BREAST CANCER
LEADING QUESTIONS FOR INDEPTH INTERVIEWS

GENERAL INSTRUCTIONS:

Background: Now that we have the organigrams and their descriptions, we wish to go further into detail analysing the health management systems by obtaining more background information not included in the organigrams. Thus we will be able to compare modules of the health management systems with each other.

Interviews: The information we ask for refers to the actual regional situation (beginning of 2006). However, of course some of the activities/regulations are governed or conducted on the national level and are as such also relevant to the regional level. Please also consider these. Some of the information we ask for might already be mentioned in your Organigraph descriptions. However, because that is not the case for all regions we took these questions up again and kindly ask you to answer them here again.

You might be able to answer some of the questions yourself. The aim is not to undertake qualitative research among representatives of your regions but to get the information in the most objective way.

However, if you cannot answer yourself, please interview someone else – e.g. key contact persons from central institutions of your health management whom you have already named in the “short questionnaire” – and typewrite the answers down in this WORD-document. We ask you to choose the partners for the interviews according to their knowledge/competence regarding the respective module.

You may wish to choose the method of conducting the interview according what is most convenient to you (e.g. conduct an interview and record the interview and type the relevant information in the WORD document or directly type in the answers during the interview; maybe you also wish to send partners the questionnaire and have them typed in the answers without a face to face situation.)

Interview-Partners Information: At the end of the questionnaire, please give the name, affiliation, address, telephone and e-mail address of the persons interviewed.

We kindly ask you to return the filled-in questionnaires by April 15th 2006.

Thank you very much!!!
Module I: Breast Self-Examination Programmes
(Module Instructions: In this module, the interviewed should be asked about the specific actions of programmes targeted to raise the women’s awareness of how important it is to detect early forms of breast cancer).

1. Are there information campaigns etc. to raise the self-awareness of women regarding breast cancer?

2. Are/is there self-examination programme(s)/campaign(s) in your region? If you do not have any, please continue with next module.

3. What is the target group by the self-examination programmes (age group, population size, geographical size)?

4. Which actions/strategies/campaigns are carried out to promote the self-examination among women? What are the main activities of the breast self-examination programmes?

5. Are programmes of breast self-examination founded in national and/or regional legislation? Who issues them?

6. Are there legal regulations for the conduction of the programmes? What are they? Who issues them?

7. Are self-examination programmes part of the current political agenda (national and/or regional)?

8. Who finances the self-examination programmes?

9. Are there clearly defined targets for self-examination programmes and what are they?

10. Which organisation(s) is/are responsible for the planning of the programmes?

11. Which organisation(s) is/are responsible for the implementation of the programmes?

12. Is there an organisation or department which co-ordinates the programmes at: (a) national level and/or (b) regional level? If yes, who is it and what tasks and competencies does it have?

13. Does the programme have provisions in place for access to follow-up examination? If yes, please give brief details.

14. Which organisation monitors and/or evaluates the self-examination programmes?

15. What are the criteria/indicators used to assess the performance of the programme(s) relating to self-examination?
Module II: Clinical Examination
(Module Instructions: In this module, the interviewed should be asked about physical examinations of the breast done by a health professional to detect breast abnormalities or to evaluate patients’ reports of symptoms to find palpable breast cancers at an earlier stage of progression. This module consists of information related to manual examination – including the techniques of inspection and palpation- and breast exams carried out to make a diagnosis with the help of techniques other than mammography screenings).

1. Are non-mammography breast cancer detection examinations habitually carried out? Which ones (ultra sound, manual, etc.)? By whom (gynaecologists, general practitioners, nurses, etc.)? If yes, are they included in preventive check-ups by regular doctor visits or in which other circumstances? Are these examinations reimbursed?

2. What individuals are considered for clinical examination (age group, family history, etc.)? Are there examination intervals?

3. Are women from families with breast cancer history offered genetic testing?

4. Are guidelines used in the performing of a clinical examination? If yes, who defines, updates and issues them? Who implements those guidelines?

5. What procedures are followed if breast cancer is suspected by the clinical examination?

6. What procedures are followed if breast cancer is detected by the examination?

7. Do you have specific campaigns/programmes to identify eligible women for a clinical examination? What are they? Who is responsible for that?

8. How are such identification campaigns/programmes financed?

9. Do you have specific invitation strategies (e.g. invitation systems by direct letter or notification)? What are they? Who is responsible for that?

10. Is there a recall system for patients that are overdue?

11. Is/are there a specially set up clinical examination programme(s) financed with extra addressed funding in your region? If you do not have any, please continue with next module.

12. What are the main activities of the clinical examination programmes?

13. Are clinical breast examination programmes founded in national or regional legislation?

14. Are there legal regulations for the conduction of the programmes? What are they? Who issues them?

15. Are clinical examination programmes part of the current political agenda (national and/or regional)?

16. Who finances the clinical programmes?

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17. Which organisation(s) is/are responsible for the planning of the programmes?

18. Are there clearly defined targets for clinical examination programmes and what are they?

19. Which organisation(s) is/are responsible for the implementation of the programmes?

20. How are regional clinical examination programmes embedded in the national health system?

21. Is there a single organisation or department which co-ordinates the programmes at: (a) national level and/or (b) regional level? If yes, who is it and what tasks and competencies does it have?

22. Which organisation monitors and/or evaluates the programmes?

23. What are the criteria/indicators used to assess the performance of the programme(s) relating to clinical examination?
Module III: Mammography Screening Policy and Organisation
(Module Instructions: In this module, the interviewed should be asked about the aspects of the mammography screening procedure with which impalpable breast cancers can be detected).

1. What is the target group of mammography screening (age group, population size, geographical size)?

2. For what kind of patients is mammography screening covered by health insurance/health system (e.g. age group, family history)?

3. Are there intervals for mammography screening? If yes, how long are they?

4. Are guidelines used in the performing of a mammography screening, e.g. single view or two views? If yes, who defines, updates and issues those guidelines? Who is responsible for implementing them?

5. What procedures are followed if breast cancer is suspected by the mammography screening?

6. What procedures are followed if breast cancer is detected by the mammography screening and any further assessment?

7. What procedures are in place for informing women of the results of a mammography screening (e.g. at a clinic visit, by post, by telephone)? Do you respect a right not to know for women?

8. How do you identify eligible women for a mammography screening examination? Who is responsible for that?

9. Do you have specific invitation strategies regarding mammography screening (e.g. invitation systems by direct letter or notification)? What are they? Who is responsible for that?

10. Is there an invitation register? How is it compiled and updated? Can eligible women self-register?

11. Is there a recall system for patients that are overdue?

12. Is/are there specially set up mammography screening programme(s) financed with extra addressed funding in your region? If you do not have any, please continue with next module.

13. What are the main activities of the mammography screening programmes?

14. Are mammography screening programmes founded in national or regional legislation?

15. Are there legal regulations for the conduction of the programmes? What are they? Who issues them?

16. Are mammography screening programmes part of the current political agenda (national and/or regional)?
17. How are the mammography screening programmes financed?

18. Which organisation(s) is/are responsible for the planning of the programmes?

19. Are there clearly defined targets for mammography screening programmes and what are they? Are they related to the EUREF guidelines?

20. Which organisation(s) is/are responsible for the implementation of the programmes?

21. How are regional mammography screening programmes embedded in the national health system?

22. Is there an organisation or department which co-ordinates the programmes at: (a) national level; and/or (b) regional level? If yes, who is it and what tasks and competencies does it have?

23. Do you monitor and/or evaluate the mammography screening programmes? If yes, who does so? And what are the quality criteria/ indicators used to assess the performance of the programmes relating to mammography screening?

24. Are there any special undertakings related to the improvement of the screening programme(s) or parts of it? If yes, please give brief details including who implements them.

25. How are these undertakings financed?

26. What data concerning mammography screening are collected:
   a. Numbers invited;
   b. Participation rate;
   c. Technical repeat rate;
   d. Recall rate;
   e. Referrals for assessment;
   f. Cancer detection rate?
Module IV: Education of the Public
(Module Instructions: In this module, the interviewed should be asked about the strategies to motivate and assist people to maintain and improve their health, enabling them to develop the skills and attitudes necessary for health-related problem solving and informed decision-making).

1. Do you distribute information about risk factors causing breast cancer? What are risk factors according to your information?

2. Are there education campaigns/programmes about the benefits of breast cancer screening?

3. What measures do you undertake to reach social subgroups of the population by the education campaigns/programmes?

4. Which subgroups would you like to reach and why?

5. Is there a monitoring and/or evaluation of education campaigns/programmes? Which organisation monitors and/or evaluates these?

6. Are there education campaigns/programmes about risks and benefits of the mammography screening? What is the aim of these campaigns?

Module V: Training and Education of Health Professionals
(Module Instructions: In this module, the interviewed should be asked about the training/education strategies to improve and strengthen the breast cancer management skills of the medical, nursing and other health professionals).

1. Do health professionals receive training/education related to:
   a) mammography screening;
   b) clinical examination advice and provisions;
   c) primary and continuing treatment; and/or
   d) care of breast cancer?

2. What professional groups receive it in each of the categories named above? How often?

3. Who provides the training/education to health professionals?

4. Is there a training for health professionals regarding the improvement of communication skills? Who receives it?

5. Is the participation in training and other forms of education relating to breast cancer screening, treatment and care obligatory or optional for health professionals? If it is obligatory, who sets the obligation?

6. How is the education quality assured?
Module VI: Surveillance

(Module Instructions: In this module, the interviewed should be asked about the surveillance aspects to identify the data elements that are necessary to evaluate the disease occurrence in the region).

1. Is there a duty to notify each detected case of breast cancer? If yes, who makes the notification and who is notified?

2. Is there a national or regional register for cancer or breast cancer?

3. Do you have a national or regional surveillance system or both? If yes, which institution is responsible for that at national and regional levels?

4. Is surveillance mandatory? Is it founded in national or regional legislation?

5. How does the surveillance system work? Explain briefly:
   
   a. Which organisations/institutes are collecting data at the local, regional and national level and from whom is the data collected at these different levels?
   b. Which data gathering methods are used to collect this data (surveys, sentinels, continuous/systematic reporting, etc.)?
   c. Are data of privately insured patients included?
   d. Who/which organisation analyses the data?
   e. Which forms of documentation do you have? Who is responsible for the documentation?
   f. Will the data be published (e.g. in Health Report)? If yes, who publishes the data? Who is/are the addressee(s) of the data/reports?

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¹ Surveillance is the systematic collection, analysis, interpretation, and dissemination of health data on an ongoing basis, to gain knowledge of the pattern of disease occurrence and potential in a community, in order to control and prevent disease in the community.
Module VII: Treatment and Care
(Module Instructions: In this module, the interviewed should be asked about the procedures followed after detecting breast cancer and the offer of treatments).

1. If a woman is diagnosed with breast cancer who is her first contact point? What procedure follows?

2. What therapies and interventions are covered by the health insurance/health system?

3. Concerning breast cancer, do you monitor patient satisfaction regarding treatment and care provision? If so, who is responsible for that?

4. Are there any special undertakings relating to improve the quality of and access to treatment and care? If yes, please give brief details including who implements them.

5. Do patients get socio-psychological support? If yes, of what kind? Who finances this? Where is this support provided? Is it provided in special psychological support centres?

6. Are there strategies/mechanisms to involve patients in their care and treatment?

7. What kinds of strategies/mechanisms are being developed to motivate patients to look for sufficient information to fully understand their health conditions and the intended procedure of treatment?

8. What strategies/mechanisms are being used to improve and strengthen the communication between patients and health professionals?

9. How are patients encouraged to learn and to claim their rights?
Module VIII: Integrated Health Care

(Module Instructions: In this module, the interviewed should be asked about the strategies and programmes intended to create breakthrough improvements in health care services for patients with breast cancer through collaboration among health providers in order to more fully address the spectrum of the patients’ problems).

1. Are there integrated care programmes for breast cancer (e.g. disease management programmes²)?
   a. If yes, how do they work? Please explain briefly.
   b. If not, please continue with the next module.

2. Who develops them? Who co-ordinates and implements them? Who certifies them and in accordance with what standards? Who is certified (e.g. GPs, nurse specialists, health institutions)?

3. What patients are allowed to participate in integrated care programmes? What are the enrolment criteria?

4. Do you collect any data relating to these programmes? If so, which data?

5. Who conducts quality assurance?

6. How is patient documentation organised? Is there a shared record?

7. What activities do you undertake to monitor patient satisfaction regarding integrated care programmes?

8. What kinds of strategies/mechanisms are being developed to encourage patients to take responsibility for managing their illnesses?

9. What kinds of strategies/mechanisms are being developed to increase patient empowerment and coping skills among patients?

10. Do the programmes include socio-psychological support? If yes, of what kind?

11. Do the programmes include specialised breast units?

12. Are specialised breast units already established in your region? If not:
   a. If there are no units and they are also not planned, please continue with the next module.
   b. If there aren’t any but it is planned to establish specialised breast units, how many specialised breast units do you plan in your region?

² Disease Management Programmes (DMP) aim at coordinated care for patients suffering from chronic diseases. Important cornerstones of these programmes are evidence based guidelines for care, collaboration of care providers at primary, secondary and tertiary levels, promotion of patient self-management and education. The processes and outcomes of care will be measured and evaluated.
13. According to what guidelines are the breast units organised and certified?
   
   a. According to EUSOMA?
   b. If it is not according to EUSOMA, what are the criteria for specialised breast units?

14. Do the specialised breast units have the possibility for triple assessment (clinical, mammogram, biopsies)?

15. How are the core teams of the specialised breast units made up?

16. How many specialised breast units do you have in your region? Are they planned because of a minimum population? Because of a number of new breast cancer cases per year? Because of another reason? Please, explain briefly.

17. Who finances the breast units? Do the units have a separate budget?

18. Do the units provide treatment and care at all the stages of the disease, from screening through to the care of the advanced disease?

19. How is rehabilitation implemented into the units? Do patients receive physical and psychological rehabilitation as well?

20. Do you monitor patient satisfaction regarding the breast units?

21. What arrangements are in place for auditing and evaluating the outcomes from the specialist breast units and for monitoring quality assurance?

**Module IX: Rehabilitation**

(Module Instructions: In this module, the interviewed should be asked about the strategies to educate and instruct the breast cancer patient in therapeutic and self-help techniques to manage his/her health condition in order to restore his/her highest level of functioning).

1. What kind of rehabilitation is received by the treated patients?

2. Is the rehabilitation also socio-psychological?

3. Is a prosthetic fitting service available?

4. Is rehabilitation covered by health insurance/health system?

5. Is ambulant home rehabilitation also covered by health insurance/health system?

6. Does home help get reimbursed for patients with breast cancer or their families?)
Module X: Self-Help Groups
(Module Instructions: In this module, the interviewed should be asked about the possibilities of getting support and orientation from specialized groups offered to women and their families who are currently undergoing breast cancer treatment and to those who have finished all treatment.

1. Are/is there self-help group(s) supported by official institutions/programmes? If yes, how are they supported?

2. Is the promotion of self-help groups part of the current political agenda (national and/or regional)?

3. Are/is there health education campaign(s)/programme(s) specially designed for self-help groups?

4. Are self-help groups integrated in policy making and/or counselling bodies of the region?

Expert Opinion: Remarks and Intraregional Variability
(In this section, the interviewed should be asked about the main regional variations in the health management of a country. In addition, the interviewed could provide supplementary information relevant to the health management evaluation).

1. The health management programmes of different regions within one country might differ substantially if a common national approach does not exist. Regarding the health management of the other regions in your country, are there substantial differences compared to the studied region? If yes, what are these main differences? What are the reasons for such differences? Please explain briefly.

2. In your opinion, is there some information not asked for in this questionnaire that should also be considered for the purpose to assess the health management in the region? Please explain briefly.