-control" if any of the following events occurred for any one of the QC materials (18):

- The mean from a single control fell outside the 99% confidence limits.
- The means from two controls fell either both above or both below the 95% confidence limits.
- The daily means of one control from eight successive runs (excluding the runs in which the mean is within 1 SD or bias range) fell either all above or all below the center line.

The second type of QC chart plotted the range of the replicates (the difference between the highest and the lowest value of a single control within a run) and compared it with the established target range, which was the overall mean of daily ranges established by the 20 characteristic runs. The NHANES guideline declared a system as "out-of-control" if any of the following events occurred for any one of the QC materials (18):

- The daily range from a single control fell outside the 99% confidence limits.
- The daily ranges from two controls fell either both above or both below the 95% confidence limits.
- The daily range of one control from eight successive runs fell either all above or all below the mean line.

If a run was declared as out of control, the system was investigated (instrument, standards, controls etc.) to determine the cause of the problem. No analyses were performed until the problem had resolved (18).

The Laboratory also participated in an external QC program offered by Baxter Diagnostics Inc (QAP) for BC1 and BC2. The individual control values obtained in all glucose assays performed each month were submitted to Baxter. These values were then compared with NHANES' own cumulative mean as well as the group cumulative mean (divided by method) (18).

### ***8.2.3 Retrospective quality assessment report***

Not in the literature.

## **8.3 Indicators used for reporting the results**

Values for diagnosis of diabetes mellitus and other categories of hyperglycaemia according to the WHO recommendations (11):

	<b>Glucose concentration, mmol/ l (mg/dl)</b>	
	<b>Whole blood</b>	<b>Plasma</b>

		<b>Venous</b>	<b>Capillary</b>	<b>Venous</b>	<b>Capillary</b>
<b>Diabetes Mellitus</b> <i>(fasting and/or 2-h post glucose load)</i>	<b>Fasting</b>	≥ 6.1 (≥ 110)	≥ 6.1 (≥ 110)	≥ 7.0 (≥ 126)	≥ 7.0 (≥ 126)
	<b>2-h post glucose load</b>	≥ 10.0 (≥ 180)	≥ 11.1 (≥ 200)	≥ 11.1 (≥ 200)	≥ 12.2 (≥ 220)
<b>Impaired Glucose Tolerance</b> <i>(fasting and 2-h post glucose load)</i>	<b>Fasting</b>	< 6.1 (< 110)	< 6.1 (< 110)	< 7.0 (< 126)	< 7.0 (< 126)
	<b>2-h post glucose load</b>	≥ 6.7 (≥ 120) and < 10.0 (< 180)	≥ 7.8 (≥ 140) and < 11.1 (< 200)	≥ 7.8 (≥ 140) and < 11.1 (< 200)	≥ 8.9 (≥ 160) and < 12.2 (< 220)
<b>Impaired Fasting Glycaemia</b> <i>(fasting and 2-h post glucose load)</i>	<b>Fasting</b>	≥ 5.6 (≥ 100) and < 6.1 (< 110)	≥ 5.6 (≥ 100) and < 6.1 (< 110)	≥ 6.1 (≥ 110) and < 7.0 (< 126)	≥ 6.1 (≥ 110) and < 7.0 (< 126)
	<b>2-h post glucose load</b>	< 6.7 (< 120)	< 7.8 (< 140)	< 7.8 (< 140)	< 8.9 (< 160)

For epidemiological or population screening purposes, the fasting or 2-h value after 75 g oral glucose may be used alone.

#### *NHANES III*

In a paper using *NHANES III* data, the thresholds for the 2-hour glucose tolerance test were (26):

1. Normal glucose tolerance: fasting and 2 hours post-challenge plasma glucose < 140 mg/dl.
2. Impaired glucose tolerance: fasting plasma glucose < 140 mg/dl and 2 hours post-challenge plasma glucose between 150 mg/dl and 200 mg/dl.
3. Diabetic: fasting plasma glucose > 140 mg/dl or 2 hours post-challenge plasma glucose > 200 mg/dl.

#### *German Federal Health Survey 1998*

The German *Federal Health Survey 1998* uses serum glucose values. A combination of measurements is required for making the diagnosis of diabetes. The threshold values are:

- ≥ 126 mg/100 ml for serum glucose after at least 3 hours fasting
- > 6.1% for HbA1c

#### *Risk factor monitoring in the Netherlands*

In the *MORGEN*-project the proportion of respondents with blood glucose ≥ 11.1 mmol/l (19).

#### *Other indicators*

The expert committee of the American Diabetes Association proposes thresholds for plasma serum in the fasting plasma glucose (FPG) test and for 2-hour postload glucose in the oral glucose tolerance test (OGTT) respectively (12).

Diagnosis	FPG	OGTT
normal fasting glucose	< 110 mg/dl	< 140 mg/dl
impaired fasting glucose (IFG) = IGT	≥ 110 and < 126 mg/dl	≥ 140 and < 200 mg/dl
provisional diagnosis of diabetes (needs to be confirmed)	≥ 126 mg/dl	≥ 200 mg/dl

#### 8.4 Discussion and conclusions

Without doubt, IGT is an important risk factor for diabetes and likely also for arteriosclerosis and other forms of vascular disease. The questionnaires of both reviewed studies included items about treatment for diabetes. The German survey had only a simple question, but this was followed by a physician interview for in-depth assessment. The more extensive list of questions of *NHANES III* may be equally effective without the need for a physician.

Blood glucose levels after 3 hours and 8 hours of fasting have been measured by the German *Federal Health Survey 1998* and *NHANES III* respectively. In addition, *NHANES III* administered an oral glucose tolerance test. The time constraints of *NHANES III* are more severe, requiring at least 8 hours fasting and a 2-hour waiting period for the subjects at the examination centre. WHO and the American Diabetes Association require 8-hour fast. We could not find evidence that the German 3-hour fast is diagnostically equivalent.

*NHANES III*, the German *Federal Health Survey 1998* and the *Health Survey for England 1999* collected glycated hemoglobin (HbA1c) data. The German survey and *NHANES* used identical equipment for assays, the English survey used newer equipment. The experts are still divided about the utility of this test for detection of undiagnosed diabetes or IGT, although it is now commonly used for assessing diabetes control. At least one prospective study found HbA1c to be a risk factor for all cause mortality, cardiovascular disease, and ischaemic disease across the whole population spectrum. Because this test does not require fasting, it may become the test of choice for surveys, if its value for risk assessment can be further documented. As a result of its stability, HbA1c may become an important indicator for monitoring trends in blood glucose levels in populations.

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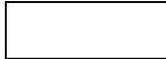
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## 10. Awareness and treatment of hypertension

Hypertension is a known risk factor for cardiovascular diseases.

Awareness and treatment are important prerequisites for controlling of hypertension. In populations studies, awareness and treatment of hypertension can be assessed either through medical records, which is expensive, time consuming and not always possible, or through questionnaires. Questionnaires are the preferred mode of obtaining information about the awareness and treatment of hypertension.

### 10.1 Questions

Agreement between data about awareness and treatment of hypertension collected using questionnaires and data obtained from the medical record reviews is found to be good. Over 80% of responses in the questionnaire agree with medical records. (1-3) The specificity of the questionnaire data decreases with age of the respondent and is higher in women (1).

#### 10.1.1 WHO MONICA Project

In the MONICA Manual (4) there are two questions about the awareness and treatment of hypertension.

1. "Have you ever been told by a doctor or other health worker that you have high blood pressure?"   
1 = yes  
2 = no (if no, record 8 in item *Question 2*)  
9 = insufficient data
2. "Are you taking (in the last two weeks) drugs for high blood pressure?"   
1 = yes  
2 = no  
3 = uncertain  
8 if *Question 1* = 2  
9 = insufficient data
3. "Have you had your blood pressure measured in the last year?"   
1 = yes  
2 = no  
9 = insufficient data

The MONICA Manual (4) has additional instructions for item *Question 2*:

Code 1 if using blood pressure lowering drugs during the last two weeks.  
 Code 2 if no blood pressure lowering drugs used.  
 Code 3 if the use of blood pressure lowering drugs is reported but the person in question is uncertain if these have been used during the last two weeks or he/she is not sure whether the drugs used were for hypertension.  
 Code 8 if *Question 1 = 2*.  
 Code 9 if insufficient information is available to use the other codes.

### ***10.1.2 Risk factor monitoring in the Netherlands***

In the *Monitoring Project on Cardiovascular Disease Risk Factors* the following questions were used for awareness and treatment of hypertension (5):

1. Have you ever been diagnosed with hypertension?
1. Yes  
2. No
- If yes:
- 2a. When was the first time (year)?
- 2b. Who made the diagnosis
1. General practitioner  
2. Specialist  
3. Company doctor  
...
- 2c. Do you have a diet for this at present?
1. Yes  
2. No
- 2d. If yes, who provided the dietary advice
1. Doctor  
2. Dietician  
3. Own initiative  
...
- 2e. Do you use antihypertensive medication?
1. Yes  
2. No

In the *MORGEN*-project awareness and treatment of hypertension was asked using following questions (5):

1. Have you ever been diagnosed with hypertension?
1. Yes  
2. No  
3. Don't know
2. If yes, do you use medication at present?
1. Yes  
2. No
3. For women only: if yes, did you ONLY have hypertension during pregnancy?
1. Yes  
2. No

The questionnaire of the *REGENBOOG* project included the following questions about awareness and treatment of hypertension (6):

1. Is your blood pressure elevated at the moment?   
1. Yes  
2. No  
3. I don't know
2. Do you use drugs to lower your blood pressure?   
1. Yes  
2. No
3. Are you on diet to lower your blood pressure?   
1. Yes  
2. No

### ***10.1.3 Risk factor monitoring in Germany***

The questionnaire for the German *Federal Health Survey 1998* included the awareness of hypertension in a long list of choices to the question

Which one of the following diseases did you ever have:

	Yes	No	Don't know
High blood pressure, hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The informant's response was further clarified in a subsequent physician interview. (7)

### ***10.1.4 UK National Health Surveys***

Question used in 1998 *Health Survey for England* (8):

1. Do you now have, or have you ever had high blood pressure (sometimes called hypertension)?   
1. Yes (Go to *Question 2*)  
2. No
2. Were you told by a doctor or nurse that you had high blood pressure?   
1. Yes (If female go to *Question 3*, other wise go to *Question 5*)  
2. No
3. Were you pregnant when you were told that you have high blood pressure?   
1. Yes (Go to *Question 4*)  
2. No
4. Have you ever had high blood pressure apart from when you were pregnant?   
1. Yes (Go to *Question 5*)  
2. No
5. How old were you when you were first told by a (doctor/nurse) that you had high blood pressure?
6. Are you currently taking any medicines, tablets or pills for high blood pressure?   
1. Yes  
2. No (Go to *Question 7*)

7. Do you still have high blood pressure?
1. Yes
  2. No
8. Have you ever taken medicines, tablets or pills for high blood pressure in the past?
1. Yes (Go to *Question 9*)
  2. No
9. Why did you stop taking (medicines/tablets/pills) for high blood pressure?
1. Doctor advised me to stop due to: improvement
  2. lack of improvement
  3. other problem
  4. Respondent decided to stop: because felt better
  5. ... for other reason
  6. Other reason
10. Are you receiving any (other) treatment or advise because of your high blood pressure?
1. Yes (Go to *Question 11*)
  2. No
11. What other treatment or advise you currently receiving because of your high blood pressure?
1. Blood pressure monitoring by GP/nurse
  2. Advise or treatment to lose weight
  3. Blood tests
  4. Change diet
  5. Stop smoking
  6. Reduce stress
  7. Other (Please specify)
12. Have you ever had your blood pressure measured by a doctor or nurse?
1. Yes (Go to *Question 13*)
  2. No
13. When was the last time your blood pressure was measured by a doctor or nurse?
1. During the last 12 months
  2. At least a year but less than 3 years ago
  3. At least 3 years but less than 5 years ago
  4. 5 years ago or more
14. Thinking about the last time your blood pressure was measured, were you told it was
1. Normal (alright/fine)
  2. Higher than normal
  3. Lower than normal
  4. Were you not told anything?
15. Is this the only time your blood pressure has been higher than normal or has it been higher than normal a number of times?
1. Only time
  2. A number of times

### 10.1.5 National Health and Nutrition Examination Survey (NHANES III), US

The following questions about the awareness and treatment of hypertension were asked during the home visit from the adults (9):

1. About how long has it been since you last had your blood pressure taken by a doctor  or other health professional?
  1. Less than 6 months
  2. 6 months, less than 1 year
  3. 1 year, less than 5 years
  4. More than five years
  5. Never
  
2. Have you ever been told by a doctor or other health professional that you had  hypertension, also called high blood pressure?
  1. Yes
  2. No
  
3. Were you told on 2 or more different visits that you had hypertension, also called high  blood pressure?
  1. Yes
  2. No
  
4. Because of your high blood pressure/hypertension, have you ever been told by a doctor or other health professional to  
1=Yes, 2=No
  - a. take prescribed medicine?
  - b. control your weight or lose weight?
  - c. cut down on salt or sodium in your diet?
  - d. do anything else?
  
5. What else were you told to do for your high blood pressure/hypertension?  
(Code all that apply)
  1. Exercise more
  2. Alcohol restriction
  3. Other
  
6. Other specify 
  10. Stop smoking
  11. Avoid stress/rest/relax
  12. Any change in eating not mentioned already
  13. Other
  
7. To lower your blood pressure are you now  
1=Yes, 2=No
  - a. taking prescribed medicine?
  - b. controlling or losing weight?
  - c. using less salt or sodium in your diet?
  - d1. exercising more?
  - d2. restricting alcohol?

More detailed coding instructions for the above questions are:

*Question 1.* An SP who has never had his/her blood pressure taken by a health professional will skip questions 2-7.

*Question 2.* If a female respondent indicates that she has had high blood pressure or hypertension only during the pregnancy, consider this a "YES" answer to any of these questions and enter Code 1.

*Question 4.* Enter Code 1 (YES) if the respondent has been advised by a doctor or other health professional to follow one or more of the treatments listed in a-d

Note that "prescribed medication" may include pills, liquids, or shots, and must be purchased by prescription.

Enter Code 2 (NO) if the respondent has not been advised to follow one or more of the above treatments or if s/he has been advised to do so for any condition other than high blood pressure (hypertension, high blood).

Note that if the SP reports being told to do something else because of his/her high blood pressure (Code 1 in answer category "d") (EXERCISE MORE-ALCOHOL RESTRICTION) will be introduced.

*Question 5.* A Code 1 (YES) answer to "d" (do anything else) will introduce three additional treatment options. Ask the respondent to specify what the other treatment options are and code all that apply. If s/he responds with an answer other than "Exercise More" or "Alcohol Restriction" enter Code 3 (OTHER). Remember the SP may mention all three options in which case all three codes should be entered.

*Question 6.* Entering a "3" for Question 5 introduces a third part to the question about treatment programs for high blood pressure. If the SP's answer is still not one of those specified ("STOP SMOKING", "AVOID STRESS/REST/RELAX", "ANY CHANGE IN EATING NOT MENTIONED ALREADY") enter Code 13 (Other) and specify the SP's answer verbatim on the line provided.

*Question 7.* Enter Code 1 (YES) if the SP is currently following the treatment either on a regular or irregular basis. (In other words, enter Code 1 (YES) even if the SP says "I am currently following the treatment but not every day like I should".)

### **10.1.6 Norwegian Age-40 Programme**

The Norwegian *Age-40 Programme* has only one question related to hypertension awareness.

	Now	Previously, but not now	Never
Do you take medication against high blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you take medication now, what is its name?

Medication name:

---

### **10.1.7 The Italian OEC Project**

The questionnaire section about awareness and treatment of hypertension preceded the section on hypercholesterolemia.

1. Has a doctor or other health professional ever told you that you have hypertension? 
  1. Yes
  2. No (go to section on hypercholesteremia)
  3. Insufficient data (go to section on hypercholesteremia)
2. During the past two weeks, have you taken medication, prescribed by a physician, to lower arterial blood pressure? 
  1. Yes
  2. No (go to section on hypercholesteremia)

3. Uncertain (go to section on hypercholesteremia)

3. How many types of medications have you taken?

Medication 1

4. Name of medication

5. Do you take it daily? Yes No

6. Number of pills per day

Number of pills per week

Medication 2

7. Name of medication

8. Do you take it daily? Yes No

9. Number of pills per day

Number of pills per week

Medication 3

10. Name of medication

11. Do you take it daily? Yes No

12. Number of pills per day

Number of pills per week

Medication 4

13. Name of medication

14. Do you take it daily? Yes No

15. Number of pills per day

Number of pills per week

## 10.2 Quality assurance

### 10.2.1 Retrospective quality assessment report

#### *WHO MONICA Project*

The detailed description about the availability and quality of data on awareness and treatment of hypertension is given in the Quality Assessment of Data on Hypertension Control in the *WHO MONICA Project* (10).

#### *Awareness of high blood pressure*

The most common deviation between MONICA questions and questions asked locally about the awareness of high blood pressure was the omission of the expression "told by a doctor or other health worker". The number of centres omitting the expression decreased from initial to middle survey and also from middle to final survey. (10)

#### *Drug treatment of high blood pressure*

For the question about the drug treatment of high blood pressure the most common deviation in the local questionnaires reference to the time period during which the drug was to have been used. While the standard MONICA question asks about the use during the "last two weeks", many local questions referred to the "present time" or to the "last week". (10)

No information about quality control of the questions on awareness and treatment of hypertension is available for *Risk factor monitoring in the Netherlands*, *Risk factor monitoring in Germany*, *UK National Health Surveys*, and *NHANES III*.

### 10.3 Indicators used for reporting the results

#### *WHO MONICA Project*

In the *WHO MONICA Project* the results about the awareness and treatment of hypertension are reported using six blood pressure categories either among all respondents or among persons with high blood pressure. Categories are following (11):

- I. Systolic blood pressure < 160 mmHg and diastolic blood pressure < 95 mmHg, on treatment for hypertension.
- II. Systolic blood pressure  $\geq$  160 mmHg or diastolic blood pressure  $\geq$  95 mmHg, on treatment for hypertension.
- III. Systolic blood pressure  $\geq$  160 mmHg or diastolic blood pressure  $\geq$  95 mmHg, not on treatment for hypertension, told about high blood pressure
- IV. Systolic blood pressure  $\geq$  160 mmHg or diastolic blood pressure  $\geq$  95mmHg, not on treatment for hypertension, never told about high blood pressure
- V. Systolic blood pressure < 160 mmHg and diastolic blood pressure < 95 mmHg, not on treatment for hypertension, never told about high blood pressure
- VI. Systolic blood pressure < 160 mmHg and diastolic blood pressure < 95 mmHg, not on treatment for hypertension, told about high blood pressure.

#### *Risk factor monitoring in the Netherlands*

In the *Monitoring Project on Cardiovascular Disease Risk Factors* in the Netherlands the hypertensives are defined as having systolic blood pressure  $\geq$  160 mmHg and/or diastolic blood pressure  $\geq$  95 mmHg and/or using antihypertensive medication (12).

#### *Risk factor monitoring in Germany*

The German *Federal Health Survey 1998* reports mean age/sex specific systolic and diastolic blood pressures for all participants and those not on antihypertensive medication (7).

#### *UK National Health Surveys*

In the *National Health Surveys* in UK the following categories are used for hypertension (8):

- I. Normotensive-untreated: systolic blood pressure < 140 mmHg and diastolic blood pressure < 90 mmHg, not currently taking drug prescribed for high blood pressure
- II. Normotensive-treated: systolic blood pressure < 140 mmHg and diastolic blood pressure < 90 mmHg, currently taking drug prescribed for high blood pressure
- III. Hypertensive-treated: systolic blood pressure  $\geq$  140 mmHg and diastolic blood pressure  $\geq$  90 mmHg, currently taking drug prescribed for high blood pressure
- IV. Hypertensive-untreated: systolic blood pressure  $\geq$  140 mmHg and diastolic blood pressure  $\geq$  90 mmHg, not currently taking drug prescribed for high blood pressure.

#### *NHANES III*

In the *NHANES III* the definitions used for hypertension are (13, 14):

- I. Systolic blood pressure  $\geq$  140 mmHg or diastolic blood pressure  $\geq$  90 mmHg or current treatment with antihypertensive drug
- II. Systolic blood pressure  $\geq$  160 mmHg or diastolic blood pressure  $\geq$  95 mmHg or current treatment with antihypertensive drug

- III. Controlled hypertension: systolic blood pressure < 140 (160) mmHg and diastolic blood pressure < 90 (95) mmHg and pharmacological treatment for hypertension.

#### 10.4 Discussion and conclusions

In *MONICA*, the *National Health Surveys* in the UK, and *NHANES III* in the USA, the awareness of hypertension was tested by asking the question(s) whether the person "ever" had hypertension. A history of episodic hypertension, such as gestational hypertension, was not always distinguished from a history of established hypertension.

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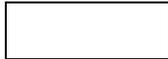
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**9. questions in the HIS/ HES Database. This database covers all interview questions and protocols examinations of national health population surveys in EU member states and EFTA/ EEA countries as well as Canada, Australia and USA.**

Source: <https://www.iph.fgov.be/hishes>

### ***Questions related to cholesterol***

**UK 2000**

71. Have you ever had your blood cholesterol level measured by a doctor or nurse?

Yes  
No

**IF Yes**

When was the last time your blood cholesterol level was measured by a doctor or nurse? Was it

... during the last 12 months, at least a year but less than 3 years ago, at least 3 years but less than 5 years ago, or 5 years ago or more?

72. Thinking about the last time your blood cholesterol level was measured, were you told it was

normal (alright/fine),  
higher than normal,  
lower than normal,  
or were you not told anything?

### ***Questions related to blood pressure***

**UK 2000**

69. May I just check, have you ever had your blood pressure measured by a doctor or nurse?

Yes  
No

**IF Yes**

When was the last time your blood pressure was measured by a doctor or nurse? Was it

... during the last 12 months, at least a year but less than 3 years ago, at least 3 years but less than 5 years ago, or 5 years ago or more?

70. Thinking about the last time your blood pressure was measured, were you told it was ...

normal (alright/fine),  
higher than normal,  
lower than normal,  
or were you not told anything?

Is this the only time your blood pressure has been higher than normal or has it been higher than normal a number of times?

Only time  
A number of times

<b>UK 1992</b>
----------------

16a. What do you believe causes chronic bronchitis?

Smoking  
Overweight  
Family or heredity  
Damp weather or clothes  
Weak chest/lungs  
Air pollution  
Working conditions  
Other, please specify: ...  
Don't know

b. What do you believe causes high blood pressure?

Smoking  
Worry/Tension/Stress  
Alcohol  
Type of diet  
Salt  
Overweight  
Lack of exercise  
Family or heredity  
Age  
Other, please specify: ...  
Don't know

c. What do you believe causes obesity or being overweight?

Worry/Tension/Stress  
Alcohol  
Overeating  
Eating wrong foods  
Lack of exercise  
Family or heredity  
'Glands' or hormones  
Other, please specify: ...

Don't know

**UK 98**

130. You mentioned that you have had high blood pressure.

Were you told by a doctor or nurse that you had high blood pressure?

Yes

No

131. Can I just check, were you pregnant when you were told that you had high blood pressure?

Yes

No

Have you ever had high blood pressure apart from when you were pregnant?

Yes

No

Apart from when you were pregnant, approximately/ Approximately how old were you when you were first told by a (doctor/nurse) that you had high blood pressure?

<b>Canada 2000</b>
--------------------

BP010 Now a few questions about your use of various health care services. Have you ever had your blood pressure taken?

Yes

No

DK, R

BP012 When was the last time?

Less than 6 months ago

6 months to less than 1 year ago

1 year to less than 2 years ago

2 years to less than 5 years ago

5 or more years ago

BP016 Why have you not had your blood pressure taken in the past 2 years? (Mark all that apply)

Have not gotten around to it

Respondent - did not think it was necessary

Doctor - did not think it was necessary

Personal or family responsibilities

Not available - at time required

Not available - at all in the area

Waiting time was too long

Transportation - problems

Language - problem

Cost  
Did not know where to go / uninformed  
Fear (e.g. painful, embarrassing, find something wrong)  
Other – Specify

***Questions related to obesity***

**Australia 2001**

AF204. DO YOU CONSIDER YOURSELF TO BE ACCEPTABLE WEIGHT, UNDERWEIGHT OR OVERWEIGHT?

Acceptable weight  
Underweight  
Overweight

AF205. HOW MUCH DO YOU WEIGH?

Kilograms  
Stone/pounds  
Pounds  
Don't know

AF206. HOW TALL ARE YOU WITHOUT SHOES?

Centimetres  
Feet/inches  
Don't know

**US 2000**

AHB.190 How tall are you without shoes?

FEET:  
2-7 Feet  
Refused  
Don't know  
Reported in Metric

INCHES:  
0-11 Inches  
Refused  
Don't know

METERS:  
0-2 meters  
Refused  
Don't Know

CENTIMETERS:

0-241 centimeters  
Refused  
Don't Know

AHB.200 How much do you weigh without shoes?

POUNDS:  
50-500 pounds  
Refused  
Don't know  
Reported in Metric

KILOGRAMS:  
22.7-226.8 kilograms  
Refused  
Don't Know

<b>Canada 2000</b>
--------------------

HW2 How tall are you without shoes on?  
... cm or inches

HW3 How much do you weigh?  
Enter amount only.

Weight: ...

DK, R

Was that in pounds or kilograms?

Pounds  
Kilograms  
DK, R are not allowed

DP07 Did you gain weight, lose weight or stay about the same?

Gained weight  
Lost weight  
Stayed about the same  
Was on a diet  
DK, R

DP08A About how much did you gain/lose?

Weight: ...

DK, R

DP08B Was that in pounds or in kilograms?

Pounds  
Kilograms  
(DK, R are not allowed)

**UK 1992**

**UK 1992**

c. What do you believe causes obesity or being overweight?

Worry/Tension/Stress

Alcohol

Overeating

Eating wrong foods

Lack of exercise

Family or heredity

'Glands' or hormones

Other, please specify: ...

Don't know

42a. How tall are you?

... cm

b. How much do you weigh?

... Kg

c. Would you say that for your height you are ?

about the right weight

too heavy

or too light

Don't know

43a. Compared to seven years ago, do you now weigh

more

less

or about the same

Can't say

b. Overall, how much more do you weigh now than you did

seven years ago?

...

Don't know

d. Overall, how much less do you weigh now, than you did

seven years ago?

...

Don't know

**UK 1993**

19. Have you lost any weight in the past month?

Yes

No

19a. Were you trying to lose weight or on a diet?

Yes

No

b. Did you lose half a stone or more, or did you lose less than this?

Lost half a stone or more

Lost less than half a stone

21. Have you gained weight in the past month?

Yes

No

### Questions related to smoking

Australia 2001
----------------

AF220. I WOULD NOW LIKE TO ASK YOU SOME QUESTIONS ABOUT SMOKING.

DO YOU CURRENTLY SMOKE?

Yes

No

AF221. DO YOU SMOKE REGULARLY, THAT IS, AT LEAST ONCE A DAY?

Yes

No

AF222. HAVE YOU EVER SMOKED REGULARLY (THAT IS, AT LEAST ONCE A DAY)?

Yes

No

AF224. DOES ANYONE ELSE IN THIS HOUSEHOLD SMOKE REGULARLY, THAT IS, AT LEAST ONCE A DAY?

Yes

No

AF225. HOW MANY OTHER PEOPLE IN THIS HOUSEHOLD  
SMOKE REGULARLY?

Number: ...  
Don't know

<b>Canada 2000</b>
--------------------

SM201A In your lifetime, have you smoked a total of 100 or  
more cigarettes (about 4 packs)?

Yes  
No

SM201B Have you ever smoked a whole cigarette?

Yes  
No  
DK, R

SM201C At what age did you smoke your first whole  
cigarette?

Age in years: ...

SM202 At the present time, do you smoke cigarettes daily,  
occasionally or not at all?

Daily  
Occasionally  
Not at all  
DK, R

SM203 At what age did you begin to smoke cigarettes daily?

Age in years: ...

SM204 How many cigarettes do you smoke each day now?

Cigarettes: ...

SM205B On the days that you do smoke, about how many  
cigarettes do you usually have?

Cigarettes: ...

SM205C In the past month, on how many days have you

smoked 1 or more cigarettes?

Days: ...

SM205D Have you ever smoked cigarettes daily?

Yes  
No  
DK, R

SM207 At what age did you begin to smoke (cigarettes) daily?

Age in years: ...

SM208 How many cigarettes did you usually smoke each day?

Cigarettes: ...

TA1 In the past month, have you smoked cigars?

Yes  
No  
DK, R

TA2 In the past month, have you smoked a pipe?

Yes  
No

TA3 In the past month, have you used snuff?

Yes  
No

TA4 In the past month, have you used chewing tobacco?

Yes  
No

US 2000

AHB.010 Have you smoked at least 100 cigarettes in your  
ENTIRE LIFE?

Yes  
No  
Refused  
Don't know

AHB.020 How old were you when you FIRST started to smoke

fairly regularly?

6-94 years of age  
95 years or older  
Never smoked regularly  
Refused  
Don't know

AHB.030 Do you NOW smoke cigarettes every day, some days or not at all?

Every day  
Some days  
Not at all  
Refused  
Don't know

AHB.050 On the average, how many cigarettes do you now smoke a day?

1-94 cigarettes  
95+ cigarettes  
Refused  
Don't know

AHB.060 On how many of the PAST 30 DAYS did you smoke a cigarette?

None  
1-30 Days  
Don't know  
Refused

AHB.070 On the average, when you smoked during the PAST 30 DAYS, about how many cigarettes did you smoke a day?

1-94 cigarettes  
95+ cigarettes  
Refused  
Don't know

<b>The Netherlands 1998</b>
-----------------------------

SD2a You have told that you smoke.

Do you ever smoke cigarettes from a packet or self-rolled cigarettes?

b You have told that you smoke once in while.

Do you ever smoke cigarettes from a packet or self-rolled cigarettes?

yes  
no  
refuses/doesn't know

S3 How many cigarettes do you smoke on an average day?

... number  
refuses/doesn't know

SD4 Do you ever smoke cigars or a pipe?

yes  
no  
refuses/doesn't know

SD5 You have told that you don't smoke. Did you smoke in the past?

yes  
no  
refuses/doesn't know

SD6 Did you do that:

daily  
not daily  
refuses/doesn't know

SD8 Do you do this:

daily  
a few times per week  
once a week  
1 to 3 times per month  
less than once per month  
refuses/doesn't know

G10. Do you smoke?

Yes, daily  
Yes, once in a while  
No, but daily in the past  
No, but once in a while in the past  
No, has never smoked  
Refuses/don't know

**The Netherlands 2001**

LRV1 Do you ever smoke yourself?

yes  
no

LRV2 Do you smoke every day?

yes, every day  
yes, sometimes  
no

LRV3a Do you smoke cigarettes? (from a pack or roll your own)

yes  
no

LRV3b How many cigarettes do you smoke on average a day or a week?

Number  
a day  
a week

LRV3c How many?

...

LRV4a Do you smoke cigars?

yes  
no

LRV4b How many cigars do you smoke on average a day or a week?

Number  
a day  
a week

LRV4c How many?

...

LRV5a Do you smoke a pipe?

yes  
no

LRV5b How many (50 gram) packets of pipe tobacco do you smoke on average a week or a month?

a week  
a month

LRV5c1 How many?

...

LRV6 Did you used to smoke cigarettes?

yes, every day  
yes, occasionally  
no

LRV6b If you count all the cigarettes you have ever smoked in your life, does it come to more than 100?

Yes  
No

LRV7 How old were you when you started smoking cigarettes?

I was ... years old



## **Appendix D – Questionnaires Hearing Impairment**

## Tables of questionnaires hearing impairment

### 1. Hearing Handicap Inventory in the Elderly – Screening Questionnaire.

Source: on most of the resulted websites and in articles

Instructions: Check one answer for each question. Do not skip a question if you avoid a situation because of a hearing problem. If you use a hearing aid, please answer according to the way you hear without the aid.

Question	Yes	No	Sometimes
1. Does a hearing problem cause you to feel embarrassed when you meet new people?			
2. Does a hearing problem cause you to feel frustrated when talking to members of your family?			
3. Do you have difficulty hearing when someone speaks in a whisper?			
4. Do you feel handicapped by a hearing problem?			
5. Does a hearing problem cause you difficulty when visiting friends, relatives, or neighbors?			
6. Does a hearing problem cause you to attend religious services less often than you would like?			
7. Does a hearing problem cause you to have arguments with family members?			
8. Does a hearing problem cause you difficulty when listening to TV or radio?			
9. Do you feel that any difficulty with your hearing limits or hampers your personal or social life?			
10. Does a hearing problem cause you difficulty when in a restaurant with relatives or friends?			

Scoring: No = 0; Sometimes = 2; Yes = 4

Interpretation of Total Scores: 0-8 = no handicap; 10-24 = mild to moderate handicap; 26-40 = severe handicap.

## 2. Hearing questionnaire which is used in the Women's Health and Aging Study.

Source: <http://www.nia.nih.gov/health/pubs/whasbook/chap14/chap14.htm>

### Table 14.4: Percent Reporting Hearing Problems

Do you use a hearing aid?

Can you hear well enough to use the telephone?

Can you hear well enough to carry on conversation in a crowded room?

Do you have trouble hearing another person if there is a radio or TV playing in the same room?

Do you have difficulty hearing when someone speaks in a whisper?

Does a hearing problem cause you to feel frustrated when talking to members of your family?<sup>4</sup>

Does a hearing problem cause you to attend church, movies, concerts or other events less often than you would like?<sup>4</sup>

Does a hearing problem cause you to have arguments with family members?<sup>4</sup>

Does a hearing problem cause you difficulty when listening to television or the radio?<sup>4</sup>

Do you feel that any difficulty with your hearing limits or hampers your personal or social life?<sup>4</sup>

<sup>4</sup> Item from Hearing Handicap Inventory for the Elderly-Screening Version. Ventry IM, Weinstein B. (1982). The Hearing Handicap Inventory for the Elderly: A new tool. *Ear Hear* 3:128-134.

**3. Questions on questionnaires from national health population surveys in the HIS/ HES Database.**

Source: <https://www.iph.fgov.be/hishes>

<b>Questions related to hearing impairment</b>
--

*Australia: National health survey 2001*

AF542. DO YOU HAVE ANY HEARING PROBLEMS OR PROBLEMS WITH YOUR EARS THAT HAVE LASTED, OR ARE EXPECTED TO LAST, FOR 6 MONTHS OR MORE?

Yes

No

AF543. WHAT HEARING OR EAR PROBLEMS DO YOU HAVE?

Total deafness

Deaf in 1 ear

Hearing loss/partially deaf

Tinnitus

Meniere's Disease/Syndrome

Otitis media

Other, please specify: ...

Don't know

---

*Canada: Canadian community health survey cycle 2000*

The next few questions deal with any health limitations which affect your daily activities. In these questions, 'long-term conditions' refer to conditions that have lasted or are expected to last 6 months or more.

RA1 Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?

Sometimes

Often

Never

The next set of questions asks about your day-to-day health. The questions are not about illnesses like colds that affect people for short periods of time. They are concerned with a person's usual abilities.

You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone.

UI06 Are you usually able to hear what is said in a group conversation with at least 3 other people without a hearing aid?

Yes  
No

UI07 Are you usually able to hear what is said in a group conversation with at least 3 other people with a hearing aid?

Yes  
No

UI07A Are you able to hear at all?

Yes  
No

UI08 Are you usually able to hear what is said in a conversation with one other person in a quiet room without a hearing aid ?

Yes  
No

UI09 Are you usually able to hear what is said in a conversation with one other person in a quiet room with a hearing aid?

Yes  
No

---

***US: National health interview survey2000***

ACN.420      Which statement best describes your hearing  
(without a hearing aid): good, a little trouble, a lot  
of trouble, deaf?

Good  
Little trouble  
Lot of trouble  
Deaf  
Refused  
Don't know

---

***UK: Health survey for England 2001***

NoVol.      Can you follow a TV programme with the volume turned  
up?  
WITH HEARING AID IF NORMALLY WORN.

Yes  
No

HearAid.    Can I check, do you wear a hearing aid most of the time?

Yes  
No

NoHrAid.    Can you hear well enough to follow a TV programme at  
a volume others find acceptable without your hearing aid?

Yes  
No

ComHear    Are your communication problems to do with your speech?

Yes  
No

Are your communication problems to do with your  
hearing?

Yes  
No

---

***UK: General household survey 2002***

1.HearDiff. Do you ever have any difficulty with your hearing?

Yes

No

3.AidDiff. Do you ever have any difficulties with your hearing even when you're wearing an aid?

Yes

No

---

***UK: Disability survey 1997***

94. Do you wear a hearing aid at all?

Yes

No

96. Do you have difficulty hearing someone talk in a quiet room?

Yes

No

97. Do you have great difficulty following a conversation if there is background noise - for example a T.V., radio or children playing?

Yes

No

98. Can you follow a TV programme with the volume turned up?

Yes

No

99. Can you hear someone talking in a loud voice in a quiet room without difficulty?

Yes

No

100. Can you hear a doorbell, alarm clock or telephone bell?

Yes

No

102. Can you follow a TV programme at a volume others find acceptable?

Yes

No

103. How old were you when you first had this difficulty with hearing?

... year

104. For how long has the difficulty you have with hearing lasted?

... number of months

105. Is this difficulty you have with your hearing greater or less than it was a year ago, that is since ... (INSERT DATE), or is it about the same?

Greater than a year ago

Less than a year ago

About the same

106. Do you think you will have this amount of difficulty with your hearing for at least the next 6 months?

Yes

No

---

***The Netherlands: Patient survey-Second Dutch national survey of general practice 2001***  
(Questions related to visual and hearing impairment on the questionnaire used in this survey were selected from the validated questionnaire of the Organisation for Economic Co-operation and Development (OECD))

GEZV16a The following questions are about what you can do, if necessary with the aids you usually use.

These are not concerned with temporary problems.

You can use CARD 19

Can you follow a conversation in a group of 3 or more persons  
(if necessary using a hearing aid)?

yes, without difficulty  
yes, with a little difficulty  
yes, with great difficulty  
no, I cannot

GEZV16b Can you conduct a conversation with one other person? (using a hearing aid if necessary)?

yes, without difficulty  
yes, with a little difficulty  
yes, with great difficulty  
no, I cannot

---

## **Appendix E - Questionnaires vision impairment**

## Tables of questionnaires vision impairment

### 1. Vision questionnaire which is used in the Women's Health and Aging Study.

Source: <http://www.nia.nih.gov/health/pubs/whasbook/chap14/chap14.htm>

#### Table 14.1: History of Ocular Conditions

Has a doctor ever told you that you had . . . ?

Glaucoma or suspected glaucoma

Cataract<sup>4</sup>

One eye only

Both eyes

No cataract

Diabetic retinopathy or eye disease from diabetes

Macular degeneration or age related maculopathy

An eye injury which permanently reduced your ability to see

Double vision

<sup>4</sup> Constructed from responses to two questionnaire items: (1) Has a doctor ever told you that you had a cataract in one eye?(2) Has a doctor ever told you that you had cataracts in both eyes, at the same time?

**Table 14.2: Vision Problems**

Do you have glasses or contact lenses?

Yes

If yes: Do you wear them . . . ?

Most of the time

Sometimes

For special reasons, such  
as reading or driving

Never

Can you see well enough to recognize someone across the room?<sup>5</sup>

Can you see well enough to watch TV?<sup>5</sup>

Can you see well enough to read the newspaper?<sup>5</sup>

Do you ever have trouble with blurred vision?

<sup>5</sup>When applicable, the phrase, "with glasses, if needed," is embedded in the questionnaire item.

**2. A visual function questionnaire. These questions were asked to non-acceptors of cataract surgery 1 year after an offer to undergo surgery.**

Source: Snellingen T, Shrestha BR, Gharti MP, Shrestha JK, Upadhyay MP, Pokhrel RP. Socioeconomic barriers to cataract surgery in Nepal: the south Asian cataract management study Br J Ophthalmol 1998;82:1424-1428 ( December )  
<http://bjo.bmjournals.com/cgi/content/full/82/12/1424>

**Table 1** Visual function questionnaire

<i>Variable</i>	<i>Question</i>	<i>Grading</i>
Self assessment of vision	In general, would you say your vision (with glasses if you are wearing them) is:	very good, 1; good, 2; fair, 3; poor, 4
Visual function:		
Limitation of daily activities	To what extent does your eye sight limit you in your daily activities?	not at all, 1; a little, 2; quite a bit, 3; a lot, 4
Recognition of face	Do you have a problem recognising the face of a person standing near you?	not at all, 1; a little, 2; quite a bit, 3; a lot, 4
Identifying small objects	Do you have a problem recognising small or minute objects (such as grains or the lines on your hand)?	not at all, 1; a little, 2; quite a bit, 3; a lot, 4
Dark adaptation	Do you have a problem adjusting to darkness after being in bright light?	not at all, 1; a little, 2; quite a bit, 3; a lot, 4
Light adaptation	Do you have a problem adjusting to brightness after being in a dark place?	

### 3. Functional screening questionnaire

Source: [http://www.lighthouse.org/aging\\_vision/summer2002/serious\\_vision\\_impairment.htm](http://www.lighthouse.org/aging_vision/summer2002/serious_vision_impairment.htm)

**Please check all that apply.**

1. Do you wear:

- glasses
- contact lenses
- intraocular lenses
- no glasses

How do you rate your vision with your present glasses:

- good
- adequate
- poor

2. Can you see signs?

3. When did you last read a newspaper or periodical?

4. Have you had pain? redness? burning? itching?

5. Have you noticed floaters?

6. Do bright lights cause glare? Do you have difficulty seeing in the dark?

7. Do you have difficulty seeing the edge of stairs or curbs?

8. Can you identify a person's facial features?

9. Do you bump into objects off to the side?

10. Are you driving? If not, why did you stop?

11. Do you have to rely on others to write checks? shop?

12. Have you had to give up a hobby or an interest because of vision?

**4.Functional vision screening questionnaire for older people from Lighthouse international.**

Source: [http://www.lighthouse.org/bigtype/functional\\_vision.htm](http://www.lighthouse.org/bigtype/functional_vision.htm)

**Do you ever feel that problems with your vision make it difficult for you to do the things you would like to do?**

- Yes            1 pt.
- No             0 pts.

**Can you see the large print headlines in the newspaper?**

- Yes            0 pts.
- No             1 pt.

**Can you see the regular print in newspapers, magazines or books?**

- Yes            0 pts.
- No             1 pt.

**Can you see the numbers and names in a telephone directory?**

- Yes            0 pts.
- No             1 pt.

**When you are walking in the street, can you see the "WALK" sign and street name signs?**

- Yes            0 pts.
- No             1 pt.

**When crossing the street, do cars seem to appear very suddenly?**

- Yes            1 pt.
- No             0 pts.

**Does trouble with your vision make it difficult for you to watch TV, play cards, sew, or do any similar type of activity?**

- Yes            1 pt.
- No             0 pts.

**Does trouble with your vision make it difficult for you to see labels on medicine bottles?**

- Yes            1 pt.
- No             0 pts.

**Does trouble with your vision make it difficult for you to read prices when you**

**shop?**

- Yes 1 pt.
- No 0 pts.

**Does trouble with your vision make it difficult for you to read your own mail?**

- Yes 1 pt.
- No 0 pts.

**Does trouble with your vision make it difficult for you to read your own handwriting?**

- Yes 1 pt.
- No 0 pts.

**Can you recognize the faces of family or friends when they are across an average size room?**

- Yes 0 pts.
- No 1 pt.

**Do you have any particular difficulty seeing in dim light?**

- Yes 1 pt.
- No 0 pts.

**Do you tend to sit very close to the television?**

- Yes 1 pt.
- No 0 pts.

**Has a doctor ever told you that nothing more can be done for your vision?**

- Yes 1 pt.
- No 0 pts.

Scores are indicated next to the answers for each item. A total score of nine (9) or more points indicates the need for a vision examination conducted by an optometrist or ophthalmologist.

**5. Self-administered questionnaire that can help identify individuals needing evaluation of their vision.**

Source: <http://www.vnh.org/PreventionPractice/ch45.html>

**Table 45.1. Visual Impairment Questionnaire**

<b>Does your vision (with glasses if you wear them) make it difficult for you to -- (place a check mark next to each question you answer yes)</b>
<input type="checkbox"/> Feed yourself?
<input type="checkbox"/> Recognize your pills or read medication labels?
<input type="checkbox"/> Dress yourself (find fasteners, button buttons)?
<input type="checkbox"/> Groom yourself (shave and wash without missing areas)?
<input type="checkbox"/> Handle your money (make change, write checks)?
<input type="checkbox"/> Recognize people (nearby, across the street)?
<input type="checkbox"/> Avoid bumping into objects when moving about in your house?
<input type="checkbox"/> Find your way around in places outside your own home (stores, shopping malls)?
<input type="checkbox"/> Read ordinary newsprint?
<b>Place a check mark next to each visual aid you now use</b>
<input type="checkbox"/> Glasses
<input type="checkbox"/> Contact lenses
<input type="checkbox"/> Magnifying lenses
<input type="checkbox"/> Portable lights
<input type="checkbox"/> Large print books
<input type="checkbox"/> Writing guides
One or more "yes" answers indicates the need for further visual acuity testing. Use of one or more visual aids is an indication for review of the patient's last optometric or ophthalmologic examination.

## 6. The VF-14 questionnaire to assess functional impairment in patients with cataracts.

Source: <http://www.medal.org/ch19.html>

### The VF-14 Questionnaire

Overview:

The VF-14 is a brief questionnaire designed to measure functional impairment on patients due to cataract. It consists of 18 questions covering 14 aspects of visual function affected by cataracts. The VF-14 shows high internal consistency and is a reliable valid instrument providing information not conveyed by visual acuity or general health status measures.

#### General Functioning

- (1) Do you have any difficulty even with glasses reading small print such as labels on medicine bottles a telephone book food labels?
- (2) Do you have any difficulty even with glasses reading a newspaper or a book?
- (3) Do you have any difficulty even with glasses reading a large-print book or large-print newspaper or numbers on a telephone?
- (4) Do you have any difficulty even with glasses recognizing people when they are close to you?
- (5) Do you have any difficulty even with glasses seeing steps stairs or curbs?
- (6) Do you have any difficulty even with glasses reading traffic signs street signs or store signs?
- (7) Do you have any difficulty even with glasses doing find handwork like sewing knitting crocheting carpentry?
- (8) Do you have any difficulty even with glasses writing checks or filling out forms?
- (9) Do you have any difficulty even with glasses playing games such as bingo dominos card games mahjong?
- (10) Do you have any difficulty even with glasses taking part in sports like bowling handball tennis golf?
- (11) Do you have any difficulty even with glasses cooking?
- (12) Do you have any difficulty even with glasses watching television?

<b>Response</b>	<b>Points</b>
not applicable	
no	4
yes with a little difficulty	3
yes with a moderate amount of difficulty	2
yes with a great deal of difficulty	1
yes and am unable to do the activty	0

### Driving

(13) Do you currently drive a car?

- if Yes go to 14
- if No go to 16

(14) How much difficulty do you have driving during the day because of your vision?

- no difficulty (4 points)
- a little difficulty (3 points)
- a moderate amount of difficulty (2 points)
- a great deal of difficulty (1 point)

(15) How much difficulty do you have driving at night because of your vision?

- no difficulty (4 points)
- a little difficulty (3 points)
- a moderate amount of difficulty (2 points)
- a great deal of difficulty (1 point)

(16) Have you ever driven a car?

- if Yes go to 17
- if No stop

(17) When did you stop driving?

- less than 6 months ago
- 6-12 months ago
- more than 12 months ago

(18) Why did you stop driving?

- vision
- other illness
- other reason

### Scoring

An item is not included in scoring if the person does not do the activity for some reason other than their vision.

Scores on all activities that the person performed or did not perform because of vision were then averaged yielding a value from 0 to 4.

This value was multiplied by 25 giving a final score from 0 to 100.

- a score of 100 indicates able to do all applicable activities
- a score of 0 indicates unable to do all applicable activities because of vision

### References:

Parrish RK II. Visual impairment visual functioning and quality of life assessments in patients with glaucoma. *Trans Am Ophth Soc.* 1996; 94: 919-1028 (page 924).

Steinberg EP Tielsch JM et al. The VF-14 An index of functional impairment in patients with cataract. *Arch Ophthalmol.* 1994; 112: 630-638.

**7. Questions on questionnaires from national health population surveys in the HIS/ HES Database.**

Source: <https://www.iph.fgov.be/hishes>

<b>Questions related to visual impairment</b>
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*Australia: National health survey 2001*

AF522. I WOULD NOW LIKE TO ASK YOU ABOUT YOUR EYESIGHT.

ARE YOU COLOUR BLIND?

Yes  
No

AF526. DO YOU HAVE ANY (OTHER) PROBLEMS WITH YOUR SIGHT?

Yes  
No  
Don't know

AF528. WHAT (OTHER) SIGHT PROBLEMS DO YOU HAVE THAT CAN BE CORRECTED, OR PARTIALLY CORRECTED, BY GLASSES OR CONTACT LENSES?

Show Prompt Card 18:

Astigmatism  
Short-sightedness/Myopia  
Age-related sight problems/Presbyopia  
Long-sightedness/Hyperopia  
Other, please specify: ...  
Don't know

AF530. DO YOU HAVE ANY (OTHER) SIGHT PROBLEMS?

Yes  
No  
Don't know

AF531. WHAT (OTHER) SIGHT PROBLEMS DO YOU HAVE?

Totally blind in both eyes  
Totally blind in 1 eye only  
Partially blind in both eyes  
Partially blind in 1 eye only  
Glaucoma  
Cataracts  
Trachoma  
Lazy eye/Strabismus  
Other, please specify: ...  
Don't know

---

*Canada: Canadian community health survey cycle 2000*

The next few questions deal with any health limitations which affect your daily activities. In these questions, 'long-term conditions' refer to conditions that have lasted or are expected to last 6 months or more.

RA1 Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?

Sometimes  
Often  
Never

The next set of questions asks about your day-to-day health. The questions are not about illnesses like colds that affect people for short periods of time. They are concerned with a person's usual abilities.

You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone.

UI01 Are you usually able to see well enough to read ordinary newsprint without glasses or contact lenses?

Yes  
No

UI02 Are you usually able to see well enough to read ordinary newsprint with glasses or contact lenses?

Yes  
No

UI03 Are you able to see at all?

Yes  
No  
DK, R

UI04 Are you able to see well enough to recognize a friend on the other side of the street without glasses or contact lenses?

Yes  
No  
DK, R

UI05 Are you usually able to see well enough to recognize a friend on the other side of the street with glasses or contact lenses?

Yes  
No

---

***US: National health interview survey2000***

ACN.430 Do you have any trouble seeing, even when wearing glasses or contact lenses?

Yes  
No  
Refused  
Don't know

ACN.440 Are you blind or unable to see at all?

Yes  
No  
Refused  
Don't know

---

***UK: Health survey for England 2001***

NoArmSee. Can you see well enough to recognise a friend one yard away (at arm's length)?  
WITH GLASSES OR CONTACT LENSES IF NORMALLY WORN.

Yes  
No

Glasses. Can I check, do you wear glasses or contact lenses most of the time?

Yes  
No

NoGlas. Can you see well enough to recognise a friend across the road (four yards away) without glasses or contact lenses?

Yes  
No

ComVis. Are your communication problems to do with your vision?

Yes  
No

---

***UK: Disability survey 1997***

81. Do you have difficulty recognising a friend across the road?

Yes  
No

82. Do you have difficulty reading ordinary newspaper print?

Yes  
No

83. Can I check, while you are wearing glasses or lenses, and in a room during daytime, can you tell by the light where the windows are?

Yes  
No

84. Can you see the shapes of the furniture in this room?

Yes

No

85. Can you see well enough to recognise a friend if you get close to his or her face?

Yes

No

86. Can you see well enough to recognise a friend who is an arm's length away?

Yes

No

87. Can you see well enough to read a newspaper headline?

Yes

No

88. Can you see well enough to read a large print book?

Yes

No

89. Can you see well enough to recognise a friend across the room?

Yes

No

90. How old were you when you first had this difficulty with seeing?

... year

91. For how long has the difficulty you have with seeing lasted?

... number of months

92. Is this difficulty you have with seeing greater or less than it was a year ago, that is since ... (insert date), or is it about the same?

Greater than a year ago

Less than a year ago

About the same

93. Do you think you will have this amount of difficulty with your seeing for at least the next 6 months?

Yes

No

---

***The Netherlands: Patient survey-Second Dutch national survey of general practice 2001***

(Questions related to visual and hearing impairment on the questionnaire used in this survey were selected from the validated questionnaire of the Organisation for Economic Co-operation and Development (OECD))

The following questions are about what you can do, if necessary with the aids you usually use.

These are not concerned with temporary problems.

GEZV16c Are your eyes good enough to be able to read small print in the newspaper? (using glasses or contact lenses if necessary)?

yes, without difficulty  
yes, with a little difficulty  
yes, with great difficulty  
no, I cannot

GEZV16d Can you recognise someone's face at a distance of 4 metres (with glasses or contact lenses if necessary)?

yes, without difficulty  
yes, with a little difficulty  
yes, with great difficulty  
no, I cannot

---

## **Appendix F - Questionnaires on Glaucoma**

## Tables of questionnaires on Glaucoma

### 1. A questionnaire to assess if someone is at higher risk for glaucoma.

Source: [http://www.preventblindness.org/eye\\_tests/glaucoma.html](http://www.preventblindness.org/eye_tests/glaucoma.html)

## Glaucoma

Glaucoma is a leading cause of blindness in the United States today. It is a gradual, progressive eye disease associated with pressure build-up within the eye. It usually progresses with no pain or other symptoms.

Although sight lost to glaucoma can never be restored, early diagnosis and prompt treatment may bring glaucoma under control and halt its progress. If you answer yes to the following questions, you are at a higher risk for glaucoma, and Prevent Blindness America recommends you see your doctor annually.

- Do you have diabetes?
- Do you have blood relatives with glaucoma?
- Has a doctor treated you for or said you have glaucoma?
- Have you had an eye injury or eye surgery?
- Have you noticed a change in vision in the last 12 months?
- Are you African-American and over the age of 45?
- Are you over age 65?
- Was your last eye exam more than two years ago?
- Was your last dilated eye exam more than two years ago?

If you answered yes to one or more questions, you should arrange for a professional eye exam.

## **2. Glaucoma information on the website of the Medical Algorithm Project.**

Includes a glaucoma symptom scale and a risk factor count of glaucoma in a patient with ocular hypertension.

Source: <http://www.medal.org/ch19.html>

# **Glaucoma**

## **1 Glaucoma Symptom Scale**

Overview:

The glaucoma symptom scale is a brief symptom index for evaluating patients with glaucoma. It is a modified version of the Ocular Hypertension Treatment Study (OHTS) 10-item symptom checklist.

### Symptoms

Nonvisual ocular symptoms (items 1 - 6)

- (1) burning smarting stinging
- (2) tearing
- (3) dryness
- (4) itching
- (5) soreness tiredness
- (6) blurry or dim vision

Visual ocular complaints (items 7-10)

- (7) feeling of something in the eye
- (8) hard to see in daylight
- (9) hard to see in dark places
- (10) halos around lights

Scoring:

<b>Have you experienced the problem in the last 4 weeks?</b>	<b>Points</b>
yes very bothersome	0
yes somewhat bothersome	1
yes a little bothersome	2
yes but not bothersome at all	3
no absent	4

The scores are converted to a range of 0 to 100 (by multiplying by 25).

average score for each eye =

= (SUM(points for all 10 symptoms))/ 10

average score for both eyes

= ((score for left eye) + (score for right eye)) / 2

Interpretation:

- minimum average score: 0
- maximum average score: 100
- The higher the score the less the person is bothered by glaucoma-related symptoms.

References:

Lee BL Gutierrez P et al. The glaucoma symptom scale. A brief index of glaucoma-specific symptoms. Arch Ophthalmol. 1998; 116: 861-866.

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### **3 American Academy of Ophthalmology Guidelines for Followup of Patients with Primary Open Angle Glaucoma**

Overview:

The American Academy of Ophthalmology developed guidelines for recommended followup of patients with primary acute angle glaucoma.

<b>Target IOP Achieved?</b>	<b>Progression of Damage?</b>	<b>Duration of Control in Months?</b>	<b>Followup Interval</b>
Y	N	$\leq 6$	1 – 6 months
Y	N	$> 6$	3 –12 months
Y	Y	N/A	1 week to 3 months
N	N	N/A	1 day to 3 months
N	Y	N/A	1 day to 1 month

where:

- IOP = intraocular pressure
- N/A = not applicable

<b>Target IOP Achieved?</b>	<b>Progression of Damage?</b>	<b>Duration of Control in Months?</b>	<b>Optic Nerve Evaluation</b>
Y	N	$\leq 6$	6 - 12 months
Y	N	$> 6$	6 - 18 months
Y	Y	N/A	3 - 12 months
N	N	N/A	3 - 12 months
N	Y	N/A	3 - 12 months

<b>Target IOP Achieved?</b>	<b>Progression of Damage?</b>	<b>Duration of Control in Months?</b>	<b>Visual Field Evaluation</b>
Y	N	$\leq 6$	6 - 12 months
Y	N	$> 6$	6 - 24 months
Y	Y	N/A	2 - 6 months
N	N	N/A	2 - 6 months

N	Y	N/A	1 - 6 month
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References:

American Academy of Ophthalmology. Primary open-angle glaucoma. 1996. National Guideline Clearinghouse. [www.guideline.gov](http://www.guideline.gov).

Rosenberg LF Krupin T. Chapter 12.11: Primary open-angle glaucoma. pages 12.11.1-12.11.6 (Figure 11.9). IN: Yanoff M Duker JS. Ophthalmology. Mosby. 1999.

**4 Risk Factor Count of Cummins et al for Development of Glaucoma in a Patient with Ocular Hypertension**

Overview:

Certain risk factors are associated with development of visual field defects in patients with ocular hypertension. Cummins et al developed a risk factor count which measured these factors.

Risk factors:

- (1) age
- (2) family history
- (3) intraocular pressure
- (4) cup-to-disc ratio

Parameter	Finding	Points
age	< 60 years of age	0
	>= 60 years of age	1
family history	negative for glaucoma	0
	positive for glaucoma	1
intraocular pressure	<= 28 mm Hg	0
	> 28 mm Hg	1
cup-to-disc ratio	> 0.5	1

	interocular difference > 0.2	1
	neither	0

where:

- cup-to-disc ratio = (diameter of optic nerve cup) / (diameter of optic nerve disc)
- interocular difference = ABS((left eye cup-to-disc ratio) – (right eye cup-to-disc ratio))

risk factor count =

= SUM(points for the 4 parameters)

Interpretation:

- minimum count: 0
- maximum count: 4
- The higher the count the greater the risk for developing visual field defects.
- Patients with risk factors for developing visual field defects should be screened frequently to detect early changes.

References:

Cummins D MacMillan ES et al. Simultaneous interocular brightness sense testing in ocular hypertension and glaucoma. Arch Ophthalmol. 1994; 112: 1198-1203.

Kass MA Hart WM Jr et al. Risk factors favoring the development of glaucomatous visual field loss in ocular hypertension. Survey Ophthalmology. 1980; 25: 155-162.

Shields MB. Textbook of Glaucoma Fourth Edition. Williams & Wilkins. 1998. Chapter 5: Optic nerve head and peripapillary retina. pages 72-107.

## 5 An Algorithm for Glaucoma Screening by Primary Care Providers

Overview:

Since glaucoma is common and a leading cause of blindness primary care providers should screen their patients for glaucoma when risk factors are present. This can help identify patients who should be referred to an ophthalmologist for evaluation.

Criteria for screening:

- (1) age >- 40 years of age
- (2) one or more risk factors for glaucoma (family history racial predisposition etc.)

Equipment required:

- (1) direct ophthalmoscope
- (2) non-contact tonometry unit
- (3) semi-automated visual field analyzer

Screening examinations:

- (1) assessment of optic disc with the direct ophthalmoscope
- (2) measurement of intraocular pressure of each eye
- (3) visual field analysis if indicated

Measure the average intraocular pressure (IOP) in each eye.

- Measure the intraocular pressure in each eye 4 times.
- Determine the average value

<b>Left Eye IOP</b>	<b>Right Eye IOP</b>	<b>Action</b>
<= 22 mm Hg	<= 22 mm Hg	discharge to next screen
<= 22 mm Hg	> 22 mm Hg	perform visual field analysis (go to next table)
> 22 mm Hg	<= 22 mm Hg	perform visual field analysis (go to next table)
> 22 mm Hg	> 22 mm Hg	refer to specialist

Visual Field Analysis with Increased IOP in One Eye

<b>Left Eye Visual Field</b>	<b>Right Eye Visual Field</b>	<b>Action</b>
normal	normal	repeat IOP in 1 month (go to next table)

normal	abnormal	refer to specialist
abnormal	normal	refer to specialist
abnormal	abnormal	refer to specialist

Repeat IOP Measurement After Normal Visual Field Analysis\

Repeat Left Eye IOP	Repeat Right Eye IOP	Action
<= 22 mm Hg	<= 22 mm Hg	discharge to next screen
<= 22 mm Hg	> 22 mm Hg	refer to specialist
> 22 mm Hg	<= 22 mm Hg	refer to specialist
> 22 mm Hg	> 22 mm Hg	refer to specialist

Limitations:

- Glaucoma-related ocular damage may occur at pressures <= 22 mm Hg.
- A person presenting with signs or symptoms of an acute glaucoma attack should be referred immediately for emergency evaluation.

References:

Vernon S. How to screen for glaucoma. *The Practitioner*. 1995; 239: 257-260. (Figure 1 page 258)

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## 6 Using the Family Score (FS) in the Evaluation of a Patient for Open Angle Glaucoma (OAG)

Overview:

Hulsman et al used the Family Score (FS) of Houlwing-Duistermaat and Van Houwelingen to evaluate a patient for open angle glaucoma. This can help identify the degree of genetic risk in the patient's family. The authors are from multiple ophthalmic institutes in Amsterdam and Rotterdam in the Netherlands.

family score =

$$= 10 * \text{SUM}(\text{factor relative 1}) \dots (\text{factor relative N})$$

factor for relative =

$$= ((\text{observed diseased status}) - (\text{expected value based on age and gender})) * (\text{kinship coefficient})$$

<b>Disease Status</b>	<b>Points</b>
affected	1
not affected	0

<b>Prevalence of Definite Open Angle Glaucoma in Cohort of 6 281 Independently Living Subjects</b>		
<b>Age</b>	<b>Male</b>	<b>Female</b>
< 55	0	0
55 - 59	0.002	0
60 - 64	0.006	0.001
65 - 69	0.008	0.009
70 - 74	0.013	0.011
75 - 79	0.019	0.006
>= 80	0.036	0.013

from Table 1 page 1728

<b>Kinship</b>	<b>Coefficient</b>
sibling	0.25
half-sibling	0.125
children	0.25

from page 1727; parents and other relatives not scored

where:

- The prevalence value for women 75-79 years of age seems out of pattern for the other ages. The patients listed as probable OAG also seemed out of pattern.
- The family score can also be calculated based on prevalence of both definite and probable open-angle glaucoma. These values are listed in Table 1 on page 1728.

Interpretation:

- A positive score indicates a genetic risk in the family for open-angle glaucoma.
- A score of 0 is indeterminate.
- A negative score indicates that genetic risk for the family is low.
  - The odds ratio for the family score based on definitely affected relatives was 3.3 (see Table 4 page 1729).

Limitations:

- A small or young relative pool provides little information on genetic risk.

References:

Houwing-Duistermaat JJ Van Houwelingen HC. Incorporation of family history in logistic regression models. *Stat Med.* 1998; 17: 2865-2882.

Hulsman CAA Houwing-Duistermaat JJ et al. Family score as an indicator of genetic risk of primary open-angle glaucoma. *Arch Ophthalmol.* 2002; 120: 1726-1731.

**Appendix G – Questionnaires about use of medication  
(analgetics, sleeping drugs)**

## Tables of questionnaires medication

### 1. Questions used in national population risk factor surveys.

Source: The European Health Risk Monitoring project  
<http://www.ktl.fi/publications/ehrm/product1/title.htm>

<b>Use of acetylsalicylic acid</b>
------------------------------------

Many studies have shown that daily use of acetylsalicylic acid (aspirin™) in low doses is beneficial for treatment and prevention of cardiovascular disease. (1, 2)

#### 1 Questions

##### 1.1 WHO MONICA Project

In the MONICA Manual (3) there is one question about the use of aspirin™.

1. "Are you taking (in the last two weeks) aspirin tablets to prevent or treat heart disease?"
- 1 = Yes, taking tablets for this reason  
2 = No, I am not taking aspirin tablets  
3 = No, but I am taking tablets for reasons unconnected with heart condition  
9 = Insufficient data

The MONICA Manual (3) had additional instructions for *Question 1*.

Code 1 if yes.

Code 2 if the person is not taking aspirin regularly. Include here persons who had taken occasional aspirin tablets in the last two weeks.

Code 3 if the person is regularly taking aspirin for other reasons than for heart disease prevention or treatment.

Code 9 if insufficient information is available to use the other codes.

##### 1.2 Risk factor monitoring in the Netherlands

In the *Monitoring Project on Cardiovascular Disease Risk Factors* following questions were used for aspirin use (4):

1. Do you ever use aspirin?
1. Yes  
2. No
2. If yes, how many tablets/month?

3. Which brand?

In the *MORGEN*-project the information about the use of aspirin was collected when all medications used in the past week were recorded (4).

**1.3 Risk factor monitoring in Germany**

The German *Federal Health Survey 1998* collected through a physician interview information on the use of pharmacological agents. These were then grouped into 34 categories depending on their indication (5). The question asked whether, during the past 12 months, medications of a particular drug category were used :

daily, or several times per week, or 1-2 times per week, or less than once a week, or 1-3 times per month, or seldom, or never.

There was no drug category for "aspirin for heart disease".

**1.4 UK National Health Surveys**

No information available

**1.5 National Health and Nutrition Examination Survey (NHANES III), USA**

In the household adult questionnaire, the following questions about the use of acetylsalicylic acid were asked of subject aged 17 years and over (6):

1. In the past month, have you taken any aspirin, Anacin, Bufferin, Ecotrin,  Ascriptin, or Midol?
  1. Yes
  2. No
  9. Don't know
  
2. How often did you take aspirin, Anacin, Bufferin, Ecotrin, Ascriptin, or Midol  during the past month?
  - \_\_\_ times per day
  - \_\_\_ times per week
  - \_\_\_ times per month
  - 999 Don't know

**1.6 The Italian OEC Project**

The questionnaire for the Italian *OEC* project contained the following section about the use of aspirin in the prevention and treatment of cardiac disease.

1. During the past two weeks, have you taken aspirin to prevent or to treat heart disease? 
  1. Yes, have taken aspirin for that purpose
  2. No, have not taken aspirin
  3. No, but have taken aspirin for other purpose (non cardiac disease)
  4. Insufficient data
2. What is the name of the aspirin containing medication that you take? | \_\_\_\_\_|
3. Do you take it daily? Yes No
4. Number of pills per day   
Number of pills per week

## 12.2 Quality assurance

### *WHO MONICA Project*

The detailed information about the availability and quality of data on use of acetylsalicylic acid is given in the Quality Assessment of Data on Use of Aspirin in the WHO MONICA Project (7). The most common deviation from the standard MONICA format was omitting the alternative "*No, but I am taking tablets for reasons unconnected with heart condition*".

No information on retrospective quality assurance was available for *Risk factor monitoring in the Netherlands*, *Risk factor monitoring in Germany*, *UK National Health Surveys*, and *NHANES III*.

## 12.3 Indicators used for reporting the results

### *WHO MONICA Project*

In the WHO MONICA Project the prevalence of acetylsalicylic acid users among survey respondents is reported (8).

### *Risk factor monitoring in Germany*

The German Federal Health Survey 1998 reported prevalence of medication use by drug categories and ranked them by prevalence for men and women and for the old and new states (5), but no specific drug category refers to aspirin use for heart disease.

No information on the indicators for acetylsalicylic acid use was found for *Risk factor monitoring in the Netherlands*, *UK National Health Surveys*, and *NHANES III*.

## 12.4 Discussion and conclusions

If the use of prescription medication is collected by drug name (generic or brand), the drugs can then be grouped retrospectively but would also be available for analysis by individual drug entities.

Studies that focused more broadly on health and had not a narrow interest of cardiovascular disease did not always emphasize the indication for acetylsalicylic acid use or prompt the participant specifically with a question on acetylsalicylic acid use and heart disease.

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**2. Questions on questionnaires from national health population surveys in the HIS/ HES Database.**

Source: <https://www.iph.fgov.be/hishes>

<b>Questions related to use of medication</b>
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*Australia: National health survey 2001*

AF262. SOME PEOPLE TAKE SUPPLEMENTS OR REMEDIES FOR ASPECTS OF THEIR MENTAL WELL-BEING. FOR EXAMPLE, TO IMPROVE THEIR CONCENTRATION OR REDUCE STRESS.

IN THE LAST 2 WEEKS, FOR YOUR MENTAL WELL-BEING, HAVE YOU TAKEN ANY-VITAMIN OR MINERAL SUPPLEMENTS? HERBAL OR NATURAL TREATMENTS OR REMEDIES?  
Neither of these

---

*Canada: Canadian community health survey cycle 1.1 2000*

Now I'd like to ask a few questions about your use of medications, both prescription and over-the-counter.

DG1 A In the past month, that is, from ... (date one month ago to yesterday), did you take:

pain relievers such as aspirin or Tylenol (including arthritis medicine and anti-inflammatories)?

Yes  
No

DG1B tranquilizers such as Valium?

Yes  
No

DG1C diet pills such Redux, Ponderal or Fastin?

Yes  
No

DG1D anti-depressants such as Prozac, Paxil or Effexor?

Yes

No

DG1E codeine, Demerol or morphine?

Yes

No

DG1F allergy medicine such as Seldane or Chlor-Tripolon?

Yes

No

DG1G asthma medications such as inhalers or nebulizers?

Yes

No

DG1H cough or cold remedies?

Yes

No

---

***The Netherlands: Patient survey-Second Dutch national survey of general practice 2001***

ZZV25 Have you taken any medicine purchased without a prescription during the past 14 days?

yes

no

ZZV26 What medicine was this?

You can name several from CARD 42.

medicine against pain or fever, such as aspirin  
medicine for coughs, colds, flu, sore throat, etc.  
vitamins, minerals, tonics and other “pick-me-ups”  
diuretics  
medicine for the heart, blood vessels or blood pressure  
laxatives  
medicine for stomach or intestinal problems or  
indigestion  
sleeping tablets and tranquillisers, medicine to calm  
your nerves  
antibiotics such as penicillin and sulpha drugs  
medicines for the skin (for acne, eczema, itching,  
dandruff, injuries)  
medicines for rheumatism, arthritic pain, etc.  
medicines against allergies  
medicines against asthma  
hormones  
medicines against diabetes  
medicines for the eyes (eye ointment/drops)  
other medicines

ZZV27 When did you last take a medicine acquired without a prescription?

between 15 days and 1 month ago  
between 1 and 6 months ago  
between 7 and 12 months ago  
more than a year ago  
never

POKV20g If you take antibiotics (such as penicillin),  
you can more quickly get rid of complaints such as  
coughs, sore throats and earaches.

agree totally  
agree  
partly agree, partly disagree  
do not agree  
do not agree at all

POKV20h Antibiotics (such as penicillin) have few side effects.

agree totally  
agree  
partly agree, partly disagree  
do not agree  
do not agree at all

---

***The Netherlands: Continuous quality of life survey 1998***

M8 Did you/the child use medication that was bought without prescription during the past 14 days?

yes  
no  
refuses/doesn't know

M9 When did you/the child use medication that was bought without prescription for the last time?

between 15 days and 1 month ago  
1 to 6 months ago  
7 to 12 months ago  
more than 1 year ago  
never  
refuses/doesn't know

M10 What medication was this?

aspirin  
cough, cold, flu, sore throat etc.  
vitamins, minerals, tonics  
for the heart  
laxatives  
for stomach and intestinal complaints  
medication for indigestion  
sedatives and tranquillisers  
medication for nervous disorders  
for the skin  
for rheumatism, arthritis etc.  
homeopathic medication  
other medication  
medication unknown  
refuses/doesn't know

---

***UK: Disability survey 1997***

138. Can you look at this list and tell me whether you regularly buy any of these items?

SHOW CARD L

Yes  
No

Card L

Tissues/toilet paper/kitchen roll Cotton wool  
Dressings/elastoplast Elastic bandages/supports  
Talcum powder Antiseptic or soothing creams  
Vitamins  
Painkillers and other medicines not on prescription  
Disinfectant/bleach  
Other medical supplies

---

***UK: Survey of psychiatric morbidity 1993***

B1b. Those receiving medication or injections or taking pills  
What is their strength?

...

B1c. How many/much are you supposed to have each day?

...

B1d. For what condition do you take them?

...

B1e. How long have you been having this medication?

... year

B1f. Do you sometimes not take your medication even  
though you should?

Yes  
No

B1g. When was the last time this happened?

less than 1 week ago

at least 1 week but less than 1 month ago

at least 1 month ago

B1h. What was the reason for this?

Forgot

Didn't need it

Don't like to take drugs

Side effects

Other, please specify: ...

B1i. Do you sometimes take more medication/pills than the stated dose?

Yes

No

B1j. When was the last time this happened?

less than 1 week ago

B1k. What was the reason for this?

Needed more to control symptoms

Deliberate overdose

Other, please specify: ...

B1m. Have you had any other medication or treatment (condition requiring medication/injections/pills) which you don't have now?

Yes

No

B1n. Did you stop this treatment on your own accord or on professional advice?

Own accord

Professional advice

B1o. What made you decide to stop this treatment?

Side effects

Other, please specify: ...

B1p. Have you ever been offered any other medication or treatment for (condition) which you refused?

Yes

No

B1q. What was it?

...

B1r. Why did you refuse it?

Worry about side effects

Don't like medication/treatment

Other, please specify: ...

B2f. Have you had any other treatment or medication for (condition requiring counselling/therapy) which you don't have now?

Yes

No

B2g. Did you stop this treatment on your own accord or on professional advice?

On own accord

Professional advice

B2h. What made you decide to stop this treatment?

Did not work/was not strong enough

Side effects

Other, please specify:...

B2i. Have you ever been offered any other treatment or medication for (condition requiring counselling/therapy) which you refused?

Yes

No

B2j. What was it?

...

B2k. Why did you refuse it?

Worry about side effects

Don't like medication/treatment

Other, please specify:...

### 3. Questions on a face to face questionnaire used in a health interview survey, carried out by the netherlands

Source: <http://www.iph.fgov.be/epidemiologie/epien/crospen/hisen/his97en/his12.pdf>

#### C. Medicines

Now I'll ask you some question on the use of medicines.

Neither the use of medicines during hospitalisation nor "the pill" must be taken into account here.

**DR.01. Did you use any medicines during the last two weeks ?**

*Int. : These can be earlier prescribed medicines*

- 1. Yes - go to DR.03.
- 2. No
- 9. Don't know
- 1. No answer

**DR.02. When did you use any medicines for the last time?**

\_\_\_/\_\_\_/19\_\_\_

(if date unknown, use the next categories)

- 1.   weeks ago
- 2.   months ago
- 3.   years ago
- 4. Never
- 9. Don't know
- 1. No answer

*Int. : If use of medicines within two weeks, go to DR.03. otherwise go to DR.04.*

DR.03. What type of medicines did you use and who prescribed these ? Just mention the letter in front of the medicine on the next card.

Int. : Show card 4; multiple answers are possible

	Type of medicine	No	Yes	GP	Specialist	Other practitioner	Don't know
a.	Medications for cough, cold, flew, etc .....	2	1	1	2	3	9
b.	Antirheumatics.....	2	1	1	2	3	9
c.	Other pain relievers or antipyretic.....	2	1	1	2	3	9
d.	Restoratives such as vitamins, minerals, tonics.....	2	1	1	2	3	9
e.	Medications for heart, blood vessels or blood pressure.....	2	1	1	2	3	9
f.	Medications for a better brain saturation.....	2	1	1	2	3	9
g.	Diuretics .....	2	1	1	2	3	9
h.	Laxatives.....	2	1	1	2	3	9
i.	Gastro intestinal medicines, digestive preparations.....	2	1	1	2	3	9
j.	Sleepinducing medications .....	2	1	1	2	3	9
k.	Anti-depressants.....	2	1	1	2	3	9
l.	Tranquilizers and other nerve-tonics .....	2	1	1	2	3	9
m.	Antibiotics.....	2	1	1	2	3	9
n.	Remedies for the skin ( acne, eczema, itch, wounds).....	2	1	1	2	3	9
o.	Allergy remedies .....	2	1	1	2	3	9
p.	Anti-asthmatics.....	2	1	1	2	3	9
q.	Hormonal medicines during menopause .....	2	1	1	2	3	9
r.	Antidiabetic drugs (injections included) .....	2	1	1	2	3	9
s.	Medicines for epilepsy (convulsions) .....	2	1	1	2	3	9
t.	Medicines for Parkinson disease.....	2	1	1	2	3	9
u.	Ophthalmics (ointment, drops) .....	2	1	1	2	3	9
v.	Medicines to slim .....	2	1	1	2	3	9
w.	Homeopathic medicines.....	2	1	1	2	3	9
x.	Other medicines, explain .....	2	1	1	2	3	9
y.	Type of medicine unknown.....	2	1	1	2	3	9
z.	No answer .....	-1					

DR.03. What type of free medicines did you use? Just mention the letter before the medicine on the next card.

*Int. : Show card 5; multiple responses are possible*

	Kind of medicine	Yes	No
a.	Medications for cough, cold, flew, etc .....	1	2
b.	Antirheumatics.....	1	2
c.	Other pain relievers or antipyretics.....	1	2
d.	Restoratives such as vitamins, minerals, tonics.....	1	2
e.	Medications for heart, blood vessels or blood pressure.....	1	2
f.	Medications for a better brain saturation.....	1	2
g.	Diuretics .....	1	2
h.	Laxatives.....	1	2
i.	Gastro intestinal medicines, digestive preparations.....	1	2
j.	Sleepinducing medications .....	1	2
k.	Tranquilizers and other nerve-tonics .....	1	2
l.	Remedies for the skin ( acne, eczema, itch, wounds).....	1	2
m.	Allergy remedies .....	1	2
n.	Anti-asthmatics.....	1	2
o.	Ophthalmics (ointment, drops) .....	1	2
p.	Medicines to slim .....	1	2
q.	Homeopathic medicines .....	1	2
r.	Other medicines, explain .....	1	2
s.	Type of medicine unknown.....	1	2
t.	No answer .....	-1	

**Appendix G – Questionnaires about use of medication  
(analgetics, sleeping drugs)**

## Tables of questionnaires medication

### 1. Questions used in national population risk factor surveys.

Source: The European Health Risk Monitoring project  
<http://www.ktl.fi/publications/ehrm/product1/title.htm>

<b>Use of acetylsalicylic acid</b>
------------------------------------

Many studies have shown that daily use of acetylsalicylic acid (aspirin™) in low doses is beneficial for treatment and prevention of cardiovascular disease. (1, 2)

#### 1 Questions

##### 1.1 WHO MONICA Project

In the MONICA Manual (3) there is one question about the use of aspirin™.

1. "Are you taking (in the last two weeks) aspirin tablets to prevent or treat heart disease?"
- 1 = Yes, taking tablets for this reason  
2 = No, I am not taking aspirin tablets  
3 = No, but I am taking tablets for reasons unconnected with heart condition  
9 = Insufficient data

The MONICA Manual (3) had additional instructions for *Question 1*.

Code 1 if yes.

Code 2 if the person is not taking aspirin regularly. Include here persons who had taken occasional aspirin tablets in the last two weeks.

Code 3 if the person is regularly taking aspirin for other reasons than for heart disease prevention or treatment.

Code 9 if insufficient information is available to use the other codes.

##### 1.2 Risk factor monitoring in the Netherlands

In the *Monitoring Project on Cardiovascular Disease Risk Factors* following questions were used for aspirin use (4):

1. Do you ever use aspirin?
1. Yes  
2. No
2. If yes, how many tablets/month?

3. Which brand?

In the *MORGEN*-project the information about the use of aspirin was collected when all medications used in the past week were recorded (4).

**1.3 Risk factor monitoring in Germany**

The German *Federal Health Survey 1998* collected through a physician interview information on the use of pharmacological agents. These were then grouped into 34 categories depending on their indication (5). The question asked whether, during the past 12 months, medications of a particular drug category were used :

daily, or several times per week, or 1-2 times per week, or less than once a week, or 1-3 times per month, or seldom, or never.

There was no drug category for "aspirin for heart disease".

**1.4 UK National Health Surveys**

No information available

**1.5 National Health and Nutrition Examination Survey (NHANES III), USA**

In the household adult questionnaire, the following questions about the use of acetylsalicylic acid were asked of subject aged 17 years and over (6):

1. In the past month, have you taken any aspirin, Anacin, Bufferin, Ecotrin,  Ascriptin, or Midol?
  1. Yes
  2. No
  9. Don't know
  
2. How often did you take aspirin, Anacin, Bufferin, Ecotrin, Ascriptin, or Midol  during the past month?
  - \_\_\_ times per day
  - \_\_\_ times per week
  - \_\_\_ times per month
  - 999 Don't know

**1.6 The Italian OEC Project**

The questionnaire for the Italian *OEC* project contained the following section about the use of aspirin in the prevention and treatment of cardiac disease.

1. During the past two weeks, have you taken aspirin to prevent or to treat heart disease? 
  1. Yes, have taken aspirin for that purpose
  2. No, have not taken aspirin
  3. No, but have taken aspirin for other purpose (non cardiac disease)
  4. Insufficient data
2. What is the name of the aspirin containing medication that you take? | \_\_\_\_\_|
3. Do you take it daily? Yes No
4. Number of pills per day   
Number of pills per week

## 12.2 Quality assurance

### *WHO MONICA Project*

The detailed information about the availability and quality of data on use of acetylsalicylic acid is given in the Quality Assessment of Data on Use of Aspirin in the WHO MONICA Project (7). The most common deviation from the standard MONICA format was omitting the alternative "*No, but I am taking tablets for reasons unconnected with heart condition*".

No information on retrospective quality assurance was available for *Risk factor monitoring in the Netherlands*, *Risk factor monitoring in Germany*, *UK National Health Surveys*, and *NHANES III*.

## 12.3 Indicators used for reporting the results

### *WHO MONICA Project*

In the WHO MONICA Project the prevalence of acetylsalicylic acid users among survey respondents is reported (8).

### *Risk factor monitoring in Germany*

The German Federal Health Survey 1998 reported prevalence of medication use by drug categories and ranked them by prevalence for men and women and for the old and new states (5), but no specific drug category refers to aspirin use for heart disease.

No information on the indicators for acetylsalicylic acid use was found for *Risk factor monitoring in the Netherlands*, *UK National Health Surveys*, and *NHANES III*.

## 12.4 Discussion and conclusions

If the use of prescription medication is collected by drug name (generic or brand), the drugs can then be grouped retrospectively but would also be available for analysis by individual drug entities.

Studies that focused more broadly on health and had not a narrow interest of cardiovascular disease did not always emphasize the indication for acetylsalicylic acid use or prompt the participant specifically with a question on acetylsalicylic acid use and heart disease.

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URL:<http://www.ktl.fi/publications/monica/aspirin/aspirinqa.htm>, URN:NBN:fi-fe19991129
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<http://www.ktl.fi/publications/monica/surveydb/title.htm>, URN:NBN:fi-fe20001206

**2. Questions on questionnaires from national health population surveys in the HIS/ HES Database.**

Source: <https://www.iph.fgov.be/hishes>

<b>Questions related to use of medication</b>
---

*Australia: National health survey 2001*

AF262. SOME PEOPLE TAKE SUPPLEMENTS OR REMEDIES FOR ASPECTS OF THEIR MENTAL WELL-BEING. FOR EXAMPLE, TO IMPROVE THEIR CONCENTRATION OR REDUCE STRESS.

IN THE LAST 2 WEEKS, FOR YOUR MENTAL WELL-BEING, HAVE YOU TAKEN ANY-VITAMIN OR MINERAL SUPPLEMENTS? HERBAL OR NATURAL TREATMENTS OR REMEDIES?  
Neither of these

---

*Canada: Canadian community health survey cycle 1.1 2000*

Now I'd like to ask a few questions about your use of medications, both prescription and over-the-counter.

DG1 A In the past month, that is, from ... (date one month ago to yesterday), did you take:

pain relievers such as aspirin or Tylenol (including arthritis medicine and anti-inflammatories)?

Yes  
No

DG1B tranquilizers such as Valium?

Yes  
No

DG1C diet pills such Redux, Ponderal or Fastin?

Yes  
No

DG1D anti-depressants such as Prozac, Paxil or Effexor?

Yes

No

DG1E codeine, Demerol or morphine?

Yes

No

DG1F allergy medicine such as Seldane or Chlor-Tripolon?

Yes

No

DG1G asthma medications such as inhalers or nebulizers?

Yes

No

DG1H cough or cold remedies?

Yes

No

---

***The Netherlands: Patient survey-Second Dutch national survey of general practice 2001***

ZZV25 Have you taken any medicine purchased without a prescription during the past 14 days?

yes

no

ZZV26 What medicine was this?

You can name several from CARD 42.

medicine against pain or fever, such as aspirin  
medicine for coughs, colds, flu, sore throat, etc.  
vitamins, minerals, tonics and other “pick-me-ups”  
diuretics  
medicine for the heart, blood vessels or blood pressure  
laxatives  
medicine for stomach or intestinal problems or  
indigestion  
sleeping tablets and tranquillisers, medicine to calm  
your nerves  
antibiotics such as penicillin and sulpha drugs  
medicines for the skin (for acne, eczema, itching,  
dandruff, injuries)  
medicines for rheumatism, arthritic pain, etc.  
medicines against allergies  
medicines against asthma  
hormones  
medicines against diabetes  
medicines for the eyes (eye ointment/drops)  
other medicines

ZZV27 When did you last take a medicine acquired without a prescription?

between 15 days and 1 month ago  
between 1 and 6 months ago  
between 7 and 12 months ago  
more than a year ago  
never

POKV20g If you take antibiotics (such as penicillin),  
you can more quickly get rid of complaints such as  
coughs, sore throats and earaches.

agree totally  
agree  
partly agree, partly disagree  
do not agree  
do not agree at all

POKV20h Antibiotics (such as penicillin) have few side effects.

- agree totally
  - agree
  - partly agree, partly disagree
  - do not agree
  - do not agree at all
- 

***The Netherlands: Continuous quality of life survey 1998***

M8 Did you/the child use medication that was bought without prescription during the past 14 days?

- yes
- no
- refuses/doesn't know

M9 When did you/the child use medication that was bought without prescription for the last time?

- between 15 days and 1 month ago
- 1 to 6 months ago
- 7 to 12 months ago
- more than 1 year ago
- never
- refuses/doesn't know

M10 What medication was this?

- aspirin
  - cough, cold, flu, sore throat etc.
  - vitamins, minerals, tonics
  - for the heart
  - laxatives
  - for stomach and intestinal complaints
  - medication for indigestion
  - sedatives and tranquillisers
  - medication for nervous disorders
  - for the skin
  - for rheumatism, arthritis etc.
  - homeopathic medication
  - other medication
  - medication unknown
  - refuses/doesn't know
-

***UK: Disability survey 1997***

138. Can you look at this list and tell me whether you regularly buy any of these items?

SHOW CARD L

Yes

No

Card L

Tissues/toilet paper/kitchen roll Cotton wool  
Dressings/elastoplast Elastic bandages/supports  
Talcum powder Antiseptic or soothing creams  
Vitamins  
Painkillers and other medicines not on prescription  
Disinfectant/bleach  
Other medical supplies

---

***UK: Survey of psychiatric morbidity 1993***

B1b. Those receiving medication or injections or taking pills  
What is their strength?

...

B1c. How many/much are you supposed to have each day?

...

B1d. For what condition do you take them?

...

B1e. How long have you been having this medication?

... year

B1f. Do you sometimes not take your medication even  
though you should?

Yes

No

B1g. When was the last time this happened?

less than 1 week ago

at least 1 week but less than 1 month ago

at least 1 month ago

B1h. What was the reason for this?

Forgot

Didn't need it

Don't like to take drugs

Side effects

Other, please specify: ...

B1i. Do you sometimes take more medication/pills than the stated dose?

Yes

No

B1j. When was the last time this happened?

less than 1 week ago

B1k. What was the reason for this?

Needed more to control symptoms

Deliberate overdose

Other, please specify: ...

B1m. Have you had any other medication or treatment (condition requiring medication/injections/pills) which you don't have now?

Yes

No

B1n. Did you stop this treatment on your own accord or on professional advice?

Own accord

Professional advice

B1o. What made you decide to stop this treatment?

Side effects

Other, please specify: ...

B1p. Have you ever been offered any other medication or treatment for (condition) which you refused?

Yes

No

B1q. What was it?

...

B1r. Why did you refuse it?

Worry about side effects

Don't like medication/treatment

Other, please specify: ...

B2f. Have you had any other treatment or medication for (condition requiring counselling/therapy) which you don't have now?

Yes

No

B2g. Did you stop this treatment on your own accord or on professional advice?

On own accord

Professional advice

B2h. What made you decide to stop this treatment?

Did not work/was not strong enough

Side effects

Other, please specify:...

B2i. Have you ever been offered any other treatment or medication for (condition requiring counselling/therapy) which you refused?

Yes

No

B2j. What was it?

...

B2k. Why did you refuse it?

Worry about side effects

Don't like medication/treatment

Other, please specify:...

### 3. Questions on a face to face questionnaire used in a health interview survey, carried out by the netherlands

Source: <http://www.iph.fgov.be/epidemiologie/epien/crospen/hisen/his97en/his12.pdf>

#### C. Medicines

Now I'll ask you some question on the use of medicines.

Neither the use of medicines during hospitalisation nor "the pill" must be taken into account here.

**DR.01. Did you use any medicines during the last two weeks ?**

*Int. : These can be earlier prescribed medicines*

- 1. Yes - go to DR.03.
- 2. No
- 9. Don't know
- 1. No answer

**DR.02. When did you use any medicines for the last time?**

\_\_\_/\_\_\_/19\_\_\_

(if date unknown, use the next categories)

- 1.   weeks ago
- 2.   months ago
- 3.   years ago
- 4. Never
- 9. Don't know
- 1. No answer

*Int. : If use of medicines within two weeks, go to DR.03. otherwise go to DR.04.*

DR.03. What type of medicines did you use and who prescribed these ? Just mention the letter in front of the medicine on the next card.

Int. : Show card 4; multiple answers are possible

	Type of medicine	No	Yes	GP	Specialist	Other practitioner	Don't know
a.	Medications for cough, cold, flew, etc .....	2	1	1	2	3	9
b.	Antirheumatics.....	2	1	1	2	3	9
c.	Other pain relievers or antipyretic.....	2	1	1	2	3	9
d.	Restoratives such as vitamins, minerals, tonics.....	2	1	1	2	3	9
e.	Medications for heart, blood vessels or blood pressure.....	2	1	1	2	3	9
f.	Medications for a better brain saturation.....	2	1	1	2	3	9
g.	Diuretics .....	2	1	1	2	3	9
h.	Laxatives.....	2	1	1	2	3	9
i.	Gastro intestinal medicines, digestive preparations.....	2	1	1	2	3	9
j.	Sleepinducing medications .....	2	1	1	2	3	9
k.	Anti-depressants.....	2	1	1	2	3	9
l.	Tranquilizers and other nerve-tonics .....	2	1	1	2	3	9
m.	Antibiotics.....	2	1	1	2	3	9
n.	Remedies for the skin ( acne, eczema, itch, wounds).....	2	1	1	2	3	9
o.	Allergy remedies .....	2	1	1	2	3	9
p.	Anti-asthmatics.....	2	1	1	2	3	9
q.	Hormonal medicines during menopause .....	2	1	1	2	3	9
r.	Antidiabetic drugs (injections included) .....	2	1	1	2	3	9
s.	Medicines for epilepsy (convulsions) .....	2	1	1	2	3	9
t.	Medicines for Parkinson disease.....	2	1	1	2	3	9
u.	Ophthalmics (ointment, drops) .....	2	1	1	2	3	9
v.	Medicines to slim .....	2	1	1	2	3	9
w.	Homeopathic medicines.....	2	1	1	2	3	9
x.	Other medicines, explain .....	2	1	1	2	3	9
y.	Type of medicine unknown.....	2	1	1	2	3	9
z.	No answer .....	-1					

DR.03. What type of free medicines did you use? Just mention the letter before the medicine on the next card.

*Int. : Show card 5; multiple responses are possible*

	Kind of medicine	Yes	No
a.	Medications for cough, cold, flew, etc .....	1	2
b.	Antirheumatics.....	1	2
c.	Other pain relievers or antipyretics.....	1	2
d.	Restoratives such as vitamins, minerals, tonics.....	1	2
e.	Medications for heart, blood vessels or blood pressure.....	1	2
f.	Medications for a better brain saturation.....	1	2
g.	Diuretics .....	1	2
h.	Laxatives.....	1	2
i.	Gastro intestinal medicines, digestive preparations.....	1	2
j.	Sleepinducing medications .....	1	2
k.	Tranquilizers and other nerve-tonics .....	1	2
l.	Remedies for the skin ( acne, eczema, itch, wounds).....	1	2
m.	Allergy remedies .....	1	2
n.	Anti-asthmatics.....	1	2
o.	Ophthalmics (ointment, drops) .....	1	2
p.	Medicines to slim .....	1	2
q.	Homeopathic medicines .....	1	2
r.	Other medicines, explain .....	1	2
s.	Type of medicine unknown.....	1	2
t.	No answer .....	-1	

## **Appendix H - Questionnaires about breast cancer**

# Tables of questionnaires breast cancer

## 1. Questionnaire from the Scottsdale Healthcare to consider genetic counselling

Source: <http://www.shc.org/hi/pdf/GeneticRiskAssess703141003.pdf>

Should you consider genetic counseling?

Questionnaire	Yes	No
Do you have two or more close blood relatives on the same side of the family with non-smoking related cancer?		
Do two or more relatives on the same side of the family have the same type of cancer?		
Has anyone in the family been diagnosed with cancer before 50 years of age?		
Has an individual family member had more than one type of cancer?		
Has any family member had two-sided cancer (i.e., breast cancer in both breasts)?		
Do you have Ashkenazi Jewish ancestry and a history of breast, ovarian or colon cancer in the family?		

If you answered **YES** to any of these questions, please consider further evaluation at the Cancer Genetic Risk Assessment and Cancer Prevention Program.

**2. Cancer Genetic Screening Questionnaire used by Emory Clinics for genetic consultation**

Source: [http://www.emoryhealthcare.org/departments/genetics/patient\\_info/Cancer\\_History\\_Form-.pdf](http://www.emoryhealthcare.org/departments/genetics/patient_info/Cancer_History_Form-.pdf)

**Cancer Genetic Screening Questionnaire:**

**YOUR NAME:** \_\_\_\_\_ **DATE OF BIRTH:** \_\_\_\_\_

**1. HAVE YOU EVER BEEN DIAGNOSED WITH CANCER? Yes No**

*If yes, please answer the following. If you have been diagnosed with cancer more than one time, provide information about each diagnosis.*

Type/site of cancer: Your age at time of diagnosis: \_\_\_\_\_

Type/site of cancer: Your age at time of diagnosis: \_\_\_\_\_

**2. HAVE YOU EVER HAD A BENIGN (NONCANCEROUS) TUMOR?\***

\_\_\_ Yes No

\*Examples would include but are not limited to a colon polyp, a benign breast lump, or any noncancerous skin lesion.

*If yes, what type of tumor and at what site did it occur?*

Type/site of benign tumor: Your age at time of diagnosis: \_\_\_\_\_

Type/site of benign tumor: Your age at time of diagnosis: \_\_\_\_\_

**3. HAS A DOCTOR EVER TOLD YOU THAT YOU HAVE ANY UNUSUAL MOLES OR BIRTHMARKS? Yes No**

*If yes, do you remember whether the lesions had a specific name?\**

No \_\_\_\_\_ Yes: Name- \_\_\_\_\_

\*Examples include but are not limited to hamartomas, café au lait spots, papillomas.

**4. HAVE YOU EVER BEEN TOLD THAT YOU HAVE A BIRTH DEFECT OR A GENETIC (INHERITED) CONDITION? Yes No**

*If yes, please indicate the name of the condition if known.* \_\_\_\_\_

**5. DO YOU HAVE ANY MEDICAL CONDITIONS FOR WHICH YOU ARE BEING TREATED BY A DOCTOR?\*** Yes No

\* Examples include but are not limited to diabetes, heart disease, osteoporosis, thyroid disease, kidney disease, high blood pressure.

*If yes, please list the condition(s) below:*

- a. \_\_\_\_\_
- b. \_\_\_\_\_
- c. \_\_\_\_\_

**6. HAVE YOU EVER HAD SURGERY OR A SURGICAL PROCEDURE (LIKE A BIOPSY)?** \_\_\_\_\_ Yes No

If yes, please complete the following table.

	Type of Surgery	Reason for Surgery	Year that Surgery was Done
Surgery/procedure #1			
Surgery/procedure #2			
Surgery/procedure #3			
Surgery/procedure #4			
Surgery/procedure #5			

7. HAVE YOU EVER BEEN HOSPITALIZED FOR REASONS OTHER THAN SURGERY? \_\_\_\_\_ Yes No

If yes, please complete the following table.

	Reason for Hospitalization	Year that Hospitalization Occurred
Hospitalization #1		
Hospitalization #2		
Hospitalization #3		
Hospitalization #4		
Hospitalization #5		

8. ARE YOU TAKING ANY MEDICATIONS CURRENTLY? \_\_\_\_ Yes No

If yes, please complete the following table.

	Type of Medication (Name)	Dosage	How Often Do You Take The Medication Each Day?	Medical Condition for Which You Are Taking the Medication.
Medication #1				
Medication #2				
Medication #3				
Medication #4				

9. DO YOU OR HAVE YOU EVER SMOKED CIGARETTES? \_\_\_\_ Yes \_\_\_\_ No

Which statement best describes you?

\_\_\_\_ Never smoked cigarettes.

\_\_\_\_ Former smoker. How many years did you smoke? \_\_\_\_ What was your average number of cigarettes per day while you smoked? \_\_\_\_\_

\_\_\_\_ Current smoker. How many years have you smoked? How many cigarettes do you smoke per day?

**10. HOW MANY ALCOHOLIC BEVERAGES DO YOU HAVE IN A WEEK?**

- Less than 1 alcoholic beverage per week.
- 1-3 alcoholic beverages per week.
- 4-7 alcoholic beverages per week.
- 8-14 alcoholic beverages per week.
- > 14 alcoholic beverages per week.

**11. REPRODUCTIVE HISTORY**

- Age at menarche (what age did your periods begin): \_\_\_\_\_
- Have you ever used birth control pills?  yes  no If yes, how many years have you used them? \_\_\_\_\_ Type of pill used: \_\_\_\_\_
- Age at menopause: \_\_\_\_\_
- Have you ever used estrogen or hormone replacement therapy?  yes  no
- If yes, how long? \_\_\_\_\_

**12. SURVEILLANCE HISTORY**

- Do you perform monthly BSE (breast self exam)?  yes  no
- When was your last CBE (clinical breast exam, performed by a healthcare provider)? \_\_\_\_\_
- When was your last mammogram? \_\_\_\_\_
- How often do you have mammograms?  annually  less frequently
- Have you had duct lavage?  yes  no What were the results? \_\_\_\_\_
- When was your last pelvic (gynecological) exam? \_\_\_\_\_
- Have you had an ultrasound examination of your ovaries?  yes  no
- Have you had blood testing for CA-125?  yes  no Date \_\_\_\_\_
- Have you ever had a sigmoidoscopy or colonoscopy?  yes  no Date \_\_\_\_\_

**13. WHICH OF THE BELOW BEST DESCRIBES YOUR ANCESTRY? CHECK ALL THAT APPLY.**

- African American or Black  Spanish, Hispanic, or Latino
- Ashkenazi Jewish  White/Caucasian
- Asian (specify country)  Other (please specify)
- Native American/Aleutian/Eskimo  Hawaiian
- Pacific Islander, Not otherwise specified

**THANK YOU FOR COMPLETING THIS PART OF THE QUESTIONNAIRE.  
THE NEXT QUESTIONS ARE ALL ABOUT YOUR FAMILY HISTORY.**

**Cancer Family History Form:** Please fill in your name and date of birth, and complete this table for those persons in your family that have had cancer. Continue on the back of this sheet if you run out of space.

**PATIENT NAME:**

**D.O.B.**

<b>Relative</b> (fill in their name and how they are related to you – maternal aunt, sister, paternal first cousin, etc.)	<b>Still Living?</b>	<b>Age if alive</b>	<b>Age at death if deceased</b>	<b>Cancer Type(s)</b> What type of cancer has this relative had (where in the body did the cancer start)?  Did this person have more than one type of cancer?  If so, was it because the cancer spread (metastasized), or was it a brand new tumor?	<b>How old was the person when they were diagnosed with cancer?</b>
Name: _____ _____ How are they related: _____ _____	Y N DK (DK = Don't Know)				
Name: _____ _____ How are they related: _____ _____	Y N DK				
Name: _____ _____ How are they related: _____ _____	Y N DK				
Name: _____ _____ How are they related: _____ _____	Y N DK				
Name: _____ _____ How are they related: _____ _____	Y N DK				
Name: _____ _____ How are they related: _____ _____	Y N DK				

### 3. Questionnaire to assess family history of cancer used by The M.D. Anderson Cancer Center Risk Assessment Clinic

Source: <http://www3.mdanderson.org/prevention/BROV3.pdf>

THE UNIVERSITY OF TEXAS  
MD ANDERSON  
CANCER CENTER

#### Family History of Cancer

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This questionnaire will gather information about the history of cancer in your family. This information will be used by The M. D. Anderson Cancer Center Risk Assessment Clinic to help determine your risk of developing cancer and to decide if the cancers in your family may be related to an inherited gene. The information will not be used to contact your family members. Names are used only to reduce our errors as we build your family tree (pedigree). You may refuse to answer any (or all) of the questions at this time or any other time. When you return the questionnaire, you are agreeing that your family history information will be entered into a confidential computerized database. By returning the questionnaire, you also understand that there is a possibility that you might be contacted in the future about studies designed for those at an increased risk of developing cancer. You are free to refuse further participation at any time.

1. Fill in the complete name of each requested family member to the best of your ability.
2. Include only blood relatives (except your spouse), even if they are no longer living.
3. DO NOT INCLUDE ANY NON-BLOOD RELATIVES, for example adoptive parents or grandparents, step-parents, or step-brothers or sisters adopted into your family.
4. If a relative has or had cancer, the type of cancer and the age or year when they were diagnosed is important.
5. If you do not know the exact age or year, write in an approximate age or year. Please circle these so we know they are not exact.
6. Please take your time and fill in as much information as you can. You may need to speak with other family members to get the most accurate information.
7. If you are uncertain about any information, write "unknown" in the appropriate space or check the box marked unknown.
8. PLEASE PRINT! THANK YOU!

If you have a scheduled appointment, PLEASE RETURN the questionnaire within one to two weeks before your appointment.

Otherwise, return the questionnaire at your convenience and we will contact you to schedule an appointment.

The University of Texas M. D. Anderson Cancer Center  
1515 Holcombe Boulevard, Houston, Texas 77030  
Attention: Paula Trahan Rieger, RN - Box 336

Your Name: \_\_\_\_\_

Address: \_\_\_\_\_

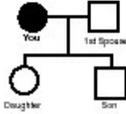
Phone: (Home) \_\_\_\_\_ (Work) \_\_\_\_\_

Are you of Ashkenazi heritage?  Yes  No

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Page 1





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DID No. _____	

**CHILDREN FROM YOUR FIRST SPOUSE OR PARTNER**

Please read across the page for each person.

Your Full Name:				Sex	Date of birth	Have you ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
_____	_____	_____	_____ (Maiden)	<input type="checkbox"/> M <input type="checkbox"/> F	____/____/____ mo/day/yr	<input type="checkbox"/> Yes <input type="checkbox"/> No		____ Age Yr. ____		____ Age Yr. ____	

**YOUR CHILDREN AND THEIR PARENT (only partnerships with children):**

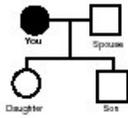
Full Name	Sex	Date of birth	Alive or dead?	Date of death	Age at death	Ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
First Middle Last (Maiden)		mo/day/yr		mo/day/yr				Age Yr. ____		Age Yr. ____	
Spouse/Partner	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
1. Children	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
2.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
3.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
4.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					

If you need space for more children with the same partner continue on next page. If you had more children with an additional partner, complete that information on Another Partner Page. If you did not have an additional partner and children, go to Your Parents, Siblings page to complete the next section.

**CHILDREN FROM YOUR FIRST SPOUSE OR PARTNER (continued)**

Full Name	Sex	Date of birth	Alive or dead?	Date of death	Age at death	Ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
First Middle Last (Maiden)		mo/day/yr		mo/day/yr				Age Yr. ____		Age Yr. ____	
5. Children	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
6.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
7.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
8.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
9.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
10.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
11.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					
12.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown					

If you need space for more children with your first partner, go to last page, Extra Page. If you had another partner and more children go to Another Partner Page. Otherwise complete the section on Your Parents, Siblings.



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DID No.	_____

**CHILDREN FROM ANOTHER SPOUSE OR PARTNER**

**YOUR CHILDREN AND THEIR PARENT (only partnerships with children):**

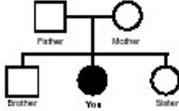
Full Name First Middle Last (Maiden)	Sex	Date of birth m/day/yr	Alive or dead?	Date of death m/day/yr	Age at death	Ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
Spouse/Partner	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
1. Children	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
2.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
3.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
4.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	

If you need space for more children with the same partner continue on next page. If you had more children with an additional partner, complete that information on Extra Page at the end. If you did not have an additional partner or children, go to Your Parents, Siblings page to complete the next section.

**CHILDREN FROM ANOTHER SPOUSE OR PARTNER (continued)**

Full Name First Middle Last (Maiden)	Sex	Date of birth m/day/yr	Alive or dead?	Date of death m/day/yr	Age at death	Ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
5. Children	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
6.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
7.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
8.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
9.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
10.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
11.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	
12.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Age _____ Yr. _____		Age _____ Yr. _____	

If you need space for more children with this partner, go to last page, Extra Page. If you had another partner and more children go to last page, Extra Page. Otherwise go to next page to complete the section on Your Parents, Siblings.



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DID No. _____

**YOUR PARENTS AND SIBLINGS**

Your Biological Parents Full Name First Middle Last (Maiden)	Date of birth m/day/yr	Alive or dead? <input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown	Date of death m/day/yr	Age at death	Ever had cancer? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	First type of cancer	Age at diagnosis or year		Second type of cancer	Age at diagnosis or year		Other major medical conditions?
							Yr. _____	Age _____		Yr. _____	Age _____	
Father							Yr. _____	Age _____		Yr. _____	Age _____	
Mother							Yr. _____	Age _____		Yr. _____	Age _____	

**YOUR FULL SIBLINGS (brothers and sisters):**

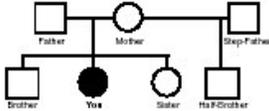
Full Name First Middle Last (Maiden)	Sex <input type="checkbox"/> M <input type="checkbox"/> F	Date of birth m/day/yr	Alive or dead? <input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown	Date of death m/day/yr	Age at death	Ever had cancer? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	First type of cancer	Age at diagnosis or year		Second type of cancer	Age at diagnosis or year		Other major medical conditions?
								Yr. _____	Age _____		Yr. _____	Age _____	
1.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
2.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
3.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
4.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	

If you need space for more brothers and sisters continue on next page. Otherwise go to Your Step-parents, Half-brothers, Half-sisters page to complete that section or go to Your Nieces, Nephews to complete that information.

**YOUR FULL SIBLINGS, BROTHERS AND SISTERS (continued)**

Full Name First Middle Last (Maiden)	Sex <input type="checkbox"/> M <input type="checkbox"/> F	Date of birth m/day/yr	Alive or dead? <input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown	Date of death m/day/yr	Age at death	Ever had cancer? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	First type of cancer	Age at diagnosis or year		Second type of cancer	Age at diagnosis or year		Other major medical conditions?
								Yr. _____	Age _____		Yr. _____	Age _____	
5.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
6.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
7.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
8.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
9.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
10.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
11.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	
12.	<input type="checkbox"/> M <input type="checkbox"/> F							Yr. _____	Age _____		Yr. _____	Age _____	

If you need space for more brothers or sisters, go to last page, Extra Page. Otherwise go to next page to complete the step-parent information or go to Your Nieces, Nephews to complete that section.



<b>OFFICE USE ONLY</b>		
Medical Record No.	_____	
Study No.	_____	
DID No.	_____	

**YOUR STEP-PARENT, HALF-BROTHERS AND HALF-SISTERS**

Your Step-Parent Full Name First Middle Last (Maiden)	Sex	Date of birth mo/day/yr	Alive or dead?	Date of death mo/day/yr	Age at death	Ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	

**YOUR HALF-BROTHERS AND HALF-SISTERS:**

Full Name First Middle Last (Maiden)	Sex	Date of birth mo/day/yr	Alive or dead?	Date of death mo/day/yr	Age at death	Ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
1.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
2.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
3.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
4.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
5.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
6.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	

If you need space for more half-brothers and sisters, or had another step-parent continue on the next page. Otherwise go to Your Nieces, Nephews page to complete that information.

**ANOTHER STEP-PARENT, HALF-BROTHERS AND HALF-SISTERS (continued)**

Step-Parent Full Name First Middle Last (Maiden)	Sex	Date of birth mo/day/yr	Alive or dead?	Date of death mo/day/yr	Age at death	Ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	

**YOUR HALF-BROTHERS AND HALF-SISTERS:**

Full Name First Middle Last (Maiden)	Sex	Date of birth mo/day/yr	Alive or dead?	Date of death mo/day/yr	Age at death	Ever had cancer?	First type of cancer	Age at diagnosis or year	Second type of cancer	Age at diagnosis or year	Other major medical conditions?
1.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
2.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
3.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
4.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
5.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
6.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	
7.	<input type="checkbox"/> M <input type="checkbox"/> F		<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Unknown			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		____ Age Yr. ____		____ Age Yr. ____	

If you need space for more half-brothers or sisters, go to last page, Extra Page. Otherwise go to next page or to Your Father's Parents page to complete these sections.

Same tables have to be filled in for:

- nieces and nephews, children of your full and half brothers and sisters
- your father parents, your paternal grandparents
- your fathers brothers and sisters, your paternal aunts and uncles
- cousins, children from your father's full and half brothers and sisters
- your mother parents, your maternal grandparents
- your mother brothers and sisters, your maternal aunts and uncles
- cousins, children from your mother's full and half brothers and sisters
- other blood relatives who had or have cancer (grandchildren, great aunts or great grandparents)

(tables not shown)

#### 4. Cancer Family History Questionnaire used by New York State Department of Health

Source: <http://www.health.state.ny.us/nysdoh/cancer/obcancer/append11.htm>

##### SAMPLE CANCER FAMILY HISTORY QUESTIONNAIRE

- Name \_\_\_\_\_
- Date \_\_\_\_\_
- Age \_\_\_\_\_
- Ethnic Background [Certain ethnic groups have an increased risk for specific kinds of cancer.]  
 \_\_\_\_\_  
 \_\_\_\_\_
- Do you have any specific concerns about cancer in yourself or your family?  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
- Do you or any members of your family have a history of cancer?  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

	Yes/No	Type of Cancer (if known)	Age at Diagnosis (if known)	Living/ Deceased
yourself				
your mother				
your father				
your sisters and brothers				
your half sisters and half brothers				
your children				
your mother's sisters and brothers				
your father's sisters and brothers				
your nieces and nephews				
your mother's parents				
your father's parents				

## 5. Part of the lifestyle questionnaire from Bio Analogics

This part includes questions about non-controllable risk factors, cancer warning signs and tobacco consumption.

Source: <http://www.bioanalogics.com/download/pdf/HRA-Q.pdf>

### Section A

#### Non-Controllable Risk Factors

##### 1.0 Family history of Coronary Heart Disease occurring before 60 years old.

Indicate the number of members of your direct family who have died or been diagnosed with Coronary Heart Disease before the age of 60.

None       1 person       More than 1

##### 2.0 Family history of Coronary Heart Disease occurring after 60 years old.

Indicate the number of members of your direct family who have died or been diagnosed with Coronary Heart Disease after the age of 60.

None       1 person       More than 1

##### 3.0 Family history of Diabetes.

Indicate the number of members of your direct family who have been diagnosed with diabetes.

None       1 person       More than 1

##### 4.0 Family history of Strokes or Cerebral Vascular Disease.

Indicate the number of members of your direct family who have died or been diagnosed with Strokes or Cerebral Vascular Disease.

None       1 person       More than 1

##### 5.0 Personal history of cancer

Have you ever been diagnosed with any type of cancer?

No       Yes

##### 6.0 Personal history of heart disease

Have you ever been diagnosed with any form of heart disease?

No       Yes

## Section B

### Personal Health History and Habits

#### 7.0 Colon/Rectal Screening

If you are over the age of 40, do you have an annual colon/rectal screening?

- Yes       No       Not Applicable

#### 8.0 PAP Smear

If you are a female over the age of 18, do you have an annual PAP smear?

- Yes       No       Not Applicable

#### 9.0 Mammogram Screening

If you are a female over the age of 35, have you had a mammogram within the past 2 years?

- Yes       No       Not applicable

#### 10.0 Prostate screening

If you are a male over the age of 40, have you had a prostate screening within the past 2 years?

- Yes       No       Not applicable

#### 11.0 Routine Health Screening

How often do you see your physician for routine check-ups or health screenings?

- On an annual basis       At least every 2 years  
 Not within the past 5 years       Never

#### 12.0 Cancer Warning Signs

Indicate if you have any of the following cancer warning signs.

- Change in bowel or bladder habits  
 Chronic indigestion or difficulty in swallowing  
 Thickening or lump in breast or elsewhere  
 Unusual bleeding or discharge, a sore that does not heal  
 Change in freckle or mole  
 Persistent cough or sore throat  
 Unexplained weight loss  
 None

## Section C

### Alcohol/Caffeine/Tobacco Consumption

#### 13.0 Consumption of alcohol

How often do you consume alcohol?

- Never drink                       2 days or less per week  
 3 days per week                       4 or more days per week

#### 14.0 Number of alcoholic beverages

On the days you drink, on the average how many drinks do you have?

- Never drink                       1 to 2 drinks  
 3 to 4 drinks                       5 or more drinks

#### 15.0 Caffeine

How often do you consume caffeine in your diet including coffee, tea, cola or chocolate?

- Never  
 Occasionally but not every day  
 1 to 3 servings daily  
 3 to 5 servings daily  
 More than 5 servings daily

#### 16.0 Smoking status

Indicate which of the following best represents your current status  
NOTE: Check all that apply.

- Have never smoked  
 Quit smoking less than 5 years ago  
 Quit smoking more than 5 years ago  
 Smoke pipe or cigar  
 Smoke less than 1 pack of cigarettes per day  
 Smoke more than 1 pack of cigarettes per day

#### 17.0 Smokeless Tobacco

Do you use smokeless tobacco?

- No  
 Yes

**6. Questions related to family history of cancer on the baseline questionnaire of a prostate, lung, colorectal and ovarian cancer screening trial**

Source: Pinsky PF, Kramer BS, Reding D, Buys S. Reported family history of cancer in the prostate, lung, colorectal and ovarian cancer screening trial. Am J Epidemiol 2003;157:792-799

**Questions:**

1. How many full and half-sisters do you have, both living and deceased?
2. How many full and- half-brothers do you have, both living and deceased ?
3. Have your parents, children, brothers, sisters, half-brothers, or half-sisters ever been diagnosed as having any type of cancer? ( Do not include basal-cell skin cancer.)  
 No  
 Yes
4. Please complete this chart for each relative (mother, children, brothers, sisters, half-brothers, half sisters) diagnosed with cancer. ( do not include basal-cell skin cancer.)  
 (if you have more than four relatives diagnosed with cancer, please include a separate page with this information.)

	Who was diagnosed as having cancer, that is, what is his or her relationship to you?	What type of cancer did he or she have?	How old was your relative when he or she was diagnosed as having cancer?
1 <sup>st</sup> relative	_____ relationship	_____ type of cancer	_____ Age
2 <sup>nd</sup> relative	_____ relationship	_____ type of cancer	_____ Age
3 <sup>rd</sup> relative	_____ relationship	_____ type of cancer	_____ Age
4 <sup>th</sup> relative	_____ relationship	_____ type of cancer	_____ Age

## 7. Questionnaire from FOX CHASE Cancer Center to assess your cancer risks

Source: [http://www.fccc.edu/clinical/cancer\\_risk.html](http://www.fccc.edu/clinical/cancer_risk.html)

### Breast or Ovarian Cancer

1. Are you female?  Yes  No
2. Do you have a family history of breast and/or ovarian cancer?  Yes  No
3. Are you over the age of 18?  Yes  No
4. Do you have at least one first-degree relative (mother, sister, or daughter) with breast or ovarian cancer?  Yes  No

If you answered yes to all of these questions, you may be at increased risk of developing breast or ovarian cancer.

### Prostate Cancer

1. Are you male?  Yes  No
2. Are you African-American?  Yes  No
3. Do you have a family history of prostate cancer?  Yes  No
4. Do you have one first-degree relative (father, brother or son) with prostate cancer?  Yes  No
5. Was your relative diagnosed at a young age?  Yes  No

If you answered yes to most of these questions, or if you are an African American male, you may be at increased risk of developing prostate cancer.

### Skin Cancer (Melanoma)

1. Do you have one or more first-degree relatives (parent, brother, sister, child) with a history of melanoma?  Yes  No

2. Do you experience severe blistering sunburns (especially at young ages)?  Yes  No
3. Do you sit in the sun with the purpose of getting tan, use tanning lamps or tanning booths?  Yes  No
4. Do you have red or blond hair and fair skin that freckles or sunburns easily?  Yes  No

If you answered yes to any of these questions, you may be at risk of developing skin cancer (melanoma).

### **Liver Cancer**

1. Have you been diagnosed with hepatitis-B virus (HBV) hepatitis C virus (HCV)?  Yes  No
2. Do you drink large amounts of alcohol?  Yes  No
3. Have you been diagnosed with cirrhosis of the liver (a progressive disorder that leads to scarring of the liver)?  Yes  No

If you answered yes to any of these questions, you may be at risk of developing liver cancer.

### **Gastrointestinal Cancer**

1. Do you or one of your close relatives have a history of colorectal cancer, colon polyps or other cancers (uterine, stomach, bile duct, urinary tract or ovarian)?  Yes  No
2. Were you previously treated for colon cancer or polyps?  Yes  No
3. Do you have inflammatory bowel disease, such as ulcerative colitis or Crohn's disease?  Yes  No
4. Have you consumed foods that contain aflatoxins? Aflatoxins are a group of chemicals produced by a mold that can contaminate certain foods, such as peanuts, corn, grains, and seeds, and are carcinogens (cancer causing agents) for liver  Yes  No

cancer.

If you answered yes to one or more of these questions, you may be at risk of developing gastrointestinal cancer.

**8. Questionnaire from the Women's Cancer network to assess risk level for developing breast cancer, ovarian cancer, endometrial cancer, cervical cancer, vulvar cancer and vaginal cancer**

Source: <http://www.wcn.org/interior.cfm?diseaseid=13&featureid=3>

**Personal History**

The following are demographic questions about yourself.

1. What is your [age](#)?
2. What is your [ethnic group](#)?
3. What is your [religion](#)?
4. What is your highest level of [education](#)?
5. What is your annual household [income](#)?
6. What is your [weight](#) (lbs)?
7. What is your [height](#) (feet & inches)?

**Personal Medical History**

The next questions are about your own personal medical history.

8. Have you ever been diagnosed with [any type of cancer](#) (besides non-melanoma skin cancer)?  
 yes  no If "no", skip 9.

9. If you answered "yes" to the previous question, enter what type of cancer(s) you have been diagnosed with (check all that apply) and the age you were diagnosed.

<input type="checkbox"/> Breast	Age: <input type="text"/>
<input type="checkbox"/> Cervix	Age: <input type="text"/>
<input type="checkbox"/> Colorectal	Age: <input type="text"/>
<input type="checkbox"/> Endometrial	Age: <input type="text"/>
<input type="checkbox"/> Hodgkin's disease	Age: <input type="text"/>
<input type="checkbox"/> Lung	Age: <input type="text"/>
<input type="checkbox"/> Ovary	Age: <input type="text"/>

<input type="checkbox"/> Vulvar	Age: <input type="text"/>
<input type="checkbox"/> Vaginal	Age: <input type="text"/>
<input type="checkbox"/> Other	Age: <input type="text"/>

10. Have you had any of the following surgeries? *Questions 11,12 & 13:*

yes  no If "no", skip 11,12,13.

11. To remove your uterus ([hysterectomy](#))?  yes Age:

12. To remove your ovaries ([oophorectomy](#))?  Age:

13. Have you had a tubal ligation ([tubes tied](#))?  yes

14. Have you ever been diagnosed with benign breast disease that resulted in a [breast biopsy](#)?  
(Benign breast disease includes moderate or atypical hyperplasia **BUT NOT** cysts, fibrocystic disease, fibroadenoma, or mild hyperplasia)

yes  no

15. How many [breast biopsies](#) have you had?

16. Have you ever had an [abnormal Pap test](#)?   
If "No" or "Never had a PAP", skip 17-21.

Have you had any of the following treatments for an [abnormal Pap test](#)? *Check all that apply.*

- 17.  With antibiotic creams
- 18.  Colposcopy with biopsy
- 19.  Cryotherapy (freezing of cervix)
- 20.  Laser therapy
- 21.  Surgery

Have you ever been diagnosed with any [of the following precancerous conditions](#)? *Check all that apply.*

- 22.  Cervical intraepithelial neoplasia (CIN)
- 23.  Vulvar intraepithelial neoplasia (VIN)

24.  Vaginal intraepithelial neoplasia (VAIN)

Have you ever been diagnosed with any of the following? *Check all that apply.*

25.  [Amenorrhea](#) (absence of menstrual periods)

26.  [Diabetes](#)

27.  [Hepatitis B or C](#)

28.  [High blood pressure](#) (hypertension)

29.  [HIV/AIDS](#)

30.  [Infertility](#) (tried to get pregnant for at least 2 years)

31.  [Kidney disease](#) (chronic)

32.  [Lupus](#)

33.  [Polycystic ovary disease](#)

34.  [Rheumatoid arthritis](#)

### Reproductive History

The next series of questions are about your reproductive history

35. How old were you when you [first started having your menstrual periods](#)?

36. Over your lifetime, would you describe your [menstrual periods](#) as usually:

37. How many times have you been [pregnant](#)?

38. How many [live births](#) have you had?

39. How old were you when you had your [first baby](#)?

40. Have you [breastfed](#) for a total of 1.5 years or more (includes the time you breastfed all of your children)?

yes  no

41. Are you still having your [menstrual periods](#)?

yes  no

42. At what age did you stop having your [menstrual periods](#)?

The next questions are about your use of hormones

43. Have you ever taken [birth control pills](#)?

44. What is the total number of years you have taken [birth control pills](#)?

45. Have you ever taken any medications to get pregnant for the [treatment of infertility](#) (such as Lupron, Clomiphene, Clomid, Serophene, Metrodin)?

yes  no

46. What is the total number of years you have taken [hormone replacement therapy \(HRT\)](#) for menopausal symptoms?

47. What type(s) of [HRTs](#) have you taken?

48. Have you ever taken any of the medications known as [selective estrogen receptor modulators \(SERMS\)](#) such as Tamoxifen or Raloxifene?

49. Did you take [SERMS](#) for:

50. Did you take [Diethylstilbesterol \(DES\)](#) while you were pregnant?

yes  no

51. Did your mother take [Diethylstilbesterol \(DES\)](#) when she was pregnant with you?

yes  no

## Sexual History

The next questions are about your sexual history

52. How old were you when you [first had sexual intercourse](#)?

53. [How many sexual partners](#) have you had over your lifetime?

54. Have you ever been diagnosed with a [sexually transmitted disease](#) such as herpes simplex (HSV), chlamydia, gonorrhea, syphilis, trichomoniasis, hepatitis B, or HIV/AIDS?

55. Have you ever been diagnosed with [human papillomavirus \(HPV\) in your genital tract](#)?

56. Have any of your partners ever been diagnosed with a [sexually transmitted disease](#) such as herpes simplex (HSV), chlamydia, gonorrhea, syphilis, trichomonosiasis, human papillomavirus (HPV) or genital warts, hepatitis B, or HIV/AIDS?

57. If you have been sexually active, during that time, has your primary method of birth control been [condoms or the diaphragm](#)?

### Family History of Cancer

58. Do you have a [family history of cancer](#) in a first-degree blood relative (mother, sister, daughter or father)?

59-91. If you answered Yes to question 58, complete the following table for your blood relatives indicated, who has had cancer. For each cancer, click on the checkbox in the column for each relative. For breast cancer you must also enter the age when your blood relative was diagnosed (you can approximate their age).

Cancer type	Mother	Sister	Sister	Daughter	Daughter	Father
Breast	<input type="checkbox"/>					
	Age: <input type="text"/>					
Ovary	<input type="checkbox"/>					
Endometrial	<input type="checkbox"/>					
Colon/rectal	<input type="checkbox"/>					
Other	<input type="checkbox"/>					

92. Do you have any other relatives [with a history of Breast, Ovarian, Endometrial or Colon/rectal cancer](#)?

### Lifestyle Factors

The next questions are about lifestyle risk factors.

93. How many [cigarettes do you smoke](#) per day?

94. Do you usually drink more than one [alcoholic drink](#) per day?  
 yes  no

95. Do you eat [3 or more servings of fruits or vegetables per day](#)?  
 yes  no

96. Do you [exercise](#) for at least 20 minutes:

## Screening Practices

The next questions are about your cancer screening practices.

97. I perform [breast self-exam](#):

98. I have a [mammogram](#):

99. I have a [yearly physical exam of breasts by a health care provider](#):

yes  no

100. I have a [PAP test](#):

101. I have a yearly [pelvic exam by a health care provider](#):

yes  no

**9. Questionnaire from the National Breast Cancer Centre to assess risk for developing breast cancer**

Source: [http://www.nbcc.org.au/resources/documents/BFT\\_familyhistory.pdf](http://www.nbcc.org.au/resources/documents/BFT_familyhistory.pdf)

## DO YOU HAVE BREAST CANCER IN YOUR FAMILY?

This information sheet is to help you work out if you have an increased chance of developing breast cancer and if so what you can do.

The information is based on what we know through research.



Take action for life.

AMF<sup>®</sup> foundation

### Most breast cancer is not inherited

Breast cancer is a common disease: about 1 in 11 women in Australia will develop breast cancer by age 75. As a result, many women have a relative with breast cancer – simply by chance. Some women have a strong family history of breast cancer, for example several close blood relatives on the same side of the family who have the disease. These women may have inherited a fault in a gene which may eventually lead to the development of breast cancer. However, this is uncommon and less than 5% of all breast cancers are caused by an inherited gene fault. And although a woman who inherits a gene fault does have an increased chance of developing breast cancer, she may never develop the disease.

### Your family history becomes more important in increasing your risk of breast cancer:

- The more blood relatives you have on the same side of the family who have had breast cancer
- The younger these relatives were when they were first diagnosed
- The more closely related these relatives are to you

### How do I find out if I may have an increased risk of developing breast cancer?

You may like to complete the tick-box questions over the page. Based on your family history, you will be in one of these three categories:

### Category 1 – Population Risk

If the current history of breast cancer in your close relatives puts you in this category, or if you have no relatives with breast cancer, your risk of breast cancer is about the same as that of the great majority of women in the general population. At the present time, you do not need to do anything more than any other woman in the population. Like all women, you are advised to:

- See your general practitioner without undue delay about any breast changes which are not normal for you
- Ask your general practitioner about how often you should have your breasts examined
- If you are over 50, ring 13 20 50 for a free screening mammogram with BreastScreen every two years

### Category 2 – Moderately Increased Risk or Category 3 – Potentially High Risk

If the current history of breast cancer in your close relatives puts you in these categories, you may have an increased risk of developing breast cancer. You will be in either Category 2 (Moderately Increased Risk) or in Category 3 (Potentially High Risk). Make an appointment to see your general practitioner to find out which of these two categories you are in according to *Advice about familial aspects of breast cancer and ovarian cancer – A guide for health professionals*. More information about each of these two categories is given below:

#### Category 2 – Moderately Increased Risk:

Although women in this group have a moderately increased risk of developing breast cancer compared with women in the general population, 75 – 90% will not get breast cancer at any time in their life.

- See your general practitioner without undue delay about any breast changes which are not normal for you
- Your general practitioner will advise you about how often you should be having mammograms and breast examinations

- If you think you need a more precise risk assessment, your general practitioner can consult a specialist cancer service or a family cancer clinic and can discuss their advice with you

#### Category 3 – Potentially High Risk:

Although women in this group have a potentially high risk of developing breast cancer compared with women in the general population, 50 – 75% will not get breast cancer at any time in their life.

- See your general practitioner without undue delay about any new breast changes which are not normal for you
- Your general practitioner may refer you to a cancer specialist. The specialist will help to plan how often you should be having mammograms and breast examinations, and will advise you about any other examinations that you may need to have
- If you want more information about your risk or that of your family, your doctor may refer you to a family cancer clinic for advice, appropriate counselling, management and genetic testing if it is appropriate for you

## QUESTIONS ABOUT BREAST CANCER IN YOUR FAMILY

You can find out if you may have an increased risk of developing breast cancer by completing the tick-box questions below. You will be in either **Category 1 (Population Risk)** or in **Category 2/3 (Moderately Increased Risk/Potentially High Risk)**. These categories are described on the reverse side of this page.

### *Instructions:*

- Please tell us about your blood relatives, your mother, sisters and daughters, and your grandmothers, aunts and nieces on both your mother's and your father's sides of the family.
- Please tick the answers below that are most appropriate to your family.
- If you are unsure of the answer, please tick **NO** or **DONT KNOW**

**1. Have any of these blood relatives – your mother, sisters, daughters, grandmothers, aunts and nieces – ever had breast cancer?**

- Yes  Go to question 2.
- No or don't know  Go to **Category 1** over the page and **DO NOT** answer any more questions.

**2. Have any of your mother, sisters or daughters – ever had breast cancer?**

- Yes  Go to question 3.
- No or don't know  Go to question 5 and **DO NOT** answer questions 3 or 4.

**3. Were any of the women in question 2 diagnosed with breast cancer before the age of 50?**

- Yes before 50  Go to **Category 2/3** over the page and **DO NOT** answer any more questions.
- No or don't know  Go to question 4.

**4. How many women in question 2 have had breast cancer?**

- One only  Go to question 5.
- Two or more  Go to **Category 2/3** over the page and **DO NOT** answer any more questions.

**5. Have any of these blood relatives – your grandmothers, aunts or nieces, on either your mother's or your father's sides of the family – ever had breast cancer?**

- Yes  Go to question 6.
- No or don't know  Go to **Category 1** over the page and **DO NOT** answer any more questions.

**6. Please tick ONE of the following statements that describes your blood relatives – your mother, sisters, grandmothers, aunts and nieces – who have ever had breast cancer:**

- I have one blood relative who has had breast cancer  Go to **Category 1** over the page.
- I have one blood relative on each side of my family who have had breast cancer  Go to **Category 1** over the page.
- I have two or more blood relatives on my mother's side who have had breast cancer  Go to **Category 2/3** over the page.  
Note: daughters and sisters can be counted on either side of the family.
- I have two or more blood relatives on my father's side who have had breast cancer  Go to **Category 2/3** over the page.  
Note: daughters and sisters can be counted on either side of the family.

This questionnaire was developed and trialed in collaboration with BreastScreen Australia

**10.** A questionnaire from the Group Health Cooperative's Center for Health Studies to assess risk of getting breast cancer.

source: <http://www.centerforhealthstudies.org/surveillanceproject/data-collection-instruments/bsrr/bsrr-in-clinic.pdf>



**Risk Factor Questionnaire 2.2**

Please inform the technologist if you are pregnant.

PLEASE ANSWER QUESTIONS WITH A MARK LIKE THIS ● NOT LIKE THIS ✗ OR ✓

**\*\*IMPORTANT INSTRUCTIONS\*\***

- Use PEN, never use pencil.
- Make no additional comments/marks.
- Please complete all four pages of this form.
- Some of this information may be used for research. All information will be kept confidential as provided by law. If you do not wish to have this information used for research, please fill in here ○

**1. First Name**

**Last Name**

**a) What is today's date?**

 /  /   
month      day      year

**b) What is your GHC Identification number?**

**c) and/or what is your Social Security Number?**

 -  - 

**d) What is your date of birth?**

 /  /   
month      day      year

Please answer the following questions to help the clinical staff with your appointment today.

**1e. What is the main reason for your visit today? (Fill in only one)**

- Routine screening
- Follow-up to routine screening exam
- Concerns about breast problems

**f) Have you had any of the following breast changes in the last 3 months? (Fill in all that apply)**

No changes. ➡ **If no changes, go to #2a**

	BOTH	LEFT	RIGHT
<b>Nipple Discharge</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Lump</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Pain</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Other</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Describe:**

**g) Are any of these changes present today?**

- Yes
- No

Please answer the following questions to help us assess your CURRENT risk of getting breast cancer.

**2a. Has a physician ever removed tissue from your breast (done a biopsy; this does not include removing fluid from a cyst using a needle)?**

- Yes
- No ➡ **If no, go to #3a**



**b) How many times has this occurred?**

- Once
- Twice
- Three Times
- Four or more
- Don't know

**c) Which breast(s) was/were involved?**

- Both breasts
- Left breast
- Right breast

**d) When was your first breast biopsy?**

  
year

**e) When was your most recent breast biopsy?**

  
year

**f) Was your most recent biopsy done at GHC?**

- Yes
- No

**3a. Have you ever been diagnosed with breast cancer?**

- No ➡ **If no, go to #4a**
- Yes, both breasts
- Yes, left breast
- Yes, right breast



**b) When was your FIRST breast cancer diagnosed?**

 -   
month      year

4a. Have you had any of the following breast procedures? (Fill in all that apply)

	BOTH BREASTS	LEFT BREAST	RIGHT BREAST
Cyst aspiration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lumpectomy (for breast cancer)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mastectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast reconstruction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast reduction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast implants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I have not had any of the above procedures

b) If you have had breast implants, are your breast implants still present?

- Yes, in both breasts  
 Yes, in the left breast  
 Yes, in the right breast  
 No

5a. When was your last mammogram?

-      
 month year

I have never had a mammogram

⇒ If never had a mammogram, go to #6

b) Was your last mammogram done at GHC?

- Yes  No

c) Do you currently weigh at least 10 pounds MORE or 10 pounds LESS than you did at your last mammogram?

- Yes more  Yes less  No

d) How many mammograms have you had in the last five years?

- None  1  2  3  4  5  6 or more  
 Don't Know

6. How old were you when you had your first menstrual period?

years old

- Don't Know  
 I have never had a menstrual period



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7a. Are you still having periods?

- Yes  
 Yes, but I am on female hormones (estrogen or progesterone; not birth control pills)  
 Yes, but they are irregular or less frequent  
 No ⇒ If no, go to #7c

b) When was the first day of your last menstrual period?

- 1-7 days ago  22-35 days ago  
 8-14 days ago  more than 35 days ago  
 15-21 days ago

If you answered any of the above, go to #8a

c) How old were you when your menstrual periods stopped?

years  Don't know

d) Why did your menstrual periods stop?

- Natural Menopause  
 Surgery  
 Hysterectomy (removal of uterus)  
 Removal of one ovary  
 Removal of both ovaries  
 Don't know if ovaries were removed  
 Oral contraceptives or Depo-Provera  
 Other reason  
 Don't know

8a. Have you ever given birth to a child? (Include all pregnancies that lasted at least 6 months live births, still births, or cesarean sections. DO NOT include miscarriages and abortions.)

- Yes  No ⇒ If no, go to #9

b) How old were you when you first gave birth?

years old

c) How many times have you given birth?

- 1  2  3  4  5 or more

9. Are you currently using birth control pills?

- Yes  No

10a. Have you ever taken female hormones? (Include estrogen, progesterone, and tamoxifen. DO NOT include birth control pills, Norplant, Depo-Provera, or fertility-enhancing hormones.)

Yes  No ➔ If no, go to #11

b) How many years in all have you taken female hormones?

- Less than 1 year       5 to 9 years  
 1 to 2 years           10 to 14 years  
 3 to 4 years           15 years or more

c) Are you currently taking any of the following hormones or medications? (Fill in all that apply)

- Hormone replacement therapy (HRT)  
 Both Estrogen and Progesterone  
 Estrogen only  
 Progesterone only  
 Tamoxifen (Nolvadex)  
 Raloxifene (Evista)  
 Other hormone:   
 Don't Know  
 I am not currently taking female hormones

11. Are you adopted?

- Yes      If you do NOT know your family history, go to #20a  
 No

**The following questions are about your BLOOD relatives (living OR dead). Do not include information about adoptive relatives, step relatives, or relatives by marriage.**

12. Have any of your MALE relatives been diagnosed with breast cancer?

- No  Father  Brother  Son  Don't Know

13. How many sisters do you have?

- None  1  2  3  4  5  6 or more  
 Don't Know

14. How many daughters do you have?

- None  1  2  3  4  5  6 or more  
 Don't Know

15. How many aunts do you have?

- None  1  2  3  4  5  6 or more  
 Don't Know

16. Have any of your female BLOOD relatives been diagnosed with breast cancer?

- Yes  No  Don't Know

Go to question #19

17. How many of your female BLOOD relatives have been diagnosed with breast cancer?

- a) Mother  No  Yes  Don't Know  
b) Sister  None  1  2  3  4  5  6 or more  
 Don't Know  
c) Daughter  None  1  2  3  4  5  6 or more  
 Don't Know  
d) Grandmother  None  1  2  
 Don't Know  
e) Aunt  None  1  2  3  4  5  6 or more  
 Don't Know

18. How many of your female BLOOD relatives were diagnosed before age 50?

- a) Mother  No  Yes  Don't Know  
b) Sister  None  1  2  3  4 or more  
 Don't Know  
c) Daughter  None  1  2  3  4 or more  
 Don't Know  
d) Grandmother  None  1  2  Don't Know  
e) Aunt  None  1  2  3  4 or more  
 Don't Know

19. Have any of the following BLOOD relatives been diagnosed with ovarian cancer?

- a) Mother  No  Yes  Don't Know  
b) Sister  None  1  2  3  4 or more  
 Don't Know  
c) Daughter  None  1  2  3  4 or more  
 Don't Know

If one or more have had ovarian cancer:

d) Of the relatives above (mother, sister, daughter) how many were diagnosed with ovarian cancer before the age of 45?

- None  1  2  3  4 or more  
 Don't Know

20a. Have you ever been diagnosed with ovarian cancer?

Yes  No ➡

If no, go to #21a

b) If yes, at what age were you diagnosed with ovarian cancer?

under age 45  50-54  
 45-49  55 or older

21a. Have you ever been treated with radiation therapy (more than one radiation dose) to the neck or chest? (for example, Hodgkin's disease, thyroid problems?)

Yes  No ➡

If no, go to #22

b) How old were you at the time of your first radiation therapy?

under age 20  
 20 years or older

c) Was this treatment for Hodgkin's Disease?

Yes  No

Please answer the following questions to help further our understanding of breast cancer risk and to assist in your care.

22. When was the last time a health care provider examined your breasts for lumps with his/her hands?

Never  
 Within the last 3 months  
 4 - 5 months ago  
 6 months - 1 year ago  
 greater than 1 year and less than 2 years  
 2 years ago or more  
 Not sure

23a. Do you currently practice breast self-examination? (examine your own breast for lumps)

Yes  No ➡

If no, go to #24

b) About how frequently do you examine your breasts for lumps?

More than once a month  
 About once a month  
 Every 2 - 3 months  
 Every 4 - 5 months  
 Every 6 months or less often

c) When you examine your breasts, about how long does it take for you to complete your examination?

minutes

24. What is your current height?

feet   inches

25. What is your current weight?

pounds

26. Are you of Hispanic, Spanish or Latino origin?

Yes  No

27. What is your racial background?

White  
 Black or African-American  
 Asian  
 Native Hawaiian or other Pacific Islander  
 American Indian or Alaska Native  
 Other, describe:

28. How many years of school have you completed?

0 to 11 years  
 High school graduate or GED  
 Some college or technical school  
 College Graduate  
 Some graduate school or advanced degree

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

PLACE ARPA STICKER HERE PLEASE AFFIX LABEL CAREFULLY

Avoid creating air bubbles and press all edges down securely.



32296

11. A genetics questionnaire from the UVa Cancer Center for breast and ovarian cancer.

Source: <http://www.healthsystem.virginia.edu/internet/cancer/breastquestionnaire.cfm>

## Genetics Questionnaire for Breast and Ovarian Cancer

Name  Address

Phone  Your Physician

**1. Check each box for you or your family member who has had cancer. Also, indicate any other cancers.**

	Breast Cancer before age 50	Ovarian Cancer at any age	Any other cancer
Yourself	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Mother	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Sister	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Daughter	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
<b>Mother's side</b>			
Grandmother	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Aunt	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Cousin	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Others (specify)	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
<b>Father's side</b>			
Grandmother	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Aunt	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Cousin	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Others	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no

**2. Add up your checks. If you have 2 or more yes checks in the breast cancer before age 50 and/or ovarian cancer at any age columns, you may be a candidate for genetic susceptibility testing for breast and ovarian cancer.**

**3. Print out and give this completed form to your physician. He or she may refer you to our Genetics Clinic.**

**12. A questionnaire given to women at the Breast Cancer Surveillance consortium**

Source: <http://breastscreening.cancer.gov/ptlong5.pdf>

**PATIENT INFORMATION FORM**

Today's date: \_\_\_\_/\_\_\_\_/\_\_\_\_ (month/day/year)  
 Date of birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ (month/day/year)  
 (Consent)

1. Have you had any of the following breast changes in the last 3 months? (check all that apply)

	Both	Left	Right
Lump	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nipple discharge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, describe: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> No changes			

2. What is the main reason for your visit today? (check one)

Routine screening  
 Follow-up to routine screening exam  
 Concerns about breast problems  
**IF CONCERNS:** Who first noticed your breast problems?  Self  
 Physician or other healthcare provider  
 Other

3. When was your last mammogram?

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ (month/year)  
 I never had a mammogram

4. When did a health care provider last examine your breasts?

Never  
 Within the last 3 months  
 4 months to 1 year ago  
 More than 1 year ago  
 Not sure

5. Have you ever been diagnosed with breast cancer?

No  Yes  
**IF YES,** please answer the following questions:  
 Which breast(s)?  Left  Right  Both  
 At what age were you first diagnosed? \_\_\_\_ years old  
 OR: Date of diagnosis: \_\_\_\_/\_\_\_\_/\_\_\_\_ (month/year)

6. Have you had any of the following breast procedures? (check all that apply)

	Left	Right	Both
Fine needle or cyst aspiration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Biopsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lumpectomy (for breast cancer)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mastectomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiation therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast reconstruction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast reduction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breast implants (still present)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> I have not had any of the above procedures			

7. Have any blood relatives been diagnosed with breast cancer?

Mother:  No  Yes  Not sure  
 Sister:  No  One  2 or more  Not sure  
 Daughter:  No  One  2 or more  Not sure

**IF YES,** were any diagnosed before age 50?

Mother:  No  Yes  Not sure  
 Sister:  No  One  2 or more  Not sure  
 Daughter:  No  One  2 or more  Not sure

8. Have you or a blood relative ever been diagnosed with ovarian cancer?

No  
 Self  
 Mother, sister, or daughter  
 Other relative  
 Not sure

9. How old were you when you had your first period?

12 or younger  
 13  
 14  
 15 or older  
 Not sure  
 Never started my period

10. Are you currently taking any of the following hormone medications? (check all that apply)

Hormone replacement therapy (HRT) (e.g. Premarin)  
**IF HRT:**  Estrogen  Progesterone  Both  
 Tamoxifen (Nolvadex)/Raloxifene (Evista)  
 Hormones for birth control  
 Other hormone: \_\_\_\_\_  
 I am not currently taking hormone medication

11. Have your menstrual periods stopped permanently? (check one)

No  
 Yes, natural menopause  
 Yes, surgical procedure  
 Yes, other reason  
 Not sure  
**IF NO or NOT SURE,** when was the first day of your last period? \_\_\_\_/\_\_\_\_/\_\_\_\_ (month/day/year)  
**IF YES,** age at last period: \_\_\_\_ years old

12. Have you ever given birth?

No  Yes  
**IF YES:** How old were you when your first child was born? \_\_\_\_ years old

13. What is your current height? \_\_\_\_ feet \_\_\_\_ inches

14. What is your current weight? \_\_\_\_\_ pounds

15. Are you of Hispanic, Spanish, or Latino origin?

No  Yes

16. What is your racial or ethnic background?

(check all that apply)  
 White  
 Black or African American  
 Asian  
 Native Hawaiian or other Pacific Islander  
 American Indian or Alaska Native  
 Other, describe: \_\_\_\_\_

17. What is the highest level of education you have completed? (check one)

Less than high school graduate  
 High school graduate or GED  
 Some college or technical school  
 College or post-college graduate

18. What kind of healthcare coverage do you have?

(check all that apply)  
 Medicare  Medicaid  Private insurance  
 Managed care (such as HMO or PPO)  
 Other, describe: \_\_\_\_\_  
 Not sure  
 I have no coverage

**Thank you for taking time to complete this questionnaire.**

