

Benchmarking Regional Health Management II (Ben RHM II)

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Content Overview

Contents

1. Executive Summary	15
2. Introduction – scope and purpose	30
3. Project organisation	31
4. Methodology	40
5. Organigraphs	62
6. Analysis of the response to the in-depth-interviews	238
7. Rapid appraisal using reference frameworks	291
8. Analysis of the health performance indicators	304
9. Identification of good practice	311
10. Discussion	334
11. Perspectives	337
12. Conclusions	343
13. References	345

Annex

Contents

Foreword	13
1. Executive Summary	15
2. Introduction – scope and purpose	30
3. Project organisation	31
3.1 Project partners and the WHO Regions for Health Network (RHN)	31
3.2 Steering Group	32
3.3 Main activities of the project	33
3.3.1 Project meetings final conference	33
3.3.2 Communication and dissemination	36
4. Methodology	40
4.1 Methodological strategy	42
4.2 Methodological tools	44
4.2.1 Questionnaire about key contacts and organigraphs	44
4.2.2 Questionnaires for in-depth interviews	45
4.2.3 Reference frameworks	46
4.2.3.1 Selection of policies and interventions for the reference framework	47
4.2.3.2 Rapid appraisal using reference frameworks	52
4.2.4 Health performance indicators	53
4.2.5 Grouping of regions by clustering	54
4.2.5.1 Methodology	55
4.2.5.2 Results	58
4.2.5.3 Discussion	62
5. Organigraphs	62
5.1 Measles	63
5.1.1 Austria (Upper-Austria)	63
5.1.2 Belgium (Flemish Community)	66
5.1.3 Bulgaria (Varna-Oblast)	69
5.1.4 Czech Republic (Moravia-Silesia)	72
5.1.5 Germany	74
5.1.5.1 North Rhine-Westphalia	74
5.1.5.2 Saxony-Anhalt	78
5.1.6 Greece (Western-Greece)	82

5.1.7	Hungary	86
5.1.7.1	Győr-Moson-Sopron County	86
5.1.7.2	Szabolcs-Szatmár-Bereg	87
5.1.8	Ireland (Dublin/Mid-Leinster and Dublin/North-East Regions)	92
5.1.9	Italy	95
5.1.9.1	Emilia-Romagna	95
5.1.9.2	Sicily	98
5.1.9.3	Veneto	101
5.1.10	Lithuania (Kaunas)	102
5.1.11	Portugal (Madeira)	108
5.1.12	Russian Federation (Chuvash Republic)	109
5.1.13	Sweden (Västra Götaland)	112
5.1.14	Switzerland (Ticino)	115
5.1.15	United Kingdom (England)	118
5.1.16	Discussion	121
5.2	Breast cancer	128
5.2.1	Austria (Upper-Austria)	129
5.2.2	Belgium (Flemish Community)	130
5.2.3	Bulgaria (Varna-Oblast)	134
5.2.4	Czech Republic (Moravia-Silesia)	136
5.2.5	Germany (North Rhine-Westphalia)	138
5.2.6	Greece (Western-Greece)	141
5.2.7	Hungary	146
5.2.7.1	Hungary (Győr-Moson-Sopron County)	146
5.2.7.2	Hungary (Szabolcs-Szatmár-Bereg)	147
5.2.8	Ireland (Dublin/Mid-Leinster and Dublin/North-East)	151
5.2.9	Italy	157
5.2.9.1	Italy (Emilia-Romagna)	157
5.2.9.2	Italy (Sicily)	160
5.2.9.3	Italy (Veneto)	163
5.2.10	Lithuania (Kaunas)	164
5.2.11	Russian Federation (Chuvash Republic)	167
5.2.12	Sweden (Västra Götaland)	170
5.2.13	Switzerland (Ticino)	172
5.2.14	United Kingdom (England)	175
5.2.15	Discussion	178
5.3	Diabetes (type II)	183
5.3.1	Austria (Upper-Austria)	183
5.3.2	Belgium (Flemish Community)	186
5.3.3	Bulgaria (Varna-Oblast)	192
5.3.4	Czech Republic (Moravia-Silesia)	194
5.3.5	Germany (North Rhine-Westphalia)	198
5.3.6	Greece (Western-Greece)	201

5.3.7	Hungary	204
5.3.7.1	Hungary (Győr-Moson-Sopron County)	204
5.3.7.2	Hungary (Szabolcs-Szatmár-Bereg)	205
5.3.8	Ireland (Dublin/Mid-Leinster and Dublin/North-East)	209
5.3.9	Italy	215
5.3.9.1	Italy (Emilia-Romagna)	215
5.3.9.2	Italy (Sicily)	218
5.3.9.3	Italy (Veneto)	221
5.3.10	Lithuania (Kaunas)	222
5.3.11	Russian Federation (Chuvash Republic)	225
5.3.12	Sweden (Västra Götaland)	228
5.3.13	United Kingdom (England)	231
5.3.14	Discussion	233
6.	Analysis of the response to the in-depth-interviews	238
6.1	Measles	238
6.1.1	Prevention	238
6.1.1.1	Type of public information and education about measles vaccination	238
6.1.1.2	Responsible organisation regarding vaccination	240
6.1.1.3	Strategies to reach social subgroups	240
6.1.1.4	Invitation system for measles immunisation	241
6.1.1.5	Register of vaccinated persons and adverse reactions	243
6.1.1.6	Target groups for first and second measles vaccination	244
6.1.1.7	Type of vaccine	247
6.1.1.8	Financing of measles vaccination	248
6.1.2	Screening	249
6.1.2.1	Focal-, catch-up or follow-up campaigns	249
6.1.3	Health service	250
6.1.3.1	Specific law for immunisation	250
6.1.3.2	Measles elimination on the political agenda	251
6.1.4	Discussion of the analysis of the responses from the participating regions	251
6.2	Breast cancer	254
6.2.1	Prevention and Screening	254
6.2.1.1	Education campaigns about the benefits of breast cancer screening	254
6.2.1.2	Invitation strategies for mammography screening	255
6.2.1.3	Invitation registers for mammography screening	255
6.2.1.4	Target group of women for mammography screening	256
6.2.1.5	Intervals for mammography screening	258

6.2.1.6	Responsibility for the planning of mammography screening programmes	259
6.2.1.7	Financing of mammography screening programmes	260
6.2.1.8	Recall systems	260
6.2.1.8.1	Recall system for clinical examination	260
6.2.1.8.2	Recall system for mammography screening	261
6.2.1.9	Use of guidelines	261
6.2.1.9.1	Guidelines for clinical examination	263
6.2.1.9.2	Guidelines for mammography screening	264
6.2.2	Treatment and care	264
6.2.2.1	Duty to notify cases of breast cancer	264
6.2.2.2	Integrated treatment and care programmes	266
6.2.2.2.1	Integrated care programmes	266
6.2.2.2.2	Disease Management Programmes	267
6.2.2.3	Establishments of breast units	268
6.2.2.4	Rehabilitation	270
6.2.2.4.1	Type of rehabilitation	270
6.2.2.4.2	Rehabilitation with socio-psychological aspects	270
6.2.2.4.3	Availability of prosthetic fitting service	271
6.2.3	Health service	271
6.2.3.1	Monitoring satisfaction regarding treatment and care	271
6.2.3.2	Part of the political agenda	271
6.2.3.2.1	Breast cancer prevention (e. g. mammography screening programmes)	272
6.2.3.2.2	Promotion of self-help groups	272
6.2.3.3	Support of self-help groups	272
6.2.4	Discussion of the analysis of the responses from the participating regions	273
6.3	Diabetes (type II)	278
6.3.1	Prevention and screening	278
6.3.1.1	Education campaigns to prevent diabetes and diabetes risk factors	278
6.3.1.2	Target population of education programmes/campaigns	280
6.3.1.3	Information and education for socio-economic subgroups	281
6.3.1.4	Special regional diabetes screening programme	281
6.3.1.5	Examination interval	281
6.3.1.6	Detection examination of pregnant women	282
6.3.2	Treatment and care	283
6.3.2.1	Implementation of regional integrated care programmes	283
6.3.2.2	Existence of a diabetes surveillance system	284
6.3.2.3	Examination intervals	285

6.3.2.3.1	Eye examination	286
6.3.2.3.2	Foot examination	286
6.3.2.4	Support of self-help groups by official institutions	287
6.3.2.5	Monitoring patient satisfaction regarding care provision	287
6.3.3	Diabetes examination and screening programmes as part of the political agenda	287
6.3.4	Discussion of the analysis of the responses from the participating regions	288
7	Results of the rapid appraisal using reference frameworks	291
7.1	Analysis of the three tracers	291
7.1.1	Measles	291
7.1.2	Breast cancer	294
7.1.3	Diabetes (type II)	296
7.1.4	Conclusions	299
7.2	Case Study – Measles in North Rhine-Westphalia	300
7.2.1	Individual reminder	302
7.2.2	Establishment of vaccination campaigns	302
7.2.3	Education of possible multipliers	302
7.2.4	Bonus system for parents	303
7.2.5	Conclusions	303
8	Analysis of the health performance indicators	304
8.1	Measles	305
8.2	Breast cancer	307
8.3	Diabetes (type II)	308
8.4	Conclusions	310
9	Identification of good practice	311
9.1	Methodology	311
9.2	Measles	313
9.2.1	First approach: analysis of indicators	313
9.2.2	Second approach: analysis of additional information	316
9.2.3	Preliminary conclusions	320
9.3	Breast cancer	320
9.3.1	First approach: analysis of indicators	320
9.3.2	Second approach: analysis of additional information	323
9.3.3	Preliminary conclusions	327
9.4	Diabetes (type II)	327
9.4.1	First approach: analysis of indicators	327
9.4.2	Second approach: analysis of additional information	328
9.4.3	Preliminary conclusions	333

9.5 Conclusions	333
10 Discussion	334
10.1 Relevance of the methodology of Ben RHM II	334
10.2 Lessons learned from the analysis of good practice	336
11 Perspectives	337
11.1 Complementarity with other EU projects	337
11.2 Projects in the environment of Ben RHM II	338
11.2.1 Development of indicators, identification of data, check of the availability of data	338
11.2.2 Design and construction of health information systems	339
11.2.3 Development of methods and tools for the assessment of public health projects and policies	340
11.2.4 Relationships between the projects	340
11.3 Lessons learned from Ben RHM II for the “Method of Open Co-ordination” (OMC)	341
11.4 Ben RHM II – and the future work of the Regions for Health Network in Europe	342
12 Conclusions	343
13 References	345

Annex

Annex

Annex 1 a:	Steering Group and members from the Regions for Health Network
Annex 1 b:	Key contacts of Health Regions
Annex 2 a:	Minutes of the first Steering Group meeting (13 th September 2004, Düsseldorf)
Annex 2 b:	Minutes of the second Steering Group meeting (22 nd April 2005, Prague)
Annex 2 c:	Minutes of the third Steering Group meeting (14 th October 2005, Linz)
Annex 2 d:	Minutes of the fourth Steering Group meeting (18 th May 2006, Dublin)
Annex 2 e:	Minutes of the fifth Steering Group meeting (2 nd October 2006, Copenhagen)
Annex 2 f:	Minutes of the sixth Steering Group meeting (18 th May 2007, Düsseldorf)
Annex 3 a:	Questionnaire about measles
Annex 3 b:	Questionnaire about breast cancer
Annex 3 c:	Questionnaires about diabetes (type II)
Annex 4:	Reference frameworks for the health management of measles, breast cancer, diabetes (type II) (Cent Eur Publ Health, 2006)
Annex 5:	Health performance indicators
Annex 6:	Flyer (March 2007)
Annex 7:	Feedback Questionnaire
Annex 8:	Financial statement
Annex 9:	Financial statement calculations

List of figures and tables

List of figures

Illus. 1:	Benchmarking methodology for “Benchmarking Regional Health Management II (Ben RHM II)”	43
Illus. 2:	Reference framework – measles - interventions implemented for measles immunisation and elimination	49
Illus. 3:	Reference framework – breast cancer - screening and care	50
Illus. 4:	Reference framework – diabetes (type II) – primary prevention, screening, secondary and tertiary prevention	51
Illus. 5:	Clusters of regions after K-means clustering	60
Illus. 6:	Information on education about measles on TV or radio	239
Illus. 7:	Existence of invitation system for measles immunisation	242
Illus. 8:	Existence of a register for vaccinated persons	243
Illus. 9:	Kind of register for vaccinated persons	244
Illus. 10:	Immunisation schedule: first measles vaccination	245
Illus. 11:	Immunisation schedule: second measles vaccination	247
Illus. 12:	Existence of focal-, catch-up or follow campaigns	250
Illus. 13:	Existence of invitation register for mammography screening	256
Illus. 14:	Target group of women for mammography screening	257
Illus. 15:	Use of guidelines for clinical examination	263
Illus. 16:	Duty to notify cases of breast cancer	265
Illus. 17:	Existence of Disease Management Programmes	268
Illus. 18:	Existence of breast units	269
Illus. 19:	Existence of education campaigns to prevent diabetes (type II)	279
Illus. 20:	Target population of education campaigns	280
Illus. 21:	Examination interval for the detection (screening) of diabetes (type II)	282
Illus. 22:	Existence of implemented regional care programmes	284
Illus. 23:	Existence of diabetes surveillance system	285
Illus. 24a:	Rapid appraisal of measles interventions (part a)	292
Illus. 24b:	Rapid appraisal of measles interventions (part b)	293
Illus. 24c:	Rapid appraisal of measles interventions (part c)	294
Illus. 25a:	Rapid appraisal of breast cancer interventions (part a)	294
Illus. 25b:	Rapid appraisal of breast cancer interventions (part b)	295
Illus. 25c:	Rapid appraisal of breast cancer interventions (part c)	296
Illus. 26a:	Rapid appraisal of diabetes (type II) interventions (part a)	297
Illus. 26b:	Rapid appraisal of diabetes (type II) interventions (part b)	298
Illus. 26c:	Rapid appraisal of diabetes (type II) interventions (part c)	299
Illus. 27:	Reference framework – measles - interventions implemented for measles immunisation and elimination – Moravia-Silesia (CZ)	318
Illus. 28:	Reference framework – measles - interventions implemented for measles immunisation and elimination: Varna-Oblast (BG)	319
Illus. 29:	Reference framework – breast cancer – screening and care – Emilia-Romagna	325
Illus. 30:	Reference framework – breast cancer – screening and care – Varna-Oblast (BG)	326
Illus. 31:	Reference framework – diabetes (type II) – primary prevention, screening, secondary and tertiary prevention – Emilia-Romagna (IT)	331
Illus. 32:	Reference framework – diabetes (type II) – primary prevention, screening, secondary and tertiary prevention – Saxony-Anhalt	332

List of tables

Table 1a: Presentations on Ben RHM II	37
Table 1b: Presentations on Ben RHM II given after completion of the project	37
Table 1c: Presentations on Ben RHM II in preparation	40
Table 2: Calculation of interventions applied in the region X	52
Table 3: Assigning of colours according to interventions in the region X	52
Table 4: Ben RHM II – Regions and regions participating in the clustering study	56
Table 5: Set of variables for the clustering	57
Table 6: Data framework	57
Table 7: Cluster membership after K-means technique	58
Table 8: Comparison of clusters	61
Table 9: Financing of measles immunisation in the participating regions	248
Table 10: Intervals for mammography screening	259
Table 11: Measles 2005: Availability of regional data regarding the health performance indicators selected by the Steering Group	314
Table 12: Measles 2005: Health performance indicators selected by the Steering Group	316
Table 13: Breast cancer 2005: Availability of regional data regarding the health performance indicators selected by the Steering Group	321
Table 14: Breast cancer 2005: Health performance indicators selected by the Steering Group	323
Table 15: Diabetes (type II) 2004: Availability of regional data regarding the healthperformance indicators selected by the Steering Group	328

Foreword

For years, countries in Europe have been struggling with the notion of how best to structure and adapt health systems in order to provide universal access for all citizens, effective care for better health outcomes, efficient use of resources, and high quality services and responsiveness to patient concerns. Today, there is emerging consensus that better health systems are essential to achieving improved health outcomes. This consensus was reaffirmed by the World Health Organisation (WHO) in the World Health Report 2000 where health systems were broadly defined as: “Comprising all the actors, institutions and resources that are devoted to producing action where the primary aim is to improve, maintain or restore health.” The report identified three overall goals for health systems to be effective, responsive and fair:

- effective in contributing to better health throughout the entire population;
- responsive to people's expectations, including safeguarding patient dignity, confidentiality and autonomy and being sensitive to the specific needs and vulnerabilities of all population groups; and
- fair in how individuals contribute to funding the system so that everyone has access to the services available and is protected against potentially impoverishing levels of spending.

Today, in many countries in Europe, health systems operate in a decentralised environment. This trend reveals the need for a closer examination of the health systems and the work carried out at the regional level in Europe. The first “Benchmarking Regional Health Management” (Ben RHM) project was established by the EU under the framework of the Health Monitoring Programme (HMP) with the aim to enhance knowledge of regional health policies in terms of governance of health programmes and processes, the administration of regional public health authorities, financing institutions and providers and institutional arrangements for monitoring activities (“Policy Development” and “Assurance” of the Public Health Trias). The intent was to support a learning process among regions in Europe, using the variations between different regional health care regulations and activities. The results showed an immense variety in the organisation, implementation and evaluation of different measles immunisation and breast cancer screening programmes. The participating regions gained knowledge and understanding of different ways of working and obtained information on how to improve

their own prevention and screening programmes. Despite the differences in data revealing variation in socio-economic and historical backgrounds, it was agreed that an interregional benchmarking with the aim of identifying “good practice models” would be feasible.

To enable a continual learning process among regions in Europe and to achieve more transparency amongst the different regional health systems, Ben RHM II (2004-2007) was established. Ben RHM II involved a far larger group of regions and gave special consideration to political and socio-demographic backgrounds as well as epidemiological developments. This allowed for a comprehensive benchmarking and the identification of good practice models for each group, enabling regions to implement changes according to the procedures most similar to theirs.

This report will reveal the importance of work at the regional level and reiterate the need for benchmarking practices and utilization of various methodological tools for good practice. We hope that the findings will inspire other regions to work towards better health systems governance.



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1 Executive Summary

A. AIMS AND OBJECTIVES

Interregional comparative and evaluative studies of health management systems in Europe are needed to assess the effectiveness of programmes and activities. The project “Benchmarking Regional Health Management II” (Ben RHM II) follows this path.

In Ben RHM II, the health management systems of 19 European regions were compared with regard to their structures, processes, policies and health outcomes. The benchmarking process served to identify points where structures and methods for reaching the envisaged targets could be improved.

B. METHOD

The analysis was conducted along three tracers (cf. chapter 4). The tracers of Ben RHM II are: *Measles immunisation* which was chosen as a tracer because the focus of health management lies on prevention. *Breast cancer screening* was selected as a tracer for focussing on screening. The tracer *diabetes* was chosen to focus on care.

The analysis was done along two complementary strands. The first was to construct “organigraphs” to show at a glance how the health management systems are organised (cf. chapter 4.2.1) and to compile key contacts in the regions.

Parallel to this strand, evidence-based policies and interventions regarding the three project tracers were selected based on literature reviews and expertise. The policies and interventions were listed in “reference frameworks” containing a time and an intervention dimension (cf. chapter 4.2.3). With the “reference frameworks”, a rapid appraisal of the health interventions and policies could be performed.

To reflect the major public health concerns regarding the management of measles, breast cancer and diabetes (type II), health performance indicators were defined for each of the tracers. The selection and definition of the indicators was done under consideration of the ECHI list of indicators (cf. chapter 4.2.4). The quantitative data regarding the indicators had to be collected. Furthermore, in-depth interviews were carried out in each participating region to get detailed information on the health managements (cf. chapter 4.2.2).

To enable the participants of the Ben RHM II project to identify effective health interventions and programmes from regions similar to their own in structure and development, to learn from these and to improve their own health management, it was advised to organise the regions into groups (so called clusters). Similar regions were thus organised in groups based on their political and socio-economic situation as well as any other factor having an influence on the effectiveness of health interventions and programmes (cf. chapter 4.2.5).

Finally, with the instruments developed, “organigraphs”, in-depth interviews, “reference frameworks” and health performance indicators, diverse criteria for identifying good practice were available. For a benchmarking, an identification approach of good practice has to first focus on the availability of the indicator data and to find regions that perform well. Then closer looks on the qualitative data reveal how good practice identification can be pursued.

C. RESULTS

C.1 Organigraphs

“Organigraphs” were developed as a new approach to charting how organisations work. An “organigraph” is intended to map processes in order to understand critical interactions, what relationships exist, how information spreads through the organisation and so demonstrate how the organisation – or the regional health management respectively – works.

All 19 of the participating regions submitted “organigraphs” for *measles*. Programme descriptions were received from 16 regions. Whilst the “organigraphs” can give an overview of the health management system, the programme descriptions can give a number of more detailed insights into the system. The “organigraphs” and programme descriptions reflect very well the complexity of the health management system that can involve so many different organisations and actors at the different levels, national, regional and local.

“Organigraphs” for *breast cancer* were received from 17 of the 19 regions. Programme descriptions were received from 15 regions. “Organigraphs” for *diabetes* were received from 17 of the 19 regions. Programme descriptions were received from 15 regions. (cf. chapter 5)

C.2 Reference Frameworks and Rapid Appraisal

Three “reference frameworks” structure and compile evidence-based and feasible health policies and intervention for each of the tracers – the implementation of any of the policies and interventions presented in the “reference frameworks” would be a singular and *prima facie* good practice. These “reference frameworks” present a matrix against which health plans and health programmes can be compared and used for a *rapid appraisal* (a regional approach to quantitatively check the amount of applied policies and interventions of the “reference frameworks”). All of these aspects were considered in Ben RHM II and were utilised. (cf. chapter 4.2.3 and chapter 7)

For the *rapid appraisal*, out of 19 regions participating in the project, 13 participants identified the interventions from the “reference frameworks” applied in their region with regard to *measles*. Significant differences between the regions were established. For example, Moravia-Silesia (CZ) had implemented almost all the interventions recommended in the “reference frameworks”, while Ticino (CH) had carried out only a small number of them. Important differences in the implementation of interventions were also revealed within a country. While Saxony-Anhalt (DE) registered a considerable number of first-dose interventions, North Rhine-Westphalia (DE) reported few interventions with regard to the first dose.

With regard to *breast cancer*, 13 participants identified the interventions from the “reference frameworks” implemented in their own regions. Considerable differences were established concerning the implementation of breast cancer interventions. Out of eleven regions which sent information for the rapid appraisal of breast cancer interventions, North Rhine-Westphalia (DE) and Dublin/Mid-Leinster and Dublin/North-East (IE) reported a large number of the interventions recommended in the “reference frameworks”. On the other hand, Ticino (CH) and Madeira (PT) had implemented only a few of the recommended interventions.

Significant intra-national differences in breast cancer management were also confirmed. Although Emilia-Romagna (IT) and Veneto (IT) reported a similar number of interventions from the “reference frameworks” with regard to the undiagnosed level of the settings “population and social system”, Veneto (IT) had implemented fewer interventions in the individual/immediate setting than Emilia Romagna (IT).

Concerning the health management of *diabetes* (type II), eleven project participants identified the interventions from the “reference frameworks” applied in their own region. It was confirmed that Moravia-Silesia (CZ) had implemented most of the interventions from the

“reference frameworks”, while Dublin/Mid-Leinster and Dublin/North-East (IE) had carried out only a few of them.

Although there are limitations to the merely quantitative rapid appraisal method, the advantages of the method are clear. The method is relatively easy to use and, compared to the little effort, very beneficial and helpful. It can immediately be seen which areas policy makers should examine more closely to improve the health management in their region. Also regions can be compared against each other. However, a ranking of the regions is avoided by this method – which can be seen as an advantage.

C.3 Health Performance Indicators

There are five health performance indicators identified by the Ben RHM II Steering Group for measles, seven for breast cancer and four for diabetes. All refer to the *regional level* (cf. chapter 8).

Measles: 1st Uptake dose (percentage); 2nd Uptake dose (percentage); Incidence (per 100.000); Mortality (per 100.000); Hospitalisation (percentage of cases)

Breast cancer: Incidence (per 100.000 women); Mortality (per 100.000 women); Fatality (percentage of cases); 5-year survival rate (percentage of women diagnosed with breast cancer); 10-year survival rate (percentage of women diagnosed with breast cancer); Participation in mammography screening (percentage of women aged 50-69 years old); Detection (per 100.000 women screened)

Diabetes (type II): Incidence (per 100.000); Prevalence (per 100.000); Participation in education programmes (percentage of diabetics); Hospitalisation (percentage of diabetics)

The majority of the regions delivered information on the indicators. However, not all data received corresponded to the health performance indicators selected by the Steering Group. Major differences in the way regional information is calculated and reported were identified. The main differences and shortages of information are described in the following.

C.4 Measles

Based on the information received at the regional level, significant differences were confirmed regarding the way the first-dose information was handled and reported by the regions. Not all data corresponded to the first-dose indicator selected by the Steering Group. Not all first-dose data were calculated based on the population aged 12 months recommended by WHO for the first dose.

With regard to the *2nd dose uptake* indicator, for the years 1999 to 2005 two regions did not provide any regional information concerning this indicator: Some provided national data instead of regional data, some did not provide any information at all.

Important differences were also established concerning the calculation of this parameter. Not all data corresponded to the second-dose indicator selected by the Steering Group. None second-dose data were based on the population aged 9 months to 15 years old as recommended by WHO.

C.5 Breast cancer

No epidemiological information concerning breast cancer was received from four of the participating regions. Concerning *breast cancer incidence*, measured in new cases per 100.000 individuals, Sicily (IT) delivered national information. Western-Greece (EL) and Saxony-Anhalt (DE) informed the Ben RHM II secretariat that for the years 1999 to 2005 no such information was available at the regional level. Emilia-Romagna (IT) and England (UK) delivered sub-national data in which the regions are only partially considered.

Concerning the *5-year survival rate* (as percentage of women diagnosed with breast cancer), a significant shortage of information was confirmed. Only two regions from all participants, Sicily (IT) and Varna-Oblast (BG), delivered this precise information for all years from 1999 to 2005.

With regard to the *10-year survival rate* (as percentage of women diagnosed with breast cancer), a significant shortage of information was also confirmed. Six participants let the secretariat know that for the years 1999 to 2005 the indicator was not available at the regional level. Nine other regions did not deliver any kind of information on the 10-year survival rate.

C.6 Diabetes (type II)

Concerning the three project tracers, the greatest lack of regional data was identified for information related to diabetes (type II). Six participants did not deliver regional information

concerning diabetes. Two of them let the secretariat know that they were unable to send this information because diabetes-related data were not systematically collected.

From the regions which sent some information related to diabetes, it is important to note that the majority of them provided aggregated data referring to both types of diabetes. Concerning *diabetes (type II) incidence*, measured as new cases per 100.000 population, only two regions, Moravia-Silesia (CZ) and Szabolcs-Szatmár-Bereg (HU), supplied this type of information.

With regard to *diabetes (type II) prevalence*, defined as the number of cases per 100.000 population, only Moravia-Silesia (CZ) and Szabolcs-Szatmár-Bereg (HU) provided data satisfying these specifications and exclusively on diabetes type II.

Dublin/Mid-Leinster (IE) also delivered prevalence information on diabetes type II. They sent this type of information for two population groups: the 50-60-year-old population for the year 1998 and for the population aged 20 years old and older for 2005.

After conducting the analysis of the health performance indicators, it can be concluded that the regional data situation is very heterogeneous. A great number of the data for health performance indicators does not exist or is not available at the regional level. Comparing the situation among the three tracers, indicators on measles are well available, indicators on diabetes hardly. The main reason why many of the information were not available was because the data are not collected systematically. Comparing the situation within countries a heterogeneous situation could be observed as well when considering regions from one country as the availability of data also differs between the regions in one country.

C.7 Cluster Analysis

The cluster analysis brought up four clusters. *Cluster 1* has a high disposable income per inhabitant and a very low unemployment rate. It is characterised by medium population density, a high percentage of seniors and an average male population. In addition, *cluster 1* has a very high number of physicians per 100.000 inhabitants.

Cluster 2 has a relatively low income and a very high unemployment rate. It has a low population density and a small male population. This cluster is also characterised by a low percentage of seniors as well as a small number of physicians. Regarding the prevailing health care system, most of its members have a mixed system. In relation to the system of government, half of the regions have a federal arrangement as political system and the other half are unitary states.

Cluster 3 is characterised by a medium percentage of seniors, an average number of physicians and a medium male population. Additionally, *cluster 3* has a high disposable income and a low unemployment rate. The majority of the members of this cluster have a Statutory Health Insurance-based health system and a Federation as government system.

Cluster 4 has a very low population density. This cluster is characterised by a large number of males in relation to females, a small elderly population and a low number of physicians. *Cluster 4* also has a high income and a low unemployment rate. All regions belonging to this cluster have a tax-based health care system and they are all unitary states.

The study demonstrated that the clustering analysis is a useful instrument to identify population groups with similar demographic and socio-economic characteristics. Nevertheless, the clustering results should be considered with caution since the clustering techniques are considerably affected by the variables used. Clusters will always be defined by the set of variables employed by the analyst. Therefore a cluster does not lead to a single or definite solution (cf. chapter 4.2.5).

C.8 In-Depth Interviews

The response rate to the in-depth interviews was very good (cf. chapter 6). These interviews revealed great differences in the health management of the three tracers in the European regions. The analyses of the responses showed an immense variety in the organisation, implementation and evaluation of different immunisation programmes, breast cancer and diabetes (type II) care and screening programmes.

Some selected main results shall here be presented and discussed: It is apparent from the analysis in the preceding paragraphs that the responses showed immense differences in the policy, organisation and management of *measles immunisation* programmes in the participating regions. These differences may be explained to some degree by differences in health systems in operation within the regions e.g. publicly funded versus health insurance systems, or by the socio-political or socio-economic background and culture of the different regions. However, it is very informative to note the significant differences in either policy, organisation or management approach to measles immunisation programmes by regions within the same country operating within the same national environment, e.g. in Italy. Why should this be so? It may signal the degree of autonomy exerted by a given region. Just as there may be differences of approach between regions of different countries so also there may be differences between autonomous regions within the same country.

The establishment of an invitation/reminder/recall system for measles immunisation is an evidence-based intervention included in the reference framework for measles. The analysis of responses shows that this norm has been implemented by 12 of the 18 regions that responded and it is reasonable to assume that other regions should follow suit. However, it is clearly demonstrated by 1 of the 6 regions that has not implemented a formal written invitation system, that a personal approach by the visiting nurse or family doctor is an effective alternative for that region since uptake of measles vaccination is exceedingly high, 99.8%, and the incidence of measles is zero. This demonstrates that it is for the policy makers and managements of the regions to choose which interventions are the most appropriate for adoption by their region.

Focal, catch-up or follow-up campaigns for measles immunisation are included as an evidence-based intervention in the reference framework. The analysis of responses shows that such campaigns are being carried out in 7 of the 18 regions, but not in the other 11 regions. The latter group includes a number of regions where uptake of measles vaccination is high and where incidence of measles is zero; but this group also includes a number of regions whose performance indicators are comparatively less favourable. This once again demonstrates that it is a matter for policy makers and management in each region to choose interventions are appropriate for their region.

Education programmes about the benefits of *breast cancer screening* have been established in 13 of the 17 regions that responded. There is no screening programme in 2 of the other 4 regions and of the remaining 2, 1 reported a good mammography screening participation rate of 75% in 2005 despite the absence of an education programme. No information on participation rate was received from the other region. The fact that such a large majority of regions has established an education programme suggests that this can be regarded as a good practice norm. However, these programmes can have many different formats depending on the choice of the region and this gives rise to difficulties of comparison as there is no information on the effectiveness of the different formats. The reference framework for breast cancer includes, as an evidence-based intervention, education of physicians and the political community regarding the risks and benefits of mammography screening.

The analysis of responses shows that invitation strategies for mammography screening have been developed in 13 of the 17 regions that responded. Of the remaining 4 regions, 2 have no invitation strategy and 2 have no screening programme. The mammography screening participation rate in 1 of the 2 regions without an invitation strategy is low and no information on participation rate was received from the other region. Identification and invitation

of eligible women for mammography screening (every two/three years) is included in the reference framework for breast cancer.

When asked about special education campaigns or programmes for the prevention of *diabetes (type II)*, 12 of the 17 regions that responded said that they have implemented them whereas 5 regions said they have no such campaigns or programmes in place.

Given the continuously growing number of diabetics, preventive measures aimed at reducing the risk factors for diabetes through lifestyle or other actions seem to be an almost essential part of the armament of any public health authority in the battle against diabetes. Evidence-based preventive measures shown to contribute to a reduction in risk factors such as obesity and hyperlipaemia therefore assume a particular significance.

Because of the significance of such preventive measures, the analysis of the responses from the regions that had implemented education campaigns about the prevention of diabetes were further analysed in terms of target population. It was hoped that this would be of interest to all regions but that it would be particularly informative for those regions that had not yet implemented any campaigns.

None of the regions that responded has found a way to comprehensively inform socio-economic subgroups about the prevention of diabetes and some regions point out that the “normal population” is hardly being reached.

D. SYNTHESIS: IDENTIFICATION OF GOOD PRACTICE IN REGIONAL HEALTH MANAGEMENT

D.1 Methodology

To identify good practice models, only those data available on the regional level and which precisely satisfy the health performance indicators selected by the Steering Group were considered in the good practice analysis (cf. chapter 9). In a first step, the regional data received from the participants on the health performance indicators selected by the Steering Group were reviewed to select a year in order to perform a more-in-detail analysis.

In a second step, the relevance of the indicators was re-examined to identify which of them should be further employed because they better reflect the disease burden and could be used by policy-makers in the formulation and evaluation of health programmes and interventions related to the disease and are thus of utmost importance as criteria for identifying good practices.

In a third step, it was defined which optimal values the identified health performance indicators should have to achieve health and well-being among the population.

In a fourth step, Ben RHM II regions with optimal or even better indicator values were identified for a final analysis. Using the second examination approach, in a fifth and last step, the information taken from the “organigraphs”, “reference frameworks” and in-depth interviews, from the identified regions with optimal values, will be examined and compared to recognise good practice.

D.2 Measles

The analysis to identify good practice in the health management of measles was limited because of a lack of quantitative information. After examining the availability of regional data, only four participants could be considered for the analysis. They were taken into account since they were the only regions which presented actual information concerning the health performance indicators selected by the Steering Group. Of the four participants, *only Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ), both members of cluster 2 (see chapter 4.2.5), reported optimal values for the indicators*. They presented high uptake rates and no measles cases for the year 2005. After examining the information from the “organigraphs”, in-depth interviews and “reference frameworks”, similarities among these two regions were confirmed. Both regions keep registers about vaccinated persons and adverse reactions; children in these two regions receive their first measles immunisation dose at the same point in time and both regions use MMR vaccine. Another feature shared by both regions is the fact that both have a specific immunisation law and that measles elimination is part of the current political agenda. Moreover, in Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ) there is an individual reminder, an invitation system and home-visiting interventions are carried out. Both have obligatory immunisation.

These the interventions from the “reference frameworks” which are carried out in both regions as well as the other similarities among the regions, could be considered as aspects making good practice in the health management of measles since they are conducted in both regions and both regions presented optimal health outcomes. Nevertheless, because of a shortage of information, a definitive correlation between the health outcomes and the interventions/programmes carried out in both regions could not be established. It is worth noting that both regions are from the same cluster.

D.3 Breast cancer

Like in the measles analysis, the identification of good practice for breast cancer also was limited because of a lack of quantitative information. After examining the data availability of the indicators selected by the Steering Group and their optimal values, only two regions could be considered for a further analysis: Varna-Oblast (BG) and Emilia-Romagna (IT), which supplied information on two of the selected indicators for the year 2005.

When examining the information from the “organigraphs”, in-depth interviews and “reference frameworks”, similarities among these two regions were confirmed. Both regions report breast cancer cases at the regional level. Moreover, Varna-Oblast (BG) and Emilia-Romagna (IT) have Disease-Management-Programmes implemented in the regions. With regard to the information and education of health professionals, the “organigraphs” and system descriptions show that Varna-Oblast (BG) and Emilia-Romagna (IT) refer to provision of information and education for health professionals regarding mammography screening.

These similarities and the interventions from the “reference frameworks” which are carried out in both regions could be examples of good practice in the health management of breast cancer. Nevertheless, they should be considered with caution since there are not sufficient data to confirm this. Because of a shortage of information, it is not possible thus to establish a definitive correlation between the health outcomes reported by the regions and the interventions/programmes carried out by them.

Concerning the identification of good practice for breast cancer based on the identified clusters, it was confirmed that this analysis was not possible to carry out because of the shortage of information already reported.

D.4 Diabetes (type II)

In particular the data regarding the health performance indicators on diabetes (type II) at the regional level shows that in this respect much remains to be done to achieve comparable regional data in future.

When collecting data on diabetes, care should be taken to distinguish between diabetes (type I) and diabetes (type II). This distinction will help to adequately consider both patient groups and to collect valid and reliable data. It remains to be stated that due to the analysis performed only first steps towards comprehensive benchmarking in the health management of diabetes (type II) could be carried out. Among others, education campaigns to prevent diabetes and diabetes risk factors, integrated care programmes and a diabetes surveillance system, were identified as common interventions in the analysed regions. However, they could not be

verified as good practice since the significant shortage of information. Therefore, many improvements are still required when it comes to collecting diabetes-related data.

D.5 Conclusion

The developed method to identify good practice is a recommendable tool for the benchmarking of health management approaches. The method can and should be further applied in other regional projects. With it is possible to show where health management is successful and to give other regions hints with what regions to compare themselves for improving their health managements. With the help of the “reference frameworks”, it becomes clear what interventions and policies contribute to good practice.

Yet, the results of the identification of good practice show some deficits in the health management of the three tracers in the participating regions: the data held and provided in the region is insufficient for good health management – at least when we consider the health performance indicators the Steering Group had identified and defined for good health management. Policy makers would need a better basis of data to make sound decisions for good health governance. The results of this study making these deficits apparent should thus have a great impact on the further development of the European health information system.

The results have further shown that the good practice identified in measles health management was both within one cluster (namely cluster 2). An originally intended goal to identify good practice for each of the clusters was not possible due to lacking data of quantitative information of the Health Performance Indicators.

To conclude, with the help of the developed methodology we could identify first good practices and have received many hints how the health management in the participating regions could be improved. For a deeper insight into European health management systems, benchmarking studies should be encouraged. Benchmarking processes amongst regions should also be stimulated using further tracers to identify where health managements could be improved.

E. DISCUSSION OF THE BEN APPROACH AND IDENTIFICATION OF GOOD PRACTICE

E.1 Relevance of the methodology of Ben RHM II

Ben RHM II has built on the results of many EU projects, especially ISARE which identified the public health relevant regions and ECHI which helped to identify the health performance indicators. Ben RHM II is further complementary to EU projects such as EUPHIX, ECHIM, EUREGIO, EUPHID, EURO-URHIS and PIA PHR. The results of Ben RHM II can also promote further projects as the results of Ben RHM II show that standardised data for the EU and especially regional data are important and that they can be used by the policy makers of each region in the EU for their own health policy.

The developed and implemented range of different methods provided us with the chance of combining various approaches over a certain period of time (cf. chapter 10.1). Because of the “organigraphs”, for example, it was possible to look into and to compare various management systems with the help of the three examined tracers, including their functions and ways of decision making from the national, regional and up to the local level. A comparison of the “organigraphs” by tracers shows that the regions adopt different approaches at the different levels. *It has been shown that in practice those regions do well whose “organigraphs” reflect simple structures.* Health management, in particular, tends to be hindered through complex structures rather than promoted – irrespective of the disease which is at stake. In addition, the information given in the in-depth interviews clearly illustrated the steps and measures already being taken up to now in the various European regions in the fields of prevention, treatment and follow-up care of patients.

The research work conducted led to three “reference frameworks” for the health management of measles, breast cancer and diabetes (type II) and to a refined method of applying these references frameworks for a rapid appraisal. This method is more efficient because it uses relative numbers assigned to colour shades. Thus a graphic presentation of a region can stand on its own and be informative – no comparison with a graphic presentation of the respective reference framework is needed. Through the colour shade, the rapid appraisal or so-called “reference frameworks” provide a quick overview of presently valid expert recommendations as well as of the measures carried out in their own region. They moreover allow a direct comparison of the interventions/policies implemented in their own regions with the measures taken by other European regions. The “reference frameworks” show the assets in

regional health management and also reveal areas in regional and national healthy policy which might require further actions.

In general it can be said that Ben RHM II provides profound insights into the activities already implemented in health management. A great deal of information about effective, successful and promising measures and treatment services would never have come to our notice if we had not applied these manifold research methods.

E.2 Lessons learned from the analysis of good practice

The analysis of good practice in the Ben RHM II project shows remarkable results. On the one hand, statistical data are collected, evaluated and analysed. On the other hand, those measures and actions are identified which are actually being implemented by the interviewed European regions (cf. chapter 10.2).

To identify good practice methods, only data available at the regional level should be used. Data only available at the national level were not considered for the study.

It has been shown in the course of the project that many data are being collected at the national level and not at the regional level. To turn the argument on its head, this means that no good health policy can be implemented at the regional level if corresponding data are not available. To put it in a nutshell, this can be summarised in the following words: “You cannot manage what you cannot measure”.

It turns out that some regions have no responsibility for the regional data but that some regions manage this kind of data very well. But not all regions have the tools for this. In general it can be said that good practice is not possible without good data. It has through our study in numerous cases and with the help of specific regions been shown that regional data are urgently required for implementing specific actions and recommendations for action at the regional level and for analysing them with respect to their evidence. It remains to be stated that presently no data have been collected on the successes of specific measures at the regional level and been analysed with regard to their evidence.

Yet some good practices and hints on good practice could be identified. Regions can learn for their health management by referring to the reference framework, by doing rapid appraisal, comparing their “organigraphs” and by further researching in the first insights on good practice. Ben RHM II has thus significantly contributed to the opportunity of improving health management of European regions, also with respect to a possible future application of the open method of co-ordination in health policy.

F. CONCLUSIONS AND RECOMMENDATIONS

In the participating European regions, a number of different positive approaches supporting the health management systems in an effective way could be identified. Using the outcomes of the analysis, we were able to show that there is no single ideal way of proceeding in the fields of prevention, treatment and follow-up care. The outcomes of the project Ben RHM II show that with regard to the three examined diseases many different approaches and regulations have been established in European health care provision. It is moreover revealed that not only regions with different national borders differ in prevention, treatment and follow-up care but also regions within national borders (cf. chapter 12).

Due to our research results it is urgently recommended to further improve the collection of health-relevant data at the regional level so that not only data at the national level but also at the regional level are comparable with each other. It is however not sufficient to only compare indicators. Our project has further shown that clustering is a tool to compare regions meaningfully. The clustering method used for this research project is well suited for application and recommended for other projects. Under this project a clustering method was developed and used for working on the results obtained. The method can be used for other research projects and be further improved.

Finally it has to be said that due to these different results obtained from the “organigraphs”, in depth-interviews, health performance indicators and “reference frameworks” first important steps towards comprehensive benchmarking in health management could be taken. Even if “good practice“ examples could be established (e.g. the regions Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ), both members of cluster 2 can be considered examples of good practice for the management of measles prevention), an important outcome of this regional comparison consists in the fact that most of the participating regions still have serious deficits in providing quantitative health information.

To conclude, the Ben RHM II project thus has delivered concrete methods, results and impulses for future benchmarking in this area to improve good health governance in Europe.

2 Introduction – scope and purpose

Benchmarking is a structured process of analysing and comparing different systems. It is aimed at improving the performance of different systems with regard to an envisaged target.

The benchmarking process helps to identify where structures and methods for reaching the envisaged target can be improved. As the benchmarking process is aimed at comparing systems, it furthers transparency and enables mutual learning.

Given that Europe is growing together, it will become more and more important to include the regional level since this will have a concrete impact on the framework of national politics. The provision of health care among the European countries is on the one hand facilitated by the regional approach but on the other hand European standards and requirements have to be implemented at the national level. Open borders, however, also allow new forms of cooperation between European countries. This development will in many areas lead to the fact that national borders will become less important.

In the field of health policy, three aspects can be identified which have to be considered at the European level. Currently a trend of decentralising health care systems can be observed in Europe. This means that if responsibility is conferred upon the regional level, this level will need corresponding information in order to conduct its health policy in the best possible way. Secondly, grants from the EU's structural funds are given on the basis of regional data. For regional planning processes, it is therefore important to provide updated and compatible health data. Moreover, national borders within Europe are becoming increasingly permeable, not only as far as goods are concerned but also for workforces and services, particularly in the health sector. It is thus becoming increasingly important to gather knowledge and experiences with regard to regional structures and processes from all European countries.

Responsibility for health-related matters has never exclusively been conferred upon the national level. So, for example, the surveillance and prevention of infectious diseases as well as the organisation of health promotion have always fallen within the responsibility of the regional or local level since otherwise appropriate or quick reactions would hardly be possible. Currently, the management and sustainment of health care provision is increasingly being decentralised in more and more European countries. This is the tradition in Germany and Sweden, and new developments are observed in this respect in Italy and France.

Regional data will become more and more important for the health reporting activities of the EU. The intention is not to harmonise the health and social systems in Europe but to define corridors within which the health situation should develop.

Using the tracers measles, breast cancer and diabetes (type II), the project “Benchmarking Regional Health Management II” was carried out to compare the existing health management systems in 19 European regions with regard to prevention, treatment and, if applicable, follow-up care.

Building on the work of other EU projects such as ECHI (European Community Health Indicators) (Kramers 2003) and ISARE (Indicateurs de Santé des Régions d’Europe = Health Indicators in the European Regions) (FNORS 2004), the results will help regions and Member States to improve the potential of performance-based governance.

3 Project organisation

3.1 Project partners and the WHO Regions for Health Network

Thirteen regions from the WHO Regions for Health Network (RHN) from Belgium, Bulgaria, Germany, Hungary, Italy, Lithuania, Portugal, Russian Federation, Sweden and Switzerland – together with the six regions of the Steering Group members amounting to a total of nineteen regions – declared their interest to participate and to benchmark their regions for this project. Two of these regions – from the Russian Federation (Chuvash Republic) and Switzerland (Ticino) – agreed to join the project with their own funds as they do not belong to the EU or EFTA/EEA.

For the project development it was important to include different regions with different political and socio-demographic backgrounds as well as a different epidemiological state of development into the project.

Representatives from the participating European regions were asked to support the Project Secretariat by completing the questionnaires and collecting relevant information about the regional health systems, additional background material and related data in their respective countries. A platform was created in which the members of this Regional Network on health governance could exchange their views and experiences regarding best practice. The regions were brought into dialogue with each and were given a unique opportunity. Apart from email communication the final conference of Ben RHM II (cf. 3.3.1) was a good oppor-

tunity for this exchange. The results of Ben RHM II will be further discussed among members of this project group. Many have declared to continue their work together towards improving best practice in health management. A follow-up project will be planned in 2008. The Regions for Health Network supports this activity and remains a motor to continue the work that was started in Ben RHM II.

3.2 Steering Group

The Steering Group consisted of representatives of the main beneficiary and associated beneficiaries of the project (see list in annex 1a). It also included the co-ordinator of the WHO Regions for Health Network who served as a link between the project co-ordinator and the participating regions. The Steering Group met twice during each year of the project and reviewed the methodology and working plan.

The main tasks of the Steering Group were to develop the methodology and instruments for collecting the information needed for the benchmarking process, to analyse the information and to draft the final report. The Steering Group worked hand in hand with the Ben RHM II project co-ordinator and assisted in the running of the project.

To receive feedback from the Ben RHM II project partners – including the steering group – about how well the project was conducted, the secretariat dispatched a feedback questionnaire to all partners involved in August 2007 (annex 7); after completion of the project. In this questionnaire it was asked how the partners estimated the communication and process quality of the project conduction and how they expect the results of Ben RHM II to have influence on their own work in the regions. Furthermore, partners had the possibility to communicate back any aspects that were of interest to them to the secretariat. This information can be of relevance for the dissemination and preparation of the Ben RHM II results when they will be published in scientific journals and presented at international conferences (see 3.3.2).

3.3 Main activities of the project

3.3.1 Project meetings and final conference

The first Steering Group meeting was held in the premises of the Ministry of Employment, Health and Social Affairs of the State of North Rhine-Westphalia in Düsseldorf on September 13th 2004.¹

At the meeting, the paper “Rapid Appraisal Methodology for ‘Health for All’ Policy Formulation Analysis” from Peiró et al. (2002) was reviewed. The paper is a central component of the methodology of Ben RHM II. However, the participants pointed out that the way the authors used the term “gold-standard” was ambiguous. Therefore, it was agreed to use the term “reference framework” instead.

The phases of the project and deliverables were presented to the members of the Steering Group. The deliverables were clarified. It was pointed out that questionnaires such as dispatched in Ben RHM I were not suitable any more. Instead, face to face in-depth interviews should be conducted in the respective regions to obtain the necessary information for the project. By conducting in-depth interviews, regional particularities could be better established than with a questionnaire only.

It was clarified that each member of the Steering Group should be responsible for obtaining the information and data from his or her respective region. The participants of the Regions for Health Network (RHN) should do the same in their regions.

On 11th and 12th October 2004, the members of the Steering Group participated in a benchmarking training exercise which took place at the University of Brighton. The training was conducted by Jack Taylor from Crandelta Intl. The steps of the benchmarking process, its uses and benefits were explained.

According to Crandelta Intl., benchmarking is a structured, analytical, continuous process which identifies, adapts and adopts the good practices that lead to superior performance in an organisation. The group mentioned that “continuous” did not fit in with Ben RHM II because it is a project limited to three years. However, there was a consensus that Ben RHM II could be the “starting point” of a continuous benchmarking process.

¹ Detailed minutes of these meetings can be found in the Annex 2a, 2b, 2c, 2d, 2e and 2f.

The second meeting of the Steering Group was carried out at the National Institute of Public Health in Prague on April 22nd 2005. The meeting mainly served to discuss the first results delivered by the short questionnaire and organigraphs and to review the reference frameworks and check the progress of the project.

It was pointed out that a pre-test of the reference frameworks had to be carried out. With the pre-test the existence of the policies proposed and the availability of the data required by the frameworks could be checked. The carrying out of the pre-test was assigned to Dr Jaroslav Volf and Dr Eleni Jelastopulu (see annex 2b).

With regard to the questionnaires for the conduct of the in-depth interviews, the Steering Group agreed on the necessity to submit them to a pre-test. The conduct of this pre-test was assigned to Dr Reli Mechtler and Kieran Hickey. In addition, it was agreed that the health performance indicators should be validated by Prof John Davies and Caroline Hall.

The third occasion on which the Steering Group met was at the University of Linz on October 14th 2005. At the meeting, the results of the conducted pre-tests were presented. It was agreed to send the questionnaires of the in-depth interviews to the regions at the end of the year.

The members of the Steering Group approved the reference frameworks and the health performance indicators which were to be sent to the participating regions to start with the collection of data. The Steering Group agreed that in the case of not obtaining official data for the construction of indicators, one could consult experts and ask them for estimated data.

In addition, the members of the Steering Group discussed that the structural differences among the participating regions should be considered. They agreed on the necessity of forming groups of comparable regions based on socio-economic indicators.

The Steering Group met the fourth time on May 19th 2006 at the Dr Steevens Hospital in Dublin. On this occasion, Ixhel Escamilla MPH presented a proposal on the methodology of organising the Ben RHM II-regions into groups (or clusters). In addition, the importance of conducting a rapid appraisal of regional health managements using the developed reference frameworks was discussed. It was made clear that this task was not a project deliverable. Nevertheless, with a rapid appraisal approach the implementation of policies and programmes could be monitored, their changes over time be observed and priorities be identified. Therefore, the Steering Group agreed that, through a communication from the Project Secretariat, the regions would be asked to identify which interventions from the frameworks were implemented in their region.

With regard to the health performance indicators, the Steering Group agreed to collect the required information from October 2006 onwards. It was pointed out that for the calculation of some indicators one could meet with difficulties. However, to let the public know about this problem is also very valuable because accessibility to health information is actually limited.

On October 2nd 2006, the Steering Group met at the WHO Regional Office for Europe in Copenhagen. Dr Gertrud Bureick presented a detailed analysis of the in-depth interviews carried out by the regions. It was said that, since the regions were very different in their health management and administrative structures, the information received was particularly heterogeneous in terms of scope and precision of the answers.

To group the Ben RHM II-regions, Ixhel Escamilla MPH developed a preliminary list of variables which could influence the effectiveness of health programmes and interventions. Based on the list, the search for regional data was initiated at EUROSTAT. After verifying the availability of data at EUROSTAT and confirming that not all statistics exist at the regional level, the list of variables was modified and reduced. The changed list was accepted by the members of the Steering Group.

Under the German presidency of the EU Council, the “European Health Policy“ conference was held in Düsseldorf in March 2007. Attached to this conference was the final conference of the project “Benchmarking Regional Health Management II (Ben RHM II)“.

The results and preliminary results of Ben RHM II were presented to a broad public interested in the subject. The results were put into the European health systems context by discussing them with representatives from European health observatories, health system researchers from other EU funded projects and representatives from policymaking bodies. Furthermore, experiences were exchanged with persons who have already used the intermediate Ben RHM II results in practice.

This forum on the whole allowed the participants to get an insight into the different health management systems in Europe. Using the diagnoses of breast cancer, measles and diabetes mellitus (type II), the participants of the conference gave a portrayal of the present possibilities for prevention, health care provision and rehabilitation in the European regions involved in the project. In addition to the main outcomes of the Ben RHM II project, the increasing importance of the regional level in Europe was underlined in several lectures and presentations. The event moreover provided the chance for an exchange of views between representatives of the “old” and relatively “young” European Member States as well as other European states. Contacts about activities among the project members were initiated.

The sixth Steering Group meeting was held on May 18th 2007 in the Ministry of Employment, Health and Social Affairs of the State of North Rhine-Westphalia in Düsseldorf. At the meeting, the Steering Group examined the contents of the final report.

The last meeting of the Steering Group members was a “Working Session” to wrap up the whole project. It took place at the Institute of Public Health of the State of North Rhine-Westphalia (lögD) on 9 - 10 July 2007 in Bielefeld, Germany. The members of the Steering Group finalised the methodology about good practice and identified good practice approaches.

In addition to regular telephone calls, the Steering Group also used an e-mail list to continuously ensure a good flow of information. This has proven an effective means of communication.

3.3.2 Communication and dissemination

The Project Secretariat designed a flyer for the Ben RHM II project that was continuously updated (last updated in March 2007; see annex 6) and widely distributed at conferences, fairs and meetings. This leaflet briefly informs about the project’s concept, partners and participants and contacts. A webpage (<http://www.ben-rhm.nrw.de>) – also containing the flyer – was set up to inform a wider audience about the project and its predecessor Ben RHM I.² This homepage was supportive but will not serve as an exclusive platform for publications.

First interim results of Ben RHM II were already published in an international peer-reviewed journal (see annex 4).

When	Where	Who / What
January 2006	Central European Journal Public Health; 14 (1): 39-45	Helmut Brand, Peter Schröder, John K. Davies, Ixhel Escamilla, Caroline Hall, Kieran Hickey, Eleni Jelastopulu, Reli Mechtler, Wendy Tse Yared, Jaroslav Volf, Birgit Weihrauch: Reference Frameworks for the Health Management of Measles, Breast Cancer and Diabetes (type II)

The final report of Ben RHM II is planned to be published as an issue of the lögD’s “Wissenschaftliche Reihe” (“Scientific Series”) after the final report has been approved by the Euro-

² Benchmarking Regional Health Management I (Ben RHM I), Agreement No. S12.32818700 (2001CVG3-514)

pean Commission. Issues of this scientific series are printed as books and are widely distributed for free. PDF-files of the issues are additionally published on the website of the lögd. Thus they are in the public domain which additionally promotes a far distribution of results.

When	Where	Who / What
End of 2007 / Beginning of 2008	lögd Wissenschaftliche Reihe (Institute of Public Health North Rhine-Westphalia)	Helmut Brand, Gertrud Bureick, John K. Davies, Ixhel Escamilla, Caroline Hall, Kieran Hickey, Eleni Jelastopulu, Reli Mechtler, Shouka Pelaseyed, Peter Schröder-Bäck, Jaroslav Volf: Benchmarking Regional Health Management

Moreover, presentations on Ben RHM II were given on several occasions:

Table 1a: Presentations on Ben RHM II

When	Where	Who / What
September 17 th , 2004	Lithuanian Public Health Delegation in: Institute of Public Health NRW (lögd)	Peter Schröder: Benchmarking Regional Health Management
September 29 th , 2004	Public Lecture in: Institute of Public Health NRW (lögd)	Peter Schröder: Benchmarking Regional Health Management
November 11 th , 2004	Annual Meeting of the Regions for Health Network, Valencia, Spain	Helmut Brand: Benchmarking Regional Health Policies and Reports – Experiences from Two European Projects
November 30 th , 2004	IV Jornades tècniques, Consorci Sanitari de Barcelona & WHO, Barcelona, Spain	Helmut Brand: Experiències d'observatoris de systems de salut en grans ciutats i regions: Barcelona, Montreal, Dinamarca i Northrhine Westfalia
December 8 th , 2004	Committee of the Regions, 15 th Meeting of the Commission for Economic and Social Policy, Brussels, Belgium	Helmut Brand: Benchmarking Regional Health Management
November 10 th – 12 th 2005	Annual Conference EUPHA, Graz, Austria	Peter Schröder: Benchmarking Regional Health Management
November 25 th 2005	Annual General Conference of the Regions for Health Network, Katowice, Poland	Peter Schröder: Benchmarking Regional Health Management

September 27 th - 29 th 2006	German Society of Social Medicine and Prevention (DGSM), 42 nd Wissenschaftliche Jahrestagung, Frankfurt/Main, Germany	Ixhel Escamilla: Reference framework for the health management of measles, breast cancer and diabetes mellitus (type II) (in German language) (Reference Frameworks for Public Health Systems)
October 2 nd 2006	Headquarters of the WHO Regional Office for Europe	Helmut Brand; Gertrud Bureick; Ixhel Escamilla: Presentation and discussion of first results of the Ben RHM II project with the Division of Country Health Systems, members of Health for All and other officials and the Steering Group
October 13 th 2006	Workshop: Health Research Databases, Robert-Koch-Institute, Berlin, Germany	Helmut Brand, Wolfgang Hellmeier: Regional aspects of health
November 24 th 2006	14 th Annual General Meeting of the WHO Regions for Health Network, Madeira, Portugal	Helmut Brand: Benchmarking for Regional Health Management
February 27 th 2007	University of Debrecens, Hungary	Helmut Brand: Benchmarking Regional Health Policies
March 5 th 2007,	Presentation given at the European Health Policy Conference, Düsseldorf, Germany	Helmut Brand: European cooperation under the EU Public Health Action Programme
March 6 th 2007	Presentation given at the European Health Policy Conference, Ben RHM II Final Meeting, Düsseldorf, Germany	Gertrud Bureick: Benchmarking Regional Health Policies
March 6 th 2007	Presentation given at the European Health Policy Conference, Ben RHM II Final Meeting, Düsseldorf, Germany	Ixhel Escamilla: Identifying Comparable Regions by a Cluster Analysis
March 6 th 2007	Presentation given at the European Health Policy Conference, Ben RHM II Final Meeting, Düsseldorf, Germany	Matthias Schröter: Elimination of Measles: The Application of a Reference Framework in North Rhine-Westphalia

26 th April 2007	Presentation given at the European Conference of the Project ISARE (Health Indicators in the European Regions), Prague, Czech Republic	Ixhel Escamilla: Identifying Comparable Regions by a Clustering Analysis
October 9 th - 11 th 2007	European Commission together with the Committee of Regions, Open Days, Brussels, Belgium	Helmut Brand: Workshop entitled improving public health capacities in the EU regions
October 13 th 2007	Annual EUPHA – Conference, Helsinki, Finland	Peter Schröder-Bäck: Comparing Regional Health Managements of Measles, Breast Cancer and Diabetes (Type II) ³

The following presentations are planned to be given after completion of the project:

Table 1b: Presentations on Ben RHM II given after completion of the project

When	Where	Who / What
November 28 th 2007	RHN Annual Conference	Helmut Brand: Regional Health Management in Europe – Experiences of Ben RHM II
December 2007	Ministry of Health, Szabolcs-Szatmár-Bereg Region	Helmut Brand; Peter Schröder-Bäck: How to utilise the Ben RHM II for other projects benchmarking health management in the EU

The following publications are planned after completion of the project. They shall give a further opportunity – besides the final report and the presentations – to present the results of Ben RHM II to the scientific and public policy communities. The “Central European Journal of Public Health” kindly agreed to cooperate with us so that we can place peer reviewed journal articles in this international journal. They will dedicate a “thematic issue” to Ben RHM II.

³ The abstract to this presentation (Bureick et al. 2007) won the “Best Abstract Prize 2007” of the European Public Health Association (EUPHA).

Table 1c: Publications on Ben RHM II in preparation

When	Where	Who / What
In preparation	Central European Journal of Public Health	Bureick, Gertrud; Brand, Helmut; Davies, John et al: Good practice in the regional health management of measles, breast cancer, diabetes
In preparation	British Medical Journal	Davies, John; Brand, Helmut et al: Benchmarking Health Management in Europe – Methods, Results, Perspectives
In preparation	Central European Journal of Public Health	Schröder-Bäck, Peter, Brand, Helmut, Bureick, Gertrud et al.: Compulsory immunization for measles and compulsory mammography screening – Experiences in the health management of regions in the European Union and moral decision making
In preparation	Central European Journal of Public Health	Escamilla, Ixhel: A method of grouping regions for the benchmarking of health management
In preparation	Central European Journal of Public Health	Schröter, Matthias: A Reference Framework for Measles Health Management in Practice – A Case Study from North-Rhine Westfalia

Further publications are being prepared currently and will be submitted to international journals (e.g. the European Journal of Public Health, Public Health Ethics Journal) to raise the visibility of the Ben Results.

4. Methodology

Tracers should represent public health issues where an improvement of health management promises major positive health effects. Furthermore, tracers should provide information about the whole health system (Peiro et al. 2002). To focus on different health management aspects, three different tracers were chosen in the Ben RHM II project and as such were subject to building three reference frameworks. Measles immunisation was chosen as a tracer because the focus lies on prevention. Breast cancer screening / care was selected as a tracer for focusing on screening. The tracer diabetes screening / care was chosen to focus on care.

All three of these pose serious public health problems within Europe and are exemplary for different kind of challenges needing different approaches in health management:

Measles is a leading cause of death among young children, despite the availability of a safe and effective vaccine for the past 40 years. Around 345,000 people, the majority of them children, died from measles in 2005 (WHO 2007).

Normally, children do not die directly of measles, but from its complications. The most serious complications include blindness, encephalitis, severe diarrhoea, ear infections and severe respiratory infections such as pneumonia, which is the most common cause of death related with measles (WHO 2007).

Measles is one of the most contagious diseases. Almost all non-immune children contract measles if they are exposed to the virus. Measles can also affect un-immunised adolescents and young adults. Nevertheless, measles can be prevented with a vaccination. Vaccination has had a major impact on preventing measles deaths. From 2000 to 2005, more than 360 million children globally received measles vaccine through supplementary immunisation activities. Moreover, improvements have been made in routine immunisation over this period. These accelerated activities have resulted in a significant reduction in estimated global measles deaths. Overall, global measles mortality decreased by 60% between 1999 and 2005.

Although the greatest burden of disease regarding measles is within developing countries, measles are not yet completely eliminated in Europe. Because of the importance of measles vaccination, the project “Benchmarking Regional Health Management II” focuses on the analysis of regional preventive strategies regarding the first dose of measles vaccine, the actions with regard to the second vaccination, as well as the surveillance system.

According to the World Health Organization (2006), cancer is a primary cause of death worldwide. From a total of 58 million deaths worldwide in 2005, cancer accounts for 7.6 million of all deaths. From these deaths, *breast cancer* was responsible for 502,000 deceases (World Health Organization 2006).

Worldwide, breast cancer is the most frequent cancer in women and it is also the most common cancer in females in Europe (European Network of Cancer Registries & International Agency for Research on Cancer 2002).

According to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis (European Commission 2006), demographic trends indicate a continuing increase in this significant public health problem. Systematic early detection through screening, effective diagnostic pathways and optimal treatment are recommended to reduce breast cancer mortality rates and diminish the burden of the disease in the population.

Considering these facts, the project Ben RHM II takes breast cancer as a tracer and focuses on the analysis of regional health strategies and programmes regarding the early detection and treatment of the disease.

Diabetes mellitus affects more than 170 million people worldwide and will affect 366 million people by 2030. In Europe, more than 22,5 million persons suffer from diabetes mellitus (Austrian Federal Ministry of Health and Women 2005).

“Diabetes mellitus is a chronic disease which occurs if the pancreas does not produce enough insulin, or if the body cannot process the insulin adequately. One of the most important biological effects of insulin is the acceleration of the intake of glucose in muscle and fat cells. Hyperglycemia – the excessive concentration of sugar in the blood and other metabolic disorders triggered by this malfunction subsequently cause serious damage to the organism, especially to nerves and blood vessels” (Austrian Federal Ministry of Health and Women 2005, 3).

Diabetes mellitus brings about severe complications and subsequent diseases. According to the European Health Report 2002 (World Health Organization Regional Office for Europe 2002), cardiovascular disease is three to four times higher in diabetes patients than in the rest of the population. In addition, diabetes is an important cause of perinatal mortality, one of the most common causes of kidney failure, the commonest cause of leg amputation and the commonest cause of blindness in people of working age (Austrian Federal Ministry of Health and Women 2005).

Because of its burden, serious complications and enormous economic costs involved, the prevention, early detection and treatment of diabetes mellitus in Europe were considered to be analyzed and assessed by the project “Benchmarking Regional Health Management II”.

With choosing these three quite diverse tracers – among them one infectious disease – one could focus on different kinds of health management (prevention, surveillance, treatment, health care programmes etc.).

In the following the methodology of the benchmarking approach will be explained and the tools introduced.

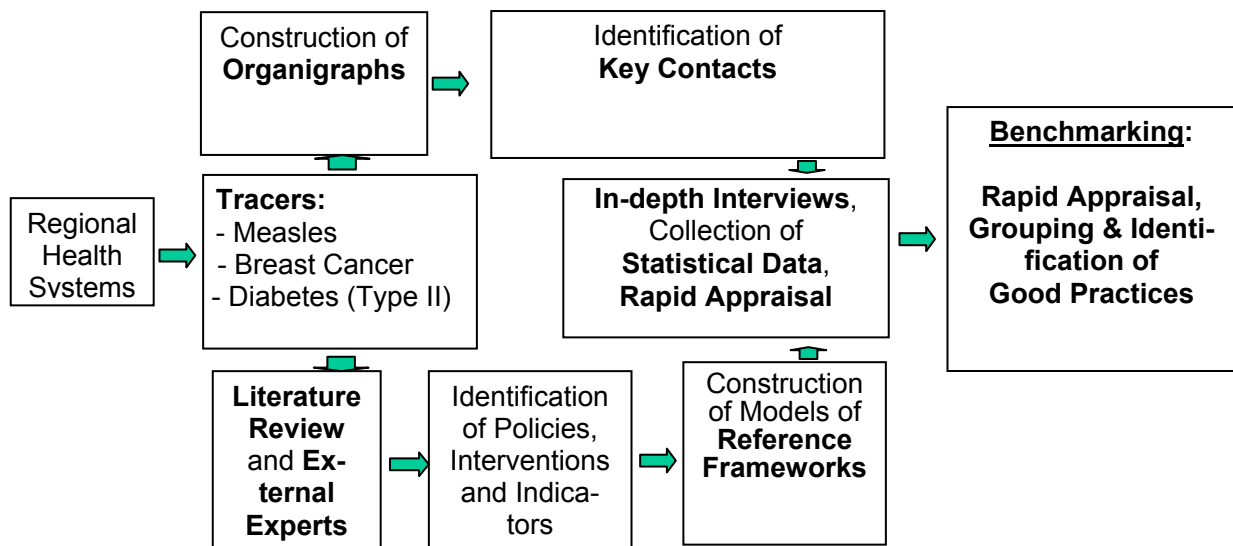
4.1 Methodological strategy

The following scheme (Illus 1.) shows the benchmarking methodology developed for this project. The regional health systems of the participating regions were analysed with respect to the three tracers “measles, breast cancer and diabetes (type II)”. This was done along two complementary strands. The first was to construct organigraphs to show at a glance how the

health management systems were organised and to identify key contacts of the health systems (cf. annex 1b).

Parallel to this strand, evidence-based policies and interventions regarding the three project tracers were selected based on literature reviews and expert opinions. The policies and interventions were listed in reference frameworks containing a time and an intervention dimension. With the reference frameworks, a rapid appraisal of the health interventions and policies carried out by the participants was performed. Health performance indicators for the assessment of the health managements were identified. Regional data with regard to these indicators was collected. In-depth interviews were carried out in each participating region to get detailed information on the health managements. Similar regions were organised in groups based on their political and socio-economic situation as well as any other factor having an influence on the effectiveness of health interventions and programmes (cluster analysis). Finally, with the instruments developed, organigraphs, in-depth interviews, reference frameworks and health performance indicators, diverse criteria for identifying good practice were available. Good practice examples and fields of action where the regions could implement changes to enhance their own health management systems were identified.

Illus. 1: Benchmarking Methodology for “Benchmarking Regional Health Management II (Ben RHM II)”



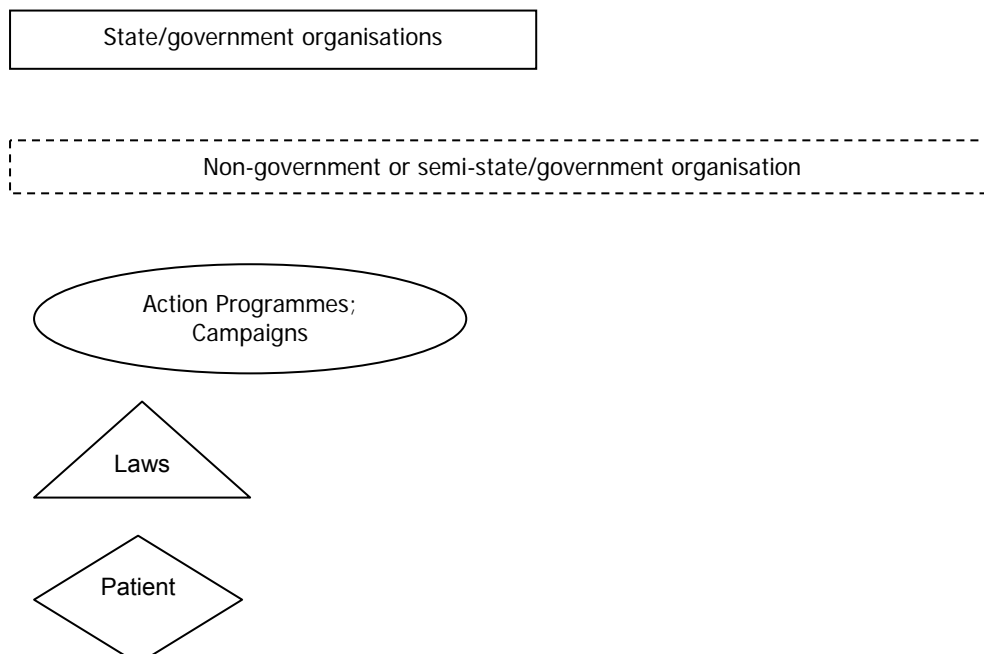
4.2 Methodological tools

4.2.1 Questionnaire about key contacts and organigraphs

A questionnaire was designed for completion by the European regions to get an overview of the relevant organisations and to facilitate further contacts.

The organigraphs will provide overviews of the organisation of the regional health management programmes for breast cancer, diabetes (type II) and measles. They depict the relationship of the different decision-making bodies to each other as well as the flow of actions within the health management system. This is essential because it is not only the outcome of regional health management that is important but also the understanding of how it is organised. Organigraphs are a good means to illustrate *how* institutions, organisations or companies function in certain sectors. They serve to describe the interaction between people and information flow (Mintzberg/van der Heyden 2000; Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein Westfalen 2004). Thus organigraphs provide an overview of the organisation of the regional health management systems for the tracers.

Organigraphs are not just diagrams but maps which can be produced with the help of different graphical forms such as for example small boxes and arrows (Mintzberg/van der Heyden 2000). For an optimal comparability of all organigraphs, we asked all project members to use the below-described “basic forms for the organigraphs” and “different kinds of arrows for different functional connections”.



development / implementation / setting conditions / enacting / instructing



co-operation / involvement / association / participation



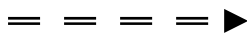
invitation



providing information / notification / reporting / recommendation



supervision / control / quality management



approval / certification



4.2.2 Questionnaires for in-depth interviews

The Steering Group developed questionnaires for each tracer to be used for the in-depth interviews.

Each questionnaire for the three tracers was checked by experts in a pre-test in two regions (Dublin/Mid-Leinster and Dublin/North East, Ireland and Upper-Austria, Austria). It turned out that some questions were not comprehensible so that the questions had to be modified and some modules had to be changed after the pre-test.

The project partners in the participating regions conducted the in-depth interviews with persons in strategically important positions in the health sector.

Using the open question method, all interview partners should get the chance to mention all important aspects from their point of view since closed/standardised questionnaires would have deprived the authors of this analysis of much of the information given. The modules of the interviews include aspects of prevention, treatment and follow-up care are described for each disease in the following paragraphs.⁴ The questions are arranged in modules. The modules are as follows:

⁴ All questionnaires can be found in annex 3 (see annex 3a for measles, annex 3b for breast cancer, annex 3c for diabetes (type II)).

Measles:

Measles Immunization Policy and Organisation, Vaccination Status – Detection of Unvaccinated Children, Invitation and Recall Systems, Incentives to Vaccination, Surveillance, Quality and Provision of Vaccine, Information and Education of the Public, Information and Education of Health Professionals, Improvements, 2nd Dose, Measles Outbreaks and Care / Treatment

Breast Cancer:

Breast Self-Examination, Clinical Examination, Mammography Screening Policy and Organisation, Education of the Public, Training und Education of Health Professionals, Surveillance, Treatment and Care and Integrated Health Care

Diabetes (type II):

Information and Education of the Public, Detection Examination and Screening, Diabetes Surveillance, Treatment and Care, Self-Care and Patient Education as well as Self-help Groups

The response rate to the in-depth interviews was very good.⁵ These interviews revealed great differences in the health management of the three tracers in the European regions. The analyses of the responses showed an immense variety in the organisation, implementation and evaluation of different immunisation programmes, breast cancer and diabetes (type II) care and screening programmes.

4.2.3 Reference frameworks

Reference Frameworks are a methodological tool to structure and compile evidence-based health policies and intervention for each of the tracers and thus get a methodological base for the benchmarking process. But also they can be used for a rapid appraisal and beyond this as a reference for developing health managing. All of these aspects were considered in Ben RHM II and were utilised. The reference frameworks encapsulate effective and feasible policies and interventions for the health management of measles, breast cancer and diabetes (type II). They were developed based on the methodology from Peiró et al. (2002).

⁵ From 19 participating regions 18 in-depth interviews on measles were returned (response rate of: 95%). From 19 participating regions 17 in-depth interviews on breast cancer were returned (response rate of: 89%). From 19 participating regions 17 in-depth interviews on diabetes (type II) were returned (response rate of: 89%).

In the following, the method how the reference frameworks for measles, breast cancer and diabetes were developed will be described and the reference frameworks will be presented. In a next step, how to make a rapid appraisal based on these will be presented. This methodology and the results were already published (Brand et al. 2006). The Ben RHM II specific results of the rapid appraisal will then later be presented (chapter 7) and further used in the benchmarking process.

4.2.3.1 Selection of policies and interventions for the reference framework

Peiró et al. constructed “gold standards” for the policy analysis of selected tracers. Against the gold standards, health plans and health policy documents could be compared.

The Ben RHM II Steering Group employed this approach and decided to change the name of “gold standard” for the term “reference framework”. It appeared more than difficult to develop a list of policies and interventions that could be regarded as gold standard, an absolute norm for health plans. There are different reasons for this. One is that the evidence of the effectiveness of policies and interventions is sometimes missing. Another reason is that due to different regional characteristics some of the policies and interventions listed in the reference frameworks might become less relevant in some regions. Furthermore, the recommended policies and interventions might change over time.

The reference frameworks list policies and interventions according to both a time and an action level dimension. Each action level contains a more detailed structure at the individual, population and system level. An extra column lists strategic points from which health sub-targets are derived. The interventions and policies that might be helpful to reach these sub-targets were assigned to these strategic points.

The policies and interventions were selected on the basis of a literature review and expert opinions. They outline evidence-based policies and interventions that could be used by policy makers of European regions and enable them to gain knowledge about appropriate interventions and policies which might be applied in the respective regions. The evidence-based policies and interventions will presumably change over time and some of them were not relevant to all regions in the same way.

As part of the Ben RHM II project, specific reference frameworks were developed for breast cancer, diabetes (type II) and measles.

The developed reference frameworks offered policy makers of each European region the possibility to compare their health management with these frameworks and to get an idea

about which policies and interventions might be useful to apply in their region.

The reference frameworks were an important element of the project and can provide policy makers with information and orientation. We were informed by our partner in Hungary (Szabolcs-Szatmár-Bereg) that the developed reference framework of the Ben RHM II project would be used in other projects about drug abuse (*interregional* between Hungary and Romania). In North Rhine-Westphalia (Germany) the reference framework for measles is also being used (see chapter 7.2). Vologda (Russian Federation) plans to use the reference framework for myocardial infarction and cardio-vascular diseases.

The corresponding reference framework developed for each of the three tracers is given on the following pages (see illus. 2, 3, 4).

Illus. 2: Reference framework – measles - interventions implemented for measles immunisation and elimination

Action Level: "Policies and Interventions Aiming at ..."				Overall Goals: Measles eradication [Incidence] & Reduction of deaths by measles [Mortality] Strategic Points [Indicators]	
		The Individual / Immediate Setting	The Population	The Social System, the Legislative, Professions	
Time	First Dose	<ul style="list-style-type: none">• Coverage with 1st dose• Individual reminder• Documentation of immunisation for parents (passes, certificates etc.)• Documentation of immunisation for Primary Care Physician (IT, patient files etc.)• (Obligation to immunise)• Home-visiting interventions⁶• Easy/cheap access to vaccination/Reduction of out of pocket costs for vaccination• Bonuses for parents• Education of agents in shared facilities about benefits/risks of vaccination• Pre-school nursery/kindergarten/school entry screening• Motivation of parents/teachers to identify non-immunised children• Offering vaccination	<ul style="list-style-type: none">• Invitation/reminder/recall system• Strategies to immunise marginal groups/sub-groups (e.g. gypsies, un-registered migrants, refugees)• Special strategies for lower socio-economic groups• Establishment of campaigns:<ul style="list-style-type: none">- Catch-up- Follow-up- Focal• Awareness raising campaigns• Educational measures about benefits/risks of vaccination• Local authorities offer information/counselling• Multi-media information resource availability (e.g. e-health)• Agenda-setting in the media	<ul style="list-style-type: none">• Legislation/Law on Infectious diseases• Strategy for measles elimination• National/regional immunisation plan with defined targets• Implementation of WHO-immunisation guidelines• Sentinels• Incentives for Primary Care Physicians• Guaranteed reimbursement of vaccination for Primary Care Physicians• Educative measures concerning risks/benefits of immunisation• Education of multipliers⁷• Risk-communication• Drug Law• Licensing of vaccine• Producer is obligated to cold-chain logistics (product liability)• Strategy for quality assurance in place and regular review and development of strategy• Serological survey	<ul style="list-style-type: none">• >95% Coverage with 1st dose• [Uptake rate 1st dose]• Reduce complications [Hospitalization rate]• Improve measles immunisation surveillance• Promote 2nd opportunity for immunisation• Improve motivation of Primary Care Physicians and parents• Improve education of health professionals• Improve knowledge of population regarding risks/benefits of immunisation• Maintain public confidence in vaccine safety• Maintain high quality of vaccine• Establish evaluation of programmes• Identify non-immunised persons
	Second Dose	<ul style="list-style-type: none">• Coverage with 2nd dose• Individual reminder• Documentation of immunisation (passes, certificates etc.)• Pre-school nursery/kindergarten/school entry screening• Motivation of parents/teachers to identify non-immunised children with second dose• Offering vaccination with second dose	<ul style="list-style-type: none">• Invitation/reminder system• Strategies to immunise sub-groups	<ul style="list-style-type: none">• Information of doctors about second dose	<ul style="list-style-type: none">• >95% Coverage with 2nd dose [Uptake rate 2nd dose]• Raise uptake rate of second dose• Identify persons not-immunised with 2nd dose
	Children with Measles	<ul style="list-style-type: none">• Identification of contacts⁸		<ul style="list-style-type: none">• Rapid communication of cases and coordination of health services• Improvement of skills in professionals to detect and to communicate cases• Participation in „Measles and Rubella Laboratory Network“• Establishment of national reference laboratory• Obligation to report cases• Surveillance of uptake rates, vaccination register• Register of severe adverse reactions• Health reporting• Implementation of surveillance guidelines of WHO• Vigorous case investigation and laboratory confirmation	<ul style="list-style-type: none">• Prevent new infections• Improve quality of diagnostics• Strengthen/Improve measles surveillance

⁶ Home visits: Home visits to promote vaccinations involve providing face-to-face services to clients in their homes. Services can include education, assessment of need, referral, and provision of vaccinations. Home-visiting interventions also can involve telephone or mail reminders.

⁷ Multiplier: Persons who by profession distribute relevant information to a great number of people (e.g. teachers, journalists).

⁸ Contacts: Persons who were in contact with persons with measles and who thus might have contracted measles.

Illus. 3: Reference framework – breast cancer - screening and care

		<i>Action Level: "Policies and Interventions Aiming at ..."</i>			Overall Goal: Reach 30% reduction in breast cancer mortality [<i>Mortality</i>], [<i>Detection rate</i>], [<i>5-year survival rate</i>], [<i>10-year survival rate</i>], [<i>Fatality</i>], [<i>Incidence</i>] Strategic Points [Indicators]
		The Individual / Immediate Setting	The Population	The Social System, the Legislative, Professions	
<i>Time</i>	Undiagnosed	<ul style="list-style-type: none"> Access to information on factors causing breast cancer and genetic determinants of breast cancer for persons at risk & their families Initiation and promotion of manual breast self-examination Easy access to mammography screening programmes for women 50-69 years Informed consent with high standard information Respecting right not to know 	<ul style="list-style-type: none"> Availability of genetic counselling and testing for women from families with breast cancer history Self-awareness campaigns Area-wide mammography screening programme according to EUREF Identification and invitation of eligible women (every two/three years) Invitation system for mammography screening Agenda-Setting in the media Promotion via local authorities, PCPs etc. 	<ul style="list-style-type: none"> Establishments of seals of approval for trustworthy information Initiation and support of research Reimbursement of non-mammography breast examinations by physicians (ultrasound, manual) Clear strategy according to EUREF guidelines Establishment of specialized breast centres according to EUREF guidelines Breast centres have possibilities for triple assessment (clinical, mammogram, biopsies) Education of physicians and the political community regarding the risks and benefits of mammography screening Education of technicians/radiologists Establishment of cancer/breast-cancer registers Obligatory reporting 	<ul style="list-style-type: none"> Educate persons about factors causing breast cancer Improve scientific knowledge about factors causing breast cancer Support other examination methods than mammography Raise self-awareness Extend mammography screening: participation rate >70% among women between 50-69 years [<i>Participation rate</i>] Increase the validity and accuracy of mammograms reading Reduce unnecessary biopsies Raise the acceptability of mammography screening Promote mammography screening programmes in public Improve the screening education of professionals Improve surveillance Set ethical standards for screening
	Diagnosed with Cancer	<ul style="list-style-type: none"> Information about alternative strategies Active offer of additional conversations according to patients' needs Psycho-social care Treatment of patients by interdisciplinary teams in dedicated breast centres Empowerment of patients to encourage to exercise their rights in participation Access of patients to information assessing the quality of the care provider Psycho-social counselling Offer of follow-up care Home-help is reimbursed by health insurances Cures are financed by health insurances 	<p>Mutual-help groups (should):</p> <ul style="list-style-type: none"> be supported (by physicians etc.) participate in development and quality assurance of health/disease management programmes Establishment of psychological support centres 	<ul style="list-style-type: none"> Training the competence of communication of health professionals (doctors, nurses) Development of DMPs (<i>see Glossary</i>)/Integrated Care Policies & initiatives to train breast cancer workforce Establishment of specialized centres (with defined minimum number of primary therapy) Certification of centres (according to EUSOMA) Establishment of internationally recognised performance indicators (e.g. mastectomy rates) Improvement of competence of physicians, nurses, staff etc. to communicate with patients Consideration of psychological factors in guidelines Improvement of psycho-social competence of health professionals Implementation of guidelines for rehabilitation Improvement of ambulant rehabilitation Establishment of severely handicapped passes (and other benefits) Cosmetic implants are covered by insurance Resource allocation for breast cancer research Strategy to integrate research outcomes into care programmes/practice 	<ul style="list-style-type: none"> Improve responding of care to individual needs Monitor patient satisfaction Improve education of professionals Improve quality of care More involvement of mutual-help groups Promote patient education Involve patients in decision-making process Improve quality of life Assure follow-up Improve rehabilitation Give research high priority

Illus. 4: Reference framework – diabetes (type II) – primary prevention, screening, secondary and tertiary prevention

		<i>Action Level</i>			Overall Goals: Reduce diabetes-related deaths Strategic Points <i>[Indicators]</i>
		The Individual / Immediate Setting	The Population	The Social System, the Legislative, the State, Professions	
<i>Time</i>	<i>Primary Prevention</i>	<ul style="list-style-type: none"> Community oriented prevention / setting approaches 	<ul style="list-style-type: none"> Information about consequences of unhealthy life-styles Provision of evidence based information Addiction prevention programmes Health promotion campaigns Lifestyle oriented prevention campaigns (e.g. campaigns on healthy food) 	<ul style="list-style-type: none"> Implementation of anti-obesity programmes Implementation of education programmes Creation of living conditions that promote healthy living (e.g. sidewalks to motivate people in cities to walk, healthy food in schools etc.) Establishment of seals of approval for trustworthy information Impact on cultural lifestyle habits (taxations, prohibitions etc.) Consumer protection laws (e.g. nutritional information) 	<ul style="list-style-type: none"> Reduce cases of diabetes <i>[Prevalence]</i> Prevent new cases of diabetes <i>[Incidence]</i> Improve the education of the population about lifestyle dependent health risks Promote healthier lifestyles
	<i>Screening</i>	<ul style="list-style-type: none"> Social-medical counselling Check-ups for people who see doctors for other reasons General screening, preferably one-step screening should be offered to each pregnant woman. Screening for overweight pregnant women 	<ul style="list-style-type: none"> Motivating measures to increase participation in health check ups in target groups People from 35 years on: regular health check-ups: urine, glucose, blood pressure, weight, blood lipids Regular health check-ups for people with family history in diabetes Screening in individuals with abdominal adiposity (men), hypertriglyceridaemia (women), hypertension, and parental diabetes history. Broadly based screening programs looking for metabolic and cardiovascular risk factors and for early disturbances of carbohydrate metabolism particularly in middle-age groups Information campaigns 	<ul style="list-style-type: none"> Financing of preventive check-ups Evidence based strategy in place for prevention of diabetes type 2, including monitoring and evaluation components Investment in professional development of workforce Provision of education programmes for professionals 	<ul style="list-style-type: none"> Raise uptake rate of medical, preventive check-ups Identify more persons at higher risk Identify more persons with diabetes Raise uptake of examinations for early detection Reduce mortality Improvement of the education of professionals Achieve pregnancy outcome in the diabetic women that approximates that of the non-diabetic woman Identify more pregnant women with diabetes
	<i>Secondary Prevention</i>	<ul style="list-style-type: none"> Promotion of self-testing Offer of patient education/seminars about self-care and lifestyle Involvement of patients and families in planning the delivery of care Education of patients' families about self-care and lifestyle 	<ul style="list-style-type: none"> Provision of education programmes for patients 	<ul style="list-style-type: none"> Improvement of competence of physicians, nurses, staff etc. to communicate with patients Training of competence of communication of health professionals (doctors, nurses) DMPs <i>(see Glossary)</i> / Integrated Care 	<ul style="list-style-type: none"> Increase number of people with diabetes self-monitoring glucose Improve number of educated patients <i>[Participation rate in education programmes]</i> Involve more patients in decision-making process Reduce hospitalisation among people with diabetes <i>[Hospitalisation rate]</i> Improve responding of care to individual needs
	<i>Tertiary Prevention</i>	<ul style="list-style-type: none"> Patient training Offer of seminars (smoking, alcohol, overweight) Screening for complications Management of long term & fatal complications Annual foot exams among people with diabetes Treatment of elevated blood pressure Dilated/annual eye exam 	Mutual-help groups (should): <ul style="list-style-type: none"> be supported (by physicians etc.) participate in development and quality assurance of health/disease management programmes Strategy for detection and management of long-term & fatal complications 	<ul style="list-style-type: none"> Assurance of insulin provision (different types, sufficient insulin) Assurance of test strips provision Raising awareness of health professionals Incentives for health professionals to detect complications 	<ul style="list-style-type: none"> Raise degree of health literacy and information about the disease/disease-management among people with diabetes More involvement of mutual-help groups Assuring tertiary prevention Reduce cases of complications: diabetic renal failure; foot ulcers; limb amputations; respiratory complications; blindness, cardiovascular diseases etc.

4.2.3.2 Rapid appraisal using reference frameworks

To rapidly appraise regional health management systems, the developed reference frameworks were applied with small modifications but otherwise in accordance with the methodology from Peiró et al. The approach taken was to calculate what percentage of the possible policies and interventions of the reference frameworks were already being applied in each region.

Table 2: Calculation of interventions applied in the region X

	A1 (Individual/ Immediate Setting)	A2 (Population)	A3 (Social System)
T1 (Primary Prevention)	5/5 (100%)	8/9 (89%)	4/10 (40%)
T2 (Secondary Prevention)	1/5 (20%)	8/10 (80%)	3/5 (60%)
T3 (Tertiary Prevention)	2/3 (66%)	10/11 (91%)	3/4 (75%)

The last table shows an example of the approach taken. Here the first cell has to be read as follows: “Five out of five, i.e. 100%, of the policies and interventions of the reference framework for that time phase and setting in that health management system have been implemented in region X.” For a better overview, different shades of colour were assigned to the calculated percentages.

Table 3: Assigning of colours according interventions in region X

	A1 (Individual/ Immediate Setting)	A2 (Population)	A3 (Social System)
T1 (Primary Prevention)	5/5 (100%)	8/9 (89%)	4/10 (40%)
T2 (Secondary Prevention)	1/5 (20%)	8/10 (80%)	3/5 (60%)
T3 (Tertiary Prevention)	2/3 (66%)	10/11 (91%)	3/4 (75%)

0- 25%	26- 50%	51- 60%	61- 70%	71- 80%	81- 90%	91- 100%
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When filling in the reference frameworks for a region with the assigned colours, it could immediately be recognised in which cell the region was doing well and in which there was potential for applying further policies and interventions.

In addition, regions could be compared against each other. However, a ranking of the regions was hardly possible as the rapid appraisal method is insensitive to the real effectiveness of the respective health management system.

4.2.4 Health performance indicators

The World Health Organisation defines health indicators as “variables which help to measure changes” (World Health Organisation 1981). An indicator is also a measurement that, when it is compared to a desired level of achievement, provides information regarding a health outcome or a relevant health determinant (Health Canada 1995).

To reflect the major public health concerns regarding the management of measles, breast cancer and diabetes (type II), health performance indicators were defined for each of these tracers in the Ben RHM II project. The analysis of health performance indicators was intended to focus the attention of policy-makers on regional health actions and interventions which should be developed to improve the health status of the regions, increase their quality of life and eliminate health disparities.

The selection of the health performance indicators of the Ben RHM II project was determined by the Steering Group. The members of the Steering Group discussed the indicators at the meetings with the group and provided comments and suggestions via e-mail and the internet. The indicators were chosen based on their public health relevance and their ability to illustrate the epidemiological situation of the participating regions, to assess the performance of the regional health managements, to monitor and report on progress towards regional health goals and to allow regional comparisons of health management systems. The selection and definition of the indicators was done while reviewing the ECHI list of indicators (Kramers 2003).

A pre-test of the indicators was carried out by the partners of the University of Brighton (UK) and the National Institute of Public Health (CZ). This pretest validated the chosen indicators.

The resulting indicators of the Ben RHM II project are listed below (cf. annex 5):

Measles:

- 1st Uptake dose (percentage)
- 2nd Uptake dose (percentage)
- Incidence (per 100.000)
- Mortality (per 100.000)
- Hospitalisation (percentage of cases)

Breast cancer:

- Incidence (per 100.000 women)
- Mortality (per 100.000 women)
- Fatality (percentage of cases)
- 5-year survival rate (percentage of women diagnosed with breast cancer)
- 10-year survival rate (percentage of women diagnosed with breast cancer)
- Participation in mammography screening (percentage of women aged 50-69 years old)
- Detection (per 100.000 women screened)

Diabetes (type II):

- Incidence (per 100.000)
- Prevalence (per 100.000)
- Participation in education programmes (percentage of diabetics)
- Hospitalisation (percentage of diabetics)

4.2.5 Grouping of regions by clustering

To enable the participants of the Ben RHM II project to identify effective health interventions and programmes from regions similar to their own in structure and development, to learn from these and to improve their own health management, it was advised in the project design to organise the regions into groups.

To identify groups of similar regions, Ixhel Escamilla MPH from the Project Secretariat conducted a clustering study. Clustering is an exploratory data analysis to sort different objects into groups or clusters. Regarding the variables used, the objects in the group are similar to each other and dissimilar to objects outside the group.

4.2.5.1 Methodology

The following steps were carried out in the study:

- I. Selection of variables.
- II. Collection of regional data.
- III. Performance of statistical tests.
- IV. Identification of clusters.

To identify variables for the study, a selection criterion was defined in a first step. It was decided to select variables with a substantial impact on the effectiveness of health interventions and programmes. Based on this criterion, socio-economic variables employed in three clustering studies (MacNabb 2002, Odoi et al. 2005, Strohmeier et al. 2005) as well as additional variables of public health relevance were analysed. After concluding the examination of variables, a set of 22 variables was selected. In a second step, regional data regarding the set of variables were collected with the help of EUROSTAT. It was confirmed that England (UK) actually consists of 9 regions. For the estimation of data regarding England (UK), the information from these regions was considered.

In addition, it was confirmed that EUROSTAT does not provide regional information on the Russian Federation. Because of the inexistence of data at the regional level, Chuvash Republic (RU) had to be excluded from the clustering study. Additionally, a shortage of information was confirmed for the regions with NUTS level 2. In order to avoid the complete elimination of these regions and continue with a sub-national analysis allowing analogue comparisons, the NUTS-2 regions were substituted. They were replaced with the corresponding territories of the next level by the classification (NUTS 1) which contains the regions (see table 4).

Table 4: Ben RHM II-regions and regions participating in the clustering study

Regions Participating in BEN			Regions Participating in the Clustering Study		
NUTS		Region	NUTS		Region
Level	Code		Level	Code	
1	be24	Flemish (BE)	1	be24	Flemish (BE)
1	cz08	Moravia-Silesia (CZ)	1	cz08	Moravia-Silesia (CZ)
1	dea	North Rhine-Westphalia (DE-NRW)	1	dea	North Rhine-Westphalia (DE-NRW)
1	dee	Saxony-Anhalt (DE-S)	1	dee	Saxony-Anhalt (DE-S)
1	gr23	Western-Greece (EL)	1	gr23	Western-Greece (EL)
2	ie021	Dublin/Mid-Leinster & Dublin/North-East (IE)	1	ie02	Southern and Eastern Ireland (IE-SE)
1	itd3	Veneto (IT-V)	1	itd3	Veneto (IT-V)
1	itd5	Emilia-Romagna (IT-E)	1	itd5	Emilia-Romagna (IT-E)
1	itg1	Sicily (IT-S)	1	itg1	Sicily (IT-S)
1	lt002	Kaunas (LT)	1	lt002	Kaunas (LT)
2	hu221	Győr-Moson-Sopron County (HU-G)	1	hu22	Nyugat-Dunántúl (HU-ND)
2	hu323	Szabolcs-Szatmár-Bereg (HU-S)	1	hu32	Észak-Alföld (HU-E)
1	at31	Upper-Austria (AT)	1	at31	Upper-Austria (AT)
1	pt30	Madeira (PT)	1	pt30	Madeira (PT)
2	se0a2	Västra-Götaland (SE)	1	se0a	Västsverige (SE-V)
2	bg131	Varna-Oblast (BG)	1	bg13	Severoiztochen (BG-S)
1	ch07	Ticino (CH)	1	ch07	Ticino (CH)
1	ukc_k	England (UK)	1	ukc_k	England (UK)
--	--	Chuvash Republic (RU)			

Regarding the timeframe of the study, the year 2002 was chosen as the analysis base year in order to cover most of the variables and regions.

From the 22 variables initially selected, 50% were removed during the data collection process because of information shortage. With regard to the regions, the decision was made to remove Severoiztochen (BG-S) and Ticino (CH) from the clustering. Income data were not available for Severoiztochen (BG-S) and Ticino (CH) failed to provide information for three variables. Using the remaining variables and regions, a data framework was constructed for further usage in the clustering (see table 5).

In a third step, descriptive statistics (e.g. mean, standard deviation, maximum and minimum scores) were carried out to identify variables with insufficient differences among the regions. After the descriptive tests were carried out, outliers were identified since clustering techniques are particularly sensitive to them. One outlier was identified and dealt with.

Next, a Pearson correlation matrix⁹ was calculated to identify and remove highly correlated variables. Three variables were identified and eliminated since they were correlated with two further variables from the study. After elimination of the three variables, the set of variables to be used in the clustering was reduced to eight variables (see table 5).

⁹ Northeastern Illinois University. Correlation (2006): <http://www.neiu.edu/~dbehrlic/hrd408/glossary.htm>, 21.11.06

Table 5: Set of variables for the clustering

No.	Variable	Acronym
1	Population density	POP_DENS
2	Proportion of population aged 65 and older in relation to the total population	YEAR_65
3	Sex ratio	SEX_RAT
4	Unemployment rate	UNEMPL
5	Disposable income of household per inhabitant	INCOM
6	Number of physicians per 100.000 inhabitants	PHYSIC
7	Type of health care system	HEALTH
8	Types of system of government	GOVERN

Once the correlation analysis had been concluded, a standardisation procedure to re-scale the remaining numeric variables was carried out. The variable mean was subtracted from each variable and the result divided by the standard deviation. After the standardisation of variables, the categorical variables were encoded. The categories of the non-numeric variables were given numeric values.

Table 6: Data framework

No.	NUTS	Region	AAGR 2000-2002	Population Density 2002	% Pop. 1-year 2002	% Pop. 65 and older 2002	Sex ratio 2002	Pobl. fem. aged 50-65 / total fem. 2002	Unempl. rate 2002	Disposable Income per inhabitant 2002	Physicians per 100.000 inhabitants 2000	Type of health care system	Type of system of government
1	be24	Flemish (BE)	0,40%	485,7	1,1%	17,0%	96,0	18,4%	4,0%	18.440,1	505,7	SHI-based	Federal Arrangement
2	cz08	Moravia-Silesian (CZ)	-0,61%	227,9	0,9%	12,4%	95,4	20,2%	13,4%	3.615,1	328,3	SHI-based	Unitary State
3	dea	North Rhine-Westphalia (DE-NRW)	0,15%	529,7	1,0%	17,4%	94,7	19,5%	7,5%	17.580,7	311,5	SHI-based	Federation
4	dee	Saxony-Anhalt (DE-S)	-1,29%	126,2	0,7%	18,3%	94,8	21,6%	19,0%	13.825,3	348,5	SHI-based	Federation
5	gr23	Western-Greece (EL)	0,18%	63,8	0,9%	17,9%	102,5	18,1%	10,7%	8.364,0	348,1	Tax-based	Unitary State
6	ie02	Southern and Eastern (IE-SE)	1,53%	78,5	1,4%	10,6%	97,8	15,3%	4,1%	16.298,5	223,4	Tax-based	Unitary State
7	itd3	Veneto (IT-V)	0,50%	246,2	1,0%	18,3%	94,9	20,0%	3,4%	15.599,3	499,2	Tax-based	Federal Arrangement
8	itd5	Emilia-Romagna (IT-E)	0,49%	180,2	0,9%	22,4%	93,6	20,8%	3,3%	18.002,5	647,7	Tax-based	Federal Arrangement
9	itg1	Sicily (IT-S)	-0,29%	193,1	1,0%	16,9%	93,5	17,9%	20,1%	10.257,5	643,3	Tax-based	Federal Arrangement
10	lt002	Kaunas (LT)	-3,67%	86,8	0,9%	14,0%	85,8	18,6%	14,0%	2.700,9	403,8	Mixed	Federal Arrangement
11	hu22	Nyugat-Dunántúl (HU-ND)	-0,06%	89,5	0,9%	15,2%	92,9	19,7%	4,0%	4.342,2	259,6	Mixed	Unitary State
12	hu32	Észak-Aktól (HU-E)	-0,16%	87,9	1,1%	14,0%	92,3	18,5%	7,8%	2.879,5	266,8	Mixed	Unitary State
13	at31	Upper-Austria (AT)	0,37%	115,2	1,0%	15,0%	95,5	17,2%	3,1%	15.952,4	247,9	SHI-based	Federation
14	pt30	Madeira (PT)	-0,02%	290,3	1,2%	13,4%	89,0	15,6%	5,0%	8.127,1	246,8	Tax-based	Federal Arrangement
15	se0a	Västsvrige (SE-V)	0,43%	57,1	1,0%	17,1%	98,6	19,2%	4,9%	14.740,4	264,0	Tax-based	Unitary State
16	ukc_k	England (UK)	0,48%	381,4	1,2%	15,6%	97,5	17,7%	4,9%	18.310,4	518,9	Tax-based	Federal Arrangement

Sources:

- EUROSTAT. Regional Statistics (2006): <http://epp.eurostat.cec.eu.int/portal>, 16.06.06.
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In a fourth step, using the eight transformed variables, four clusters were identified by applying a hierarchical clustering method. Nevertheless, the clusters were not satisfying. In a second approach, a K-means technique (Afifi AA, Clark V 1990) was applied. With this technique, the members were re-allocated and groups of comparable regions finally identified.

4.2.5.2 Results

The clusters built are listed in the membership table below (the geographical distribution of the identified clusters can be taken from illustration 5).

Table 7: Cluster membership after K-means technique

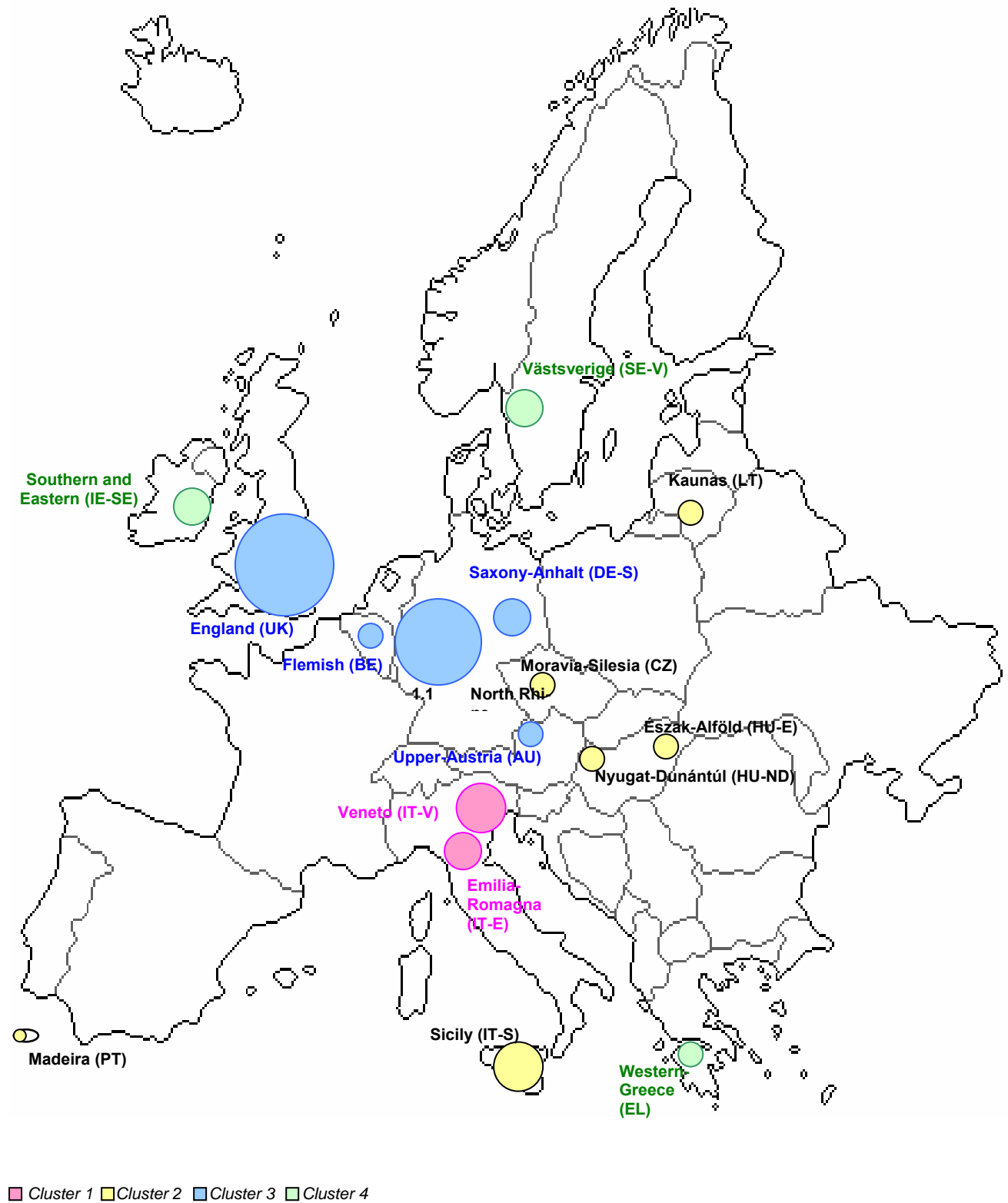
No. Case	NUTS	Region	No. Cluster	Distance
1	be24	Flemish (BE)	3	1,697
2	cz08	Moravia-Silesia (CZ)	2	1,914
3	dea	North Rhine-Westphalia (DE-NRW)	3	1,601
4	dee	Saxony-Anhalt (DE-S)	3	2,604
5	gr23	Western-Greece (EL)	4	1,704
6	ie02	Southern and Eastern (IE-SE)	4	1,877
7	itd3	Veneto (IT-V)	1	0,964
8	itd5	Emilia-Romagna (IT-E)	1	0,964
9	itg1	Sicily (IT-S)	2	3,097
10	lt002	Kaunas (LT)	2	1,843
11	hu22	Nyugat-Dunántúl (HU-ND)	2	1,636
12	hu32	Észak-Alföld (HU-E)	2	1,197
13	at31	Upper-Austria (AU)	3	2,078
14	pt30	Madeira (PT)	2	2,014
15	se0a	Västsverige (SE-V)	4	0,842
16	ukc_k	England (UK)	3	2,140

■ Cluster 1
 ■ Cluster 2
 ■ Cluster 3
 ■ Cluster 4

With regard to the specific characteristics of the clusters, cluster 1 formed by Veneto (IT-V) and Emilia-Romagna (IT-E) from Italy has a tax-based health care system and a federal arrangement as government (see Table 7). Cluster 1 has a high disposable income per inhabitant

and a very low unemployment rate. It is characterised by medium population density, a high percentage of seniors and an average male population. In addition, cluster 1 has a very high number of physicians per 100.000 inhabitants. Cluster 2 comprises the regions of Moravia-Silesia (CZ), Kaunas (LT), the two regions from Hungary (HU), Madeira (PT) and Sicily (IT-S). It has a relatively low income and a very high unemployment rate.

Illus. 5: Clusters of regions after K-means clustering



Cluster 2 has a low population density and a small male population. This cluster is also characterised by a low percentage of seniors as well as a small number of physicians. Regarding the prevailing health care system, most of its members have a mixed system. In relation to the system of government, half of the regions have a federal arrangement as political system and the other half are unitary states.

Table 8: Comparison of clusters

Measure	Means						Frequent System	
	Population density (POP_DENS)	% Pop. 65 and older (YEAR_65)	Sex ratio (SEX_RAT)	Unempl. rate (UNEMPLOY)	Disp. income per inhabitant (INCOM)	Phys. per 100.000 inhabitants (PHYSIC)	System of health care (HEALTH)	System of government (GOVERN)
All regions (N=16)	202,5	16,0%	94,7	8,1%	11.814,7	379,0	---	---
Cluster 1 (n=2)	213,2	20,4%	94,3	3,4%	16.800,9	573,5	All Tax-based	All Fed. Arrangement
Cluster 2 (n=6)	162,6	14,3%	91,5	10,7%	5.320,4	358,1	Mainly Mixed	Fed. Arrang. & Unitary St.
Cluster 3 (n=5)	327,6	16,7%	95,7	7,7%	16.821,8	386,5	Mainly SHI-based	Mainly Federation
Cluster 4 (n=3)	66,5	15,2%	99,6	6,6%	13.134,3	278,5	All Tax-based	All Unitary State

Cluster 3 includes England (UK) and four regions of Central Europe, Flemish Community (BE), North Rhine-Westphalia (DE-NRW), Saxony-Anhalt (DE-S) and Upper-Austria (AT) with a very high population density. This cluster is characterised by a medium percentage of seniors, an average number of physicians and a medium male population. Additionally, cluster 3 has a high disposable income and a low unemployment rate. The majority of the members of this cluster have an SHI-based¹⁰ health system and a Federation as government system.

Cluster 4 consists of Southern and Eastern Ireland (IE-SE), Västsverige (SE-V) and Western-Greece (EL). It has a very low population density. This cluster is characterised by a large number of males in relation to females, a small elderly population and a low number of physicians. Cluster 4 also has a high income and a low unemployment rate. All regions belonging to this cluster have a tax-based health care system and they are all unitary states.

¹⁰ SHI = Statutory Health Insurance.

4.2.5.3 Discussion

The availability of regional information proved to be a key factor for the development and outcomes of the study. Because of the shortage of regional information, several variables of public health relevance were not considered for the clustering analysis.

Because of lacking data material it was moreover not possible to consider the NUTS level 2 regions participating in the Ben RHM II project. In order to avoid the complete elimination of the NUTS 2 regions and to continue with the sub-national analysis allowing analogue comparisons, the NUTS 2 regions were substituted. They were replaced with the corresponding territories of the next classification level (NUTS 1) containing the project regions.

The study also demonstrated that the clustering analysis is a useful instrument to identify population groups with similar demographic and socio-economic characteristics. Nevertheless, the clustering results should be considered with caution since the clustering techniques are considerably affected by the variables used. Clusters will always be defined by the set of variables employed by the analyst. Therefore a cluster does not lead to a single or definite solution.

5. Organigraphs

In chapter 4 it was explained how the benchmarking process of Ben RHM II integrates and partly relies on the Organigraphs that were to be drawn for the health management of the tracers in the respective regions. In this chapter, the Organigraphs that were drawn by our project partners are presented. They are accompanied by explanatory text that describes the health management in the regions.

Both – the Organigraphs and the text – give first *important insights in the health managements of the respective regions*. Within the benchmarking process these intermediate results helped to compose the indepth interview questionnaires as the steering group was then aware of the specific complexity in health management as can be found in the participating regions.

In the following, the Organigraphs and texts are represented as delivered by the project partners. The Ben RHM II secretariat has only slightly intervened in editing. The presentation is systematic in so far as first all regional Organigraphs and texts of each tracer are presented followed by *a discussion of these results*.

5.1 Measles

5.1.1 Austria (Upper-Austria) ¹¹

Structure, Organisation and Management of the Measles Immunisation Programme of Upper Austria

The Federal Government is responsible for legislation, formulating health policy and general directives. The State Government, assisted by the Health Authority is responsible for carrying out directives and implementing laws and policies.

An immunisation programme is implemented in Upper Austria according to the immunisation concept of 1998 (Ministry of Health and Women). This immunisation concept states that recommended vaccinations should be offered free of charge for all children up to the age of 15 years.

The organisation and implementation of (measles) immunisation programmes is done at the regional level by the respective regional health authorities. In 2000, the regional government of Upper Austria together with the Regional Health Authority and the Insurance Company of Upper Austria came up with 10 targets for the region. Target 5 is directed at measles and is aimed at the elimination of endemic measles in the region by 2005 or even earlier, and certification of the elimination of the disease by 2010 (OÖ report 2000). Target 5 is likely to be changed to the effect that immunisation coverage of 90% should be reached.

To carry out the Measles Immunisation Programme according to the law and the implementation rules, the Regional Health Authority cooperates with the State Medical Council, which is the representative body for the physicians.

Vaccination strategy

Since 2003 the first MMR vaccine has to be given at 14 months and the second during the 2nd year of life. There is no system in place to invite parents to have their children immunised. Parents are in possession of immunisation schedules which are a kind of reminder and which they are supposed to consult and then have their children immunised accordingly. In Upper Austria, an incentive system (financial mother-child subsidy) is available. It is linked to the “Mutter-Kind-Pass (Mother-Child passport)” and the so called “Impfgutscheinheft” (immunisation voucher brochure).

¹¹ Author: Dr Eva Magnet, Health Authority Upper Austria, Linz.

Information and education

Although measles immunisation is currently not part of the media agenda and the general public opinion on the programmes is not measured, parents are informed by parents' advice services, physicians and the appropriate health authorities about immunisation programmes in general.

The health authorities also hold seminars/meetings for physicians and nurses working at parents' advice centres to inform them about new recommendations or changes relating to immunisation programmes.

Programme-related projects/campaigns

At the moment programme related campaigns are being organised for physicians.

Vaccination documentation/data collection

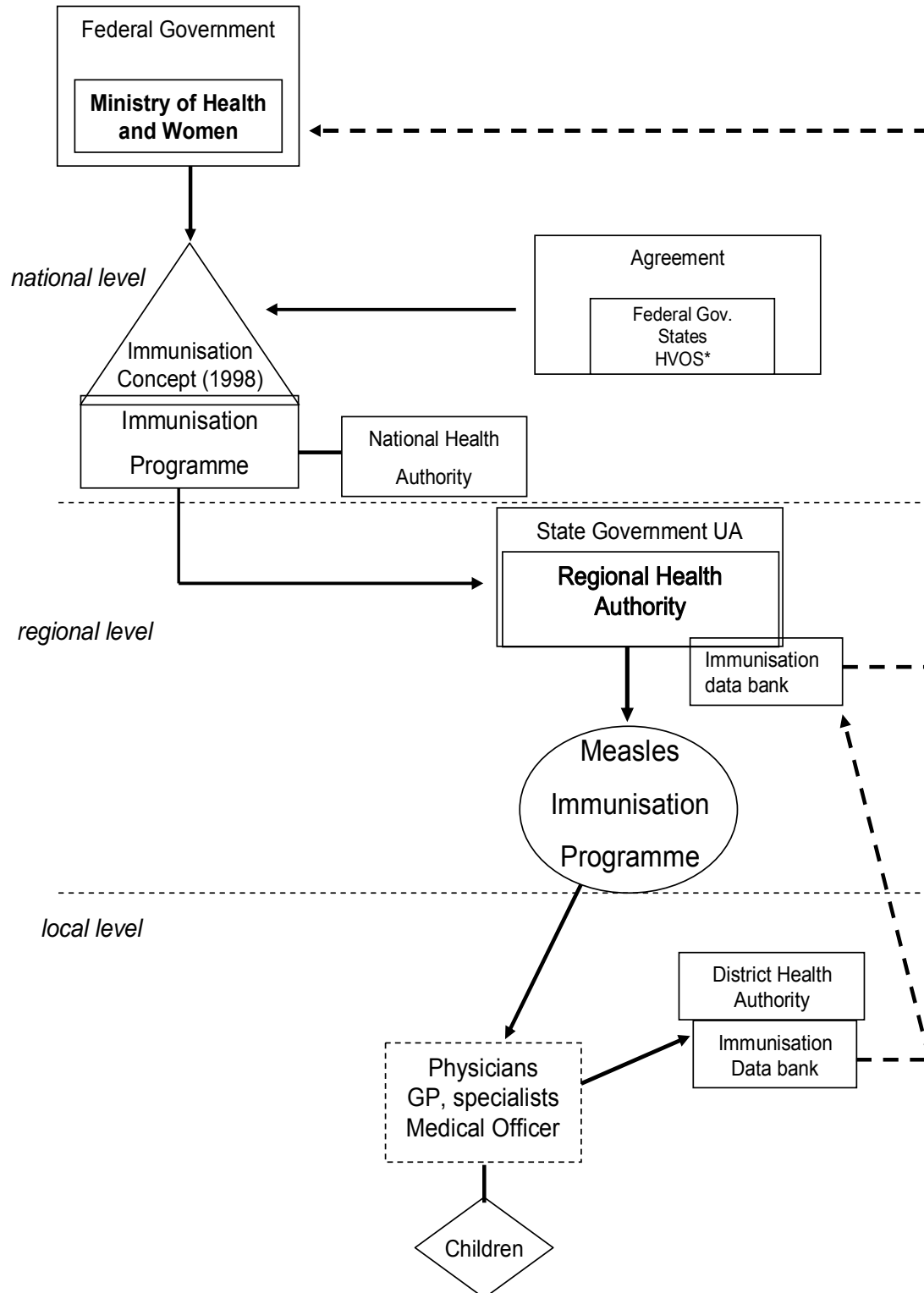
Vaccination documentation is done by the vaccination physician in a parent held "mother-child document". Each physician reports the immunisation and sends it to the District Health Authority. And each measles immunisation will be registered in the central immunisation database by the Regional Health Authority and the data will be reported to the National Health Ministry. It is planned to use the central immunisation database for a recall system.

Disease surveillance

Measles is supposed to be a notifiable disease in Austria and notification will be done in Upper Austria. The Austrian Statistics Institute presently collects national hospital measles incidence data only. Ambulatory data are not collected. A surveillance system for polio does exist, but not for measles.

Organigraph for Measles

Immunisation Programme in Upper Austria



* HVOS = Hauptverband der Sozialversicherungsträger

5.1.2 Belgium (Flemish Community) ¹²

Which institutions / organisations have the main responsibility for health management at the local, regional and national level?

The government of the Flemish Community is responsible for the prevention and prophylaxis of infectious diseases in Flanders, including the immunisation programme.

Which further institutions/organisations are involved and how do they relate to each other?

- Each year the federal government's Health Council proposes a schedule for immunisation for children (scientific advice). At an interministerial conference, the responsible health ministers (federal + different communities) decide which immunisation schedule to implement.
- The federal government (Institute for Social Security) participates in the financing of vaccines within the general immunisation schedule.
- In the Vaccine Board of Flanders, representatives of all vaccinators discuss the implementation of the immunisation programme.
 - Kind en Gezin (Flemish organisation for Child and Family Care): free immunisation and child care for children younger than 3 years (measles vaccination at 12 months)
 - CLB (Centres for counselling of pupils, incl. school medicine): responsible for preventive health care for school children (catch up in youngsters and second dose of measles vaccine in the 5th year of primary school – 10 years of age)
 - General practitioners and paediatricians: receive free vaccines; their scientific organisations (WVVH and VVK) participate in the Vaccine Board of Flanders
- There is a national committee for the elimination of measles in Belgium with scientists and representatives of the federal and regional health administrations.

Which laws regulate health management?

Two decrees and one decision of the Flemish Government:

- Profylaxedecreet: decree of 5 April 1995 concerning the prophylaxis of infectious diseases.
- Preventiedecreet: Decree of 21 November 2003 concerning preventive health care.

¹² Author: Dr Geert Top, Ministry of Flanders, Administration of Health Care, Brussels.

- Decision of the Flemish Government of 17 March 2000 concerning the tasks of the Centres for the counselling of pupils (CLB)

Who is responsible for the surveillance and how is it conducted?

- Surveillance of infectious diseases – notification to the health authorities of Flanders (health inspectorate of Flanders)
- Notification of measles is obligatory for the Centres for counselling of pupils (school medicine).

Do registries exist? If so, how do they work?

- Reported cases:

During the last years no clusters of measles were reported to the health authorities of Flanders.

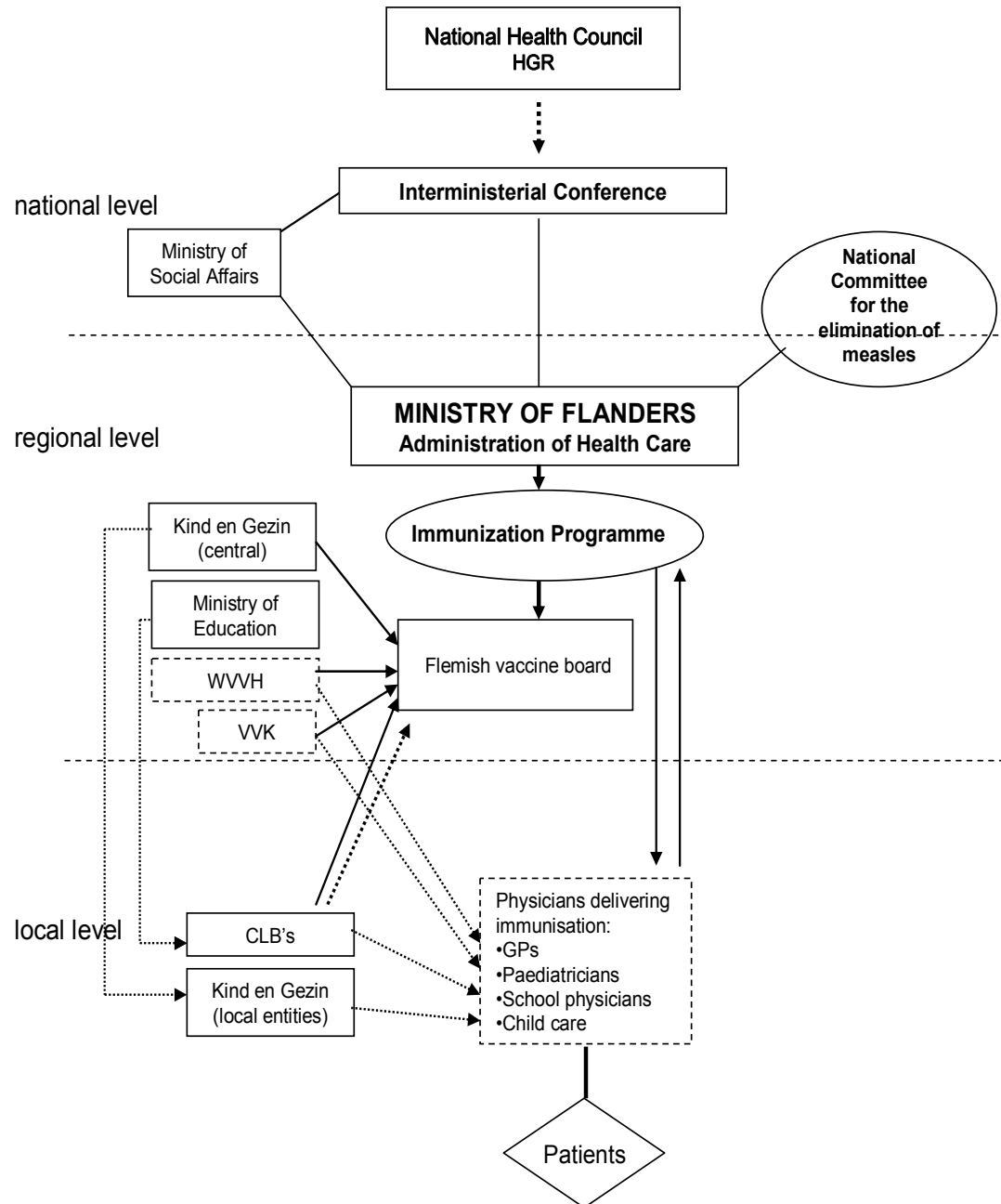
- Vaccination:

- The last vaccination coverage study was done in 1999, where measles vaccination coverage in Flanders was evaluated for children between 18 and 24 months.
- A new study was conducted in 2005 evaluating measles vaccination coverage for the first vaccination dose to be given at 12 months of age, evaluation of catch-up immunisation before 7 years and vaccination coverage for the second dose at the age of 10 years.
- There is a database (incomplete) of vaccinations of young children, the use of which was further generalised in 2005 and 2006.

Are there campaigns/action programmes of major importance?

There is a national committee for the elimination of measles in Belgium with scientists and representatives of the federal and regional health administrations, which gives advice on strategies to eliminate measles.

Organigraph for Measles Immunisation Programme in Flanders



5.1.2 Bulgaria (Varna-Oblast)¹³

Institutions engaged in the Health Management Programmes for measles are:

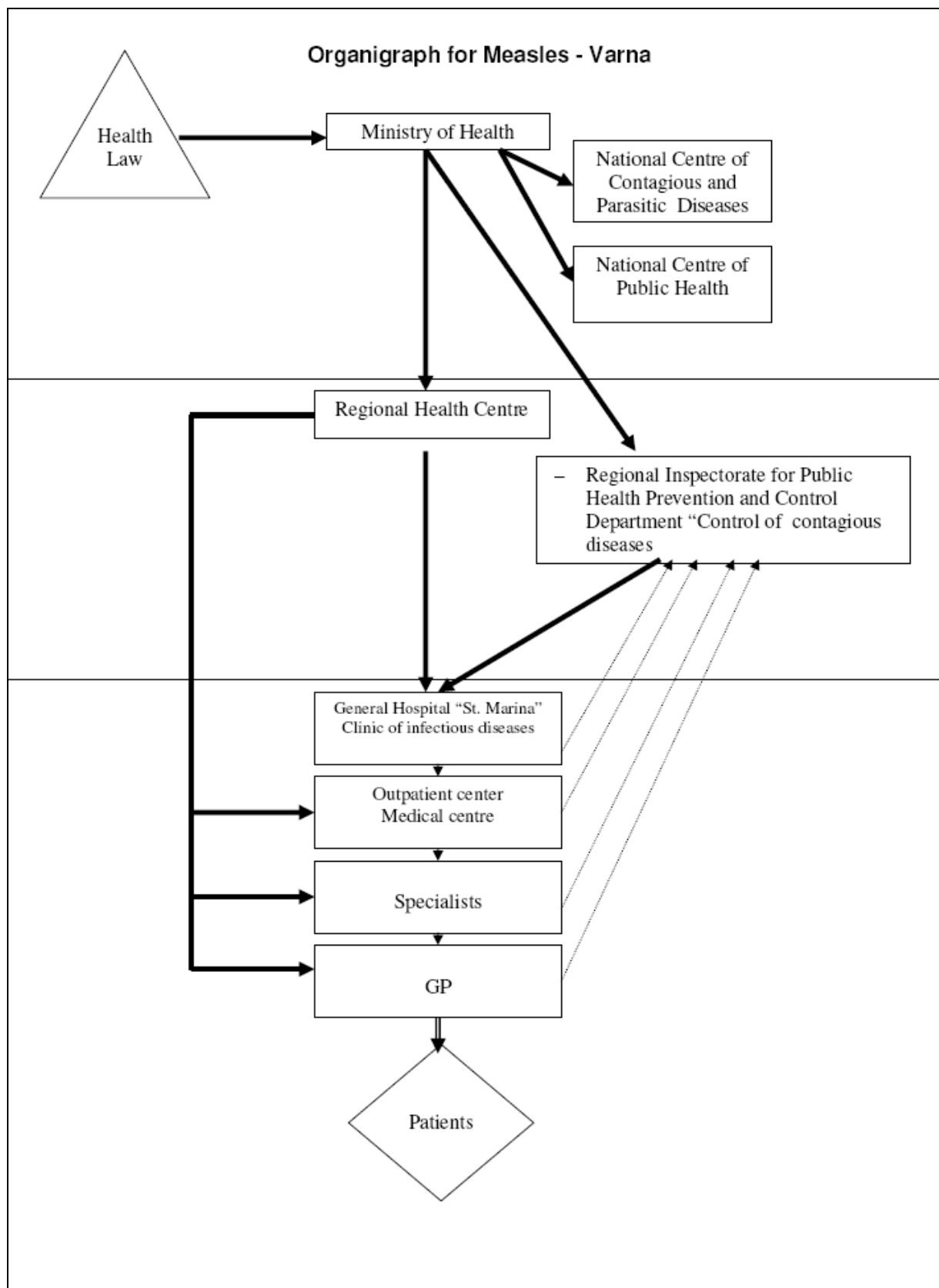
- Regional Inspectorate for Public Health Prevention and Control (RIPHPC); Directorate of Contagious Diseases Supervision, especially the Department of Epidemiological Control and Section of Virology;
- Infectious Disease Clinic – St. Marina Multiprofile Hospital for Active Treatment;
- General Practitioners

Epidemiological control related objectives of the RIPHPC are:

- Anti-epidemic activities for persons infected with measles: isolation, hospitalisation (if necessary in the case of a complicated form of the disease or bad home conditions), epidemiological investigation in order to determine the conditions for the infection (contact with another infected person, immunisation, etc.), preventive actions for contact persons (observation, immunisation of non-immunised persons of a certain age, quarantine in organised children's groups);
- Registration of all cases established by the GPs, sending of serological samples of clinically diagnosed cases for confirmation to the National Confirmatory Laboratory for measles, mumps and rubella, including conveyance of registered case data of monthly and annual analyses of acute communicable diseases to the National Statistical Institute.
- Distribution of vaccine against measles among GPs in order to immunise all people in need of immunisation according to the immunoprophylaxis calendar, report of the used vaccine doses, preparation of six-month and annual analyses of the immunoprophylaxis carried out. In 2005, a special software programme for the detection of persons in need of immunisation by their GPs and the determination of dates for the future immunisation measures was launched to prepare a report on bioproducts and to facilitate the controlling of immunisation and vaccine quantities.
- All suspected, probable or confirmed cases of measles are registered in a special book in the Department of Epidemiological Control at RIPHPC, which reports the cases on a special form to the Ministry of Health. Non-confirmed cases have to be registered as well.

¹³ Authors: Dr Aneta Kirova and Dr Anelia Shtilianova, Directorate of Contagious Diseases Supervision, Varna.

No programmes for measles eradication at the regional level have been carried out. National consultants of epidemiology, virology and other specialists from the National Center of Contagious and Parasitic Diseases take part in the Expert Commission of the Ministry of Health for the preparation of a National programme for measles and congenital rubella eradication. They provide methodological assistance in solving problems of diagnostics, treatment, anti-epidemic and preventive actions in the case of an epidemic situation.



5.1.3 Czech Republic (Moravia-Silesia)¹⁴

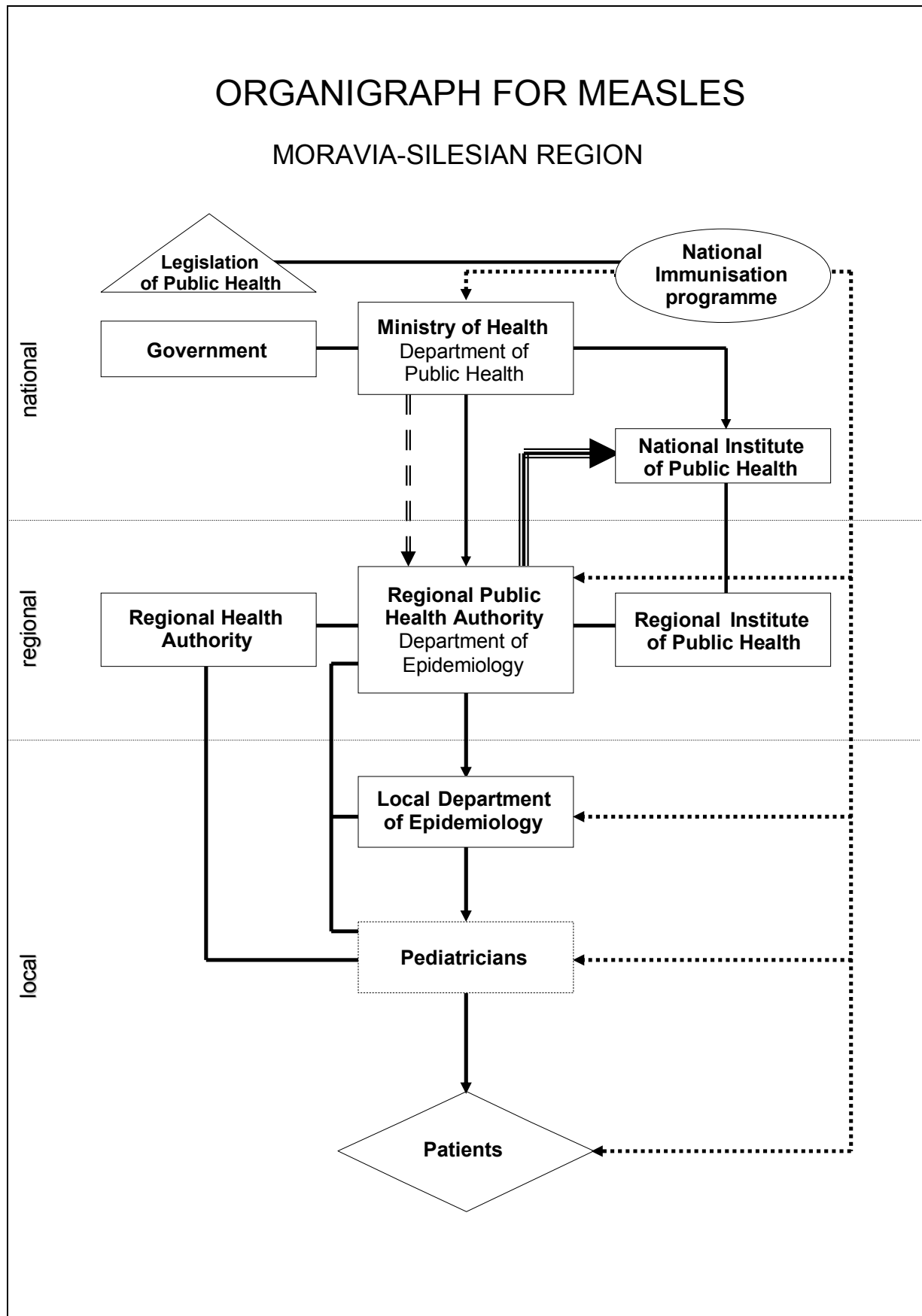
Vaccination is one of the very old preventive public health policies. Measles vaccination is one of the obligatory (law-based) immunisations. The tender for vaccine is organised by the Ministry of Health (MOH). The vaccine is paid from the national budget and distributed to paediatricians by the regional public health authorities.

Measles vaccination is organised through the regional public health authorities (PHA). They use their own local public health branches which are equipped with a local epidemiology unit. As stipulated by law, responsibility for measles vaccination lies with the parents. Vaccination providers are the registered paediatricians.

The paediatrician is responsible for inviting children to take part in the measles immunisation measures but some regions or cities have set up their own invitation systems. The National Institute of Public Health is responsible for research, methodology and for supporting the MOH and PHA as well as for reporting and QA/QC.

Side effects are reported to the National Drug Administration.

¹⁴ Author: Dr Silvia Skotnicova, University Hospital Ostrava, Czech Republic. Author of organigraph: Dr Helena Šebáková, Regional Public Health Authority, Ostrava



5.1.5 Germany

5.1.5.1 North Rhine-Westphalia¹⁵

Which institutions/organisations are mainly responsible for the health care system at the national, regional and local level?

National responsibility for all matters pertaining to health (legislation, health policy) lies with the German Federal Ministry of Health, whereas the corresponding state health ministries are responsible at state and the Lower Health Authorities (health departments) at the local level.

In North Rhine-Westphalia (NRW), responsibility for health-related matters lies with the Ministry of Employment, Health and Social Affairs (MAGS). Important instruments for the steering and development of health policy are the State Health Conference where concrete health targets are fixed for a defined period of time and in which all health care actors are involved as well as the Local Health Conferences which, as far as possible, translate the defined targets into action.

So for example at the 2001 NRW State Health Conference, an “Action Programme for the Prevention of Measles, Mumps and Rubella” was adopted with the objective to increase the number of immunised children and adolescents and to support the plan of WHO of eliminating measles altogether by the year 2010.

Which institutions/organisations play a role within the immunisation system?

Germany has no national immunisation plan but immunisation recommendations. These are updated every year by the Standing Committee on Vaccination at the Robert-Koch-Institute (STIKO). The immunisation recommendations distinguish between standard immunisations and other non-standard immunisations (for occupational indications, travelling etc).

The STIKO-recommended immunisations are in general adopted by the individual German states but they can also be modified or extended. NRW adopts the STIKO recommendations without modifications. Presently, measles immunisation is recommended for the first dose to be given between months 11-14, the second dose no sooner than 4 weeks later, and the complete measles immunisation should be finished with month 24.

¹⁵ Author: Gabriele Ahlemeyer, Institute of Public Health North Rhine-Westphalia, Münster. Author of Organigraph: Dr Peter Schröder-Bäck, Institute of Public Health North Rhine-Westphalia, Bielefeld.

Information on immunisation activities

Parents/patients are in most cases informed by their paediatrician/family doctor about upcoming immunisation events, their benefits and possible side effects. The patient may however also contact the Lower Health Authorities for consultation and advice.

Doctors may turn to the Chambers of Physicians for further information and training and obtain a corresponding certificate.

Implementation of immunisation activities

Immunisations are not mandatory but administered on a voluntary basis which, in the case of child immunisations, require the consent of their legal guardians. Immunisations are in general carried out by practice-based paediatricians or family doctors. Parents are not actively invited to have their children immunised; the immunisation status shall be checked by the doctor during regular infant routine examinations and immunisation gaps be closed if necessary. In general parents are not reminded either if they have missed an immunisation session (only in isolated cases by individual practices).

All immunisations given are recorded in an immunisation certificate which remains with the parents. Doctors practices also capture immunisation data in an electronic or written form. There is however no central capturing of immunisation data by the health authorities.

Financing of immunisations

The costs for financing standard immunisations are borne by the health insurance companies; each health insurance company decides by itself if the new or modified recommendation for immunisation should be included in its catalogue of benefits. The costs for the vaccine and for administering the immunisation dose to patients insured by the statutory health insurance funds are directly reimbursed to doctors by the health insurance funds.

In future, the “Federal Joint Committee” will decide which immunisations recommended by STIKO must be paid by the health insurance funds because they are mandatory.

Surveillance of case reports and immunisation data

Since introduction of the “Infectious Disease Control Act (IfSG)” in 2001, measles have been classified as a notifiable disease in Germany and thus also in NRW. Doctors are obliged to report both clinical cases of measles and laboratory-confirmed cases to the Lower Health Authorities. These report the cases in an anonymised form to NRW’s measles registration office which in turn reports them to RKI.

In addition to the obligation to report measles, adverse immunisation side effects must also be reported since 2001. As for measles, there will probably be a high estimated number of unreported cases.

Immunisation registry

There is no immunisation registry. During the IfSG-required school-entrance examinations carried out by the health departments, immunisation data on standard immunisations such as measles immunisations are collected throughout NRW. These data are evaluated in an anonymised form and can be used by the municipalities and by NRW for specific activities. In addition, they are transmitted to RKI.

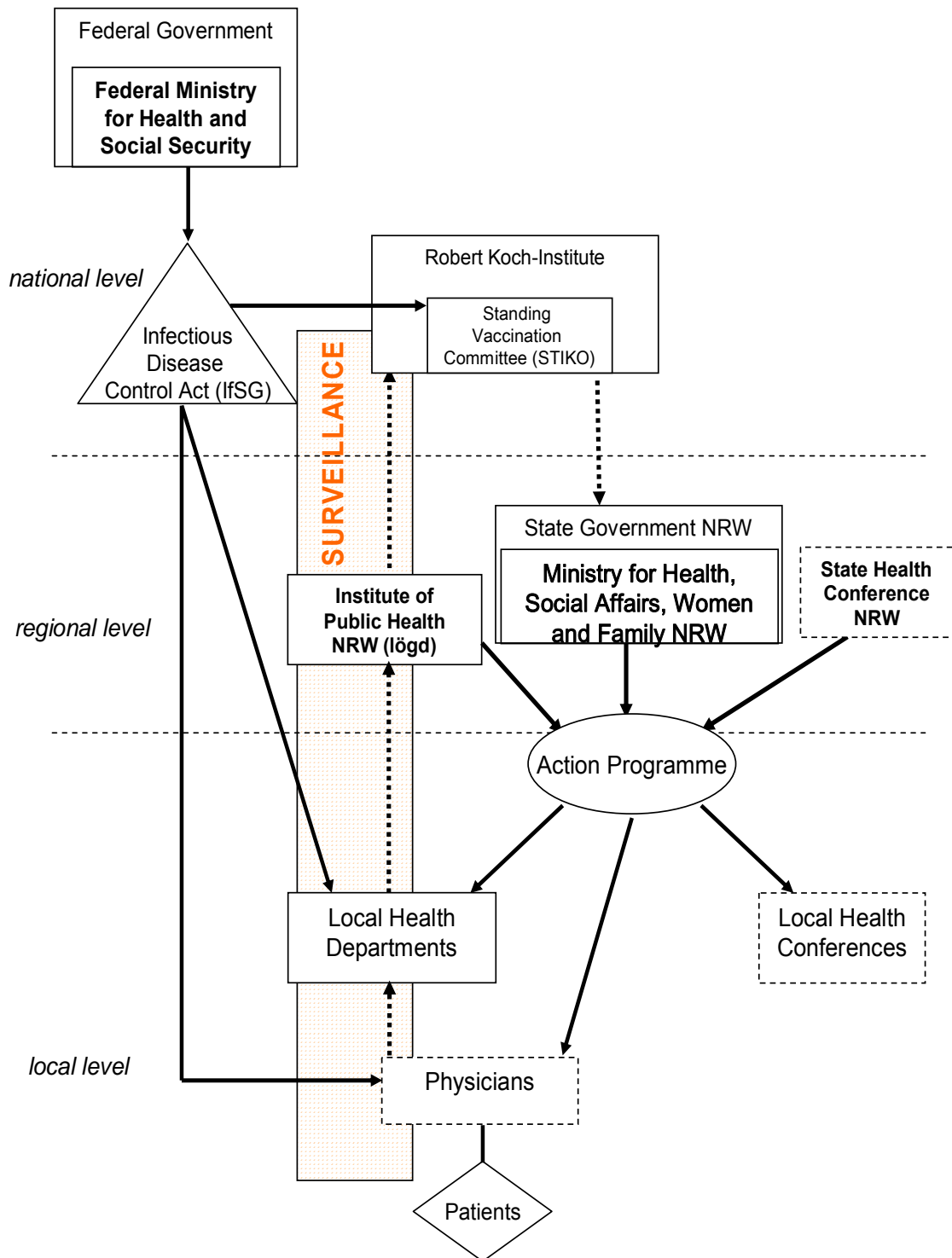
Depending on the capacities available in the health departments, immunisation data are also collected for older children/adolescents such as for school-leavers or before pupils change to a different type of school.

Major immunisation activities/immunisation campaigns

Since years ago responsibility for immunisation activities was conferred upon office-base paediatricians/doctors, immunisation activities for socially disadvantaged groups are only in isolated cases initiated by the health departments. Major immunisation events have not been carried out during recent years.

In the case of outbreaks, the Lower Health Authorities may provide incubation vaccinations.

MEASLES, North Rhine-Westphalia



5.1.5.2 Saxony-Anhalt ¹⁶

Which institutions/organisations are mainly responsible for the health care system at the national, regional and local level?

National responsibility for all health-related matters (legislation, health policy) lies with the German Federal Ministry of Health, whereas the corresponding state ministries are responsible for all health issues at state level and the Lower Health Authorities (health departments) at the local level.

In Saxony-Anhalt, the Ministry of Health and Social Affairs (MS) is responsible for all matters pertaining to health. Important instruments for the steering and development of health policy are the State Health Conference where concrete health targets are fixed for a defined period of time and in which all health care actors are involved.

At the first State Health Conference in 1998, health targets were for example formulated for Saxony-Anhalt, in 2005 the balance was drawn and adjustments made by moving the focus of interest on the development of healthy ways of behaviour and on the creation of health-promoting environments. The health target “Achieving a proper immunisation status in more than 90% of the population” has for example been pursued since 1998.

Which institutions/organisations play a role in the immunisation system?

Germany has no national immunisation plan, but immunisation recommendations. These are updated every year by the Standing Committee on Vaccination at the Robert-Koch-Institute (STIKO). The immunisation recommendations distinguish between standard immunisations and other non-standard immunisations (for occupational indications, travelling etc). The STIKO recommendations are in general adopted by the individual German states but can also be modified or extended. Saxony-Anhalt adopts the STIKO recommendations without modifications.

Presently, measles immunisation is recommended for the first dose to be given between months 11-14, the second dose no sooner than 4 weeks later, and the complete measles immunisation should be finished with month 24.

To implement the health target “Achieving a proper immunisation status in more than 90% of the population,” an “immunisation” working group was established. In this working group, all institutions and associations dealing with immunisation are represented. In agree-

¹⁶ Author: Dr Hanna Oppermann, LAV (Saxony-Anhalt Federal State Office for Consumer Protection, Magdeburg, 29.05.2007).

ment with this working group, the health ministry initiates target group-specific pilot projects for the targets groups of children and young people, employees or elderly people. All companies, institutions, associations etc. in Saxony-Anhalt may provide a contribution by running an immunisation pilot project.

Information on immunisation activities

Parents/patients are in most cases informed by their paediatrician/family doctor about upcoming immunisation events, their benefits and possible side effects. The patient may however also contact the Lower Health Authorities for consultation and advice.

Doctors may turn to the Chambers of Physicians for further information and training and may obtain a corresponding certificate.

Implementation of immunisation activities

Immunisations are not mandatory but administered on a voluntary basis which, in the case of child immunisations, require the consent of their legal guardians. Immunisations are in general carried out by practice-based paediatricians or family doctors. All immunisations given are recorded in an immunisation certificate which is kept by the parents. Doctors practices also capture immunisation data in an electronic or paperised form.

Immunisations of children up to their 7th year of life must be reported by name rather than by code. (Task conferred upon local bodies by the government in accordance with the 1997 health service act of the state of Saxony-Anhalt). Parents must give their written consent. The data (name and first name of the person immunised, date of birth, address, type and date of immunisation) are reported by the doctor who administers the immunisation to the health department where an immunisation registry is kept. If required, health departments can remind parents of immunisation gaps.

Financing of immunisations

The costs for financing standard immunisations are borne by the health insurance companies; each health insurance company decides by itself if the new or modified recommendation for immunisation should be included in its catalogue of benefits. The costs for the vaccine and for administering the immunisation dose to patients insured by the statutory health insurance funds are directly reimbursed to doctors by the health insurance funds. Health departments may offer free immunisation. They do so at their own discretion.

In future, the “Federal Joint Committee” will decide which immunisations recommended by STIKO must be paid by the health insurance funds because they are mandatory.

Surveillance of case reports and immunisation data

With the introduction of the Infectious Disease Control Act (IfSG) in 2001, measles have become a notifiable disease in Germany. In Saxony-Anhalt, measles have to be reported since 1991 and also in the years before. This obligation to report measles applies both to doctors who have to report clinical cases and to cases confirmed by laboratory examinations. Cases are reported to the responsible health department (lower health authorities) which convey the reports in an anonymised form to Saxony-Anhalt’s measles registration office which in turn reports them to RKI. Measles have for years been a very rare disease in Saxony-Anhalt. In addition to the obligation to report measles, adverse immunisation side effects must also be reported since 2001.

Immunisation registry

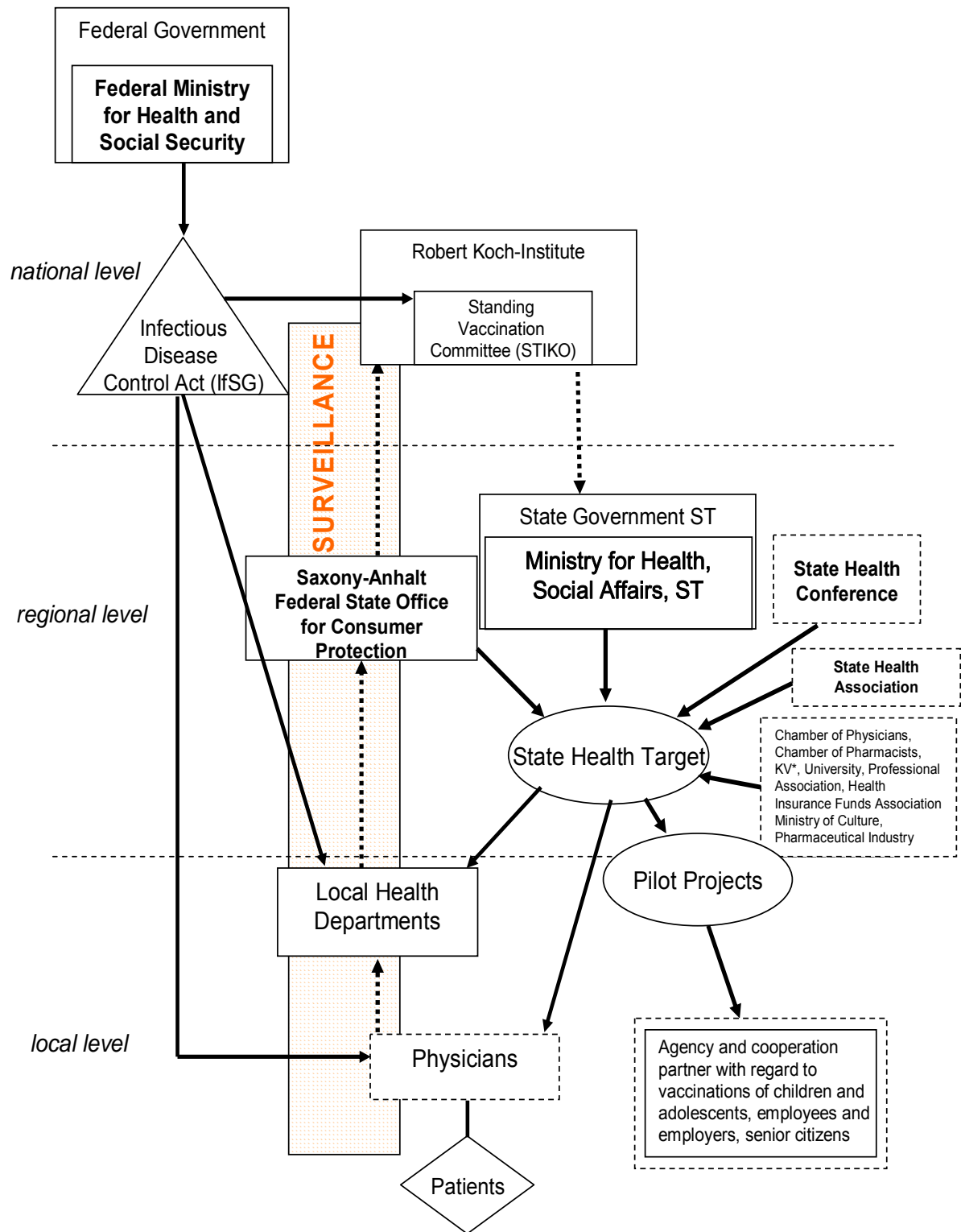
As a result of the obligation to report measles, health departments may keep regional immunisation registries for children.

During the IfSG-required school-entrance examinations carried out by the health departments, immunisation data on standard immunisations such as measles immunisations are collected throughout Saxony-Anhalt. These data are evaluated in an anonymised form and can be used by the municipalities and by the state for specific activities. In addition, they are transmitted to RKI. Health departments also collect immunisation data of third- and sixth-form pupils.

Major immunisation activities/immunisation campaigns

Immunisation campaigns for closing immunisation gaps among children are offered every year with state support by the health departments.

MEASLES, Saxony-Anhalt (ST)



* KV = Association of Statutory Health Insurance Physicians

5.1.6 Greece (Western-Greece)¹⁷

Structure, Organisation and Management of the Measles Immunisation Programme in Western Greece

The official National Immunisation Programme is planned and organised by the National Committee of Immunisation, whose members are chosen by the Minister of Health every three years. The Programme was legislatively founded in March 1991. The committee is responsible for the structure of the programme and ensures that the programme is in line with new medical developments and according to the guidelines from the WHO. The Hellenic Society of Paediatrics, the National School of Public Health and the Medical Schools assist the National Committee of Immunisation in its work. Other governmental (e.g. the Department of Public Health, Division of Disease Epidemiology or the Department of Primary Health Care, Division of Planning of Programmes) and non-governmental organisations (Medicines du Monde, Physicians Without Frontiers, the Red Cross) also plan immunisation programmes, which have to be approved by the Central Health Council before running.

The organisation and implementation of immunisation programmes is for the whole country the same, with similar agencies and organs involved in all regions. On the regional level, the Regional Health Care System (PESY) supervises the prefectural and local Departments of Public Health and ensures that the implementation of the immunisation programme is according to national plans. The prefectural Departments of Public Health are responsible for the implementation of the programme. The social insurance fund IKA, (the largest social insurance fund in Greece), PIKPA (special children's centres where vaccinations are also done), NGOs, Health Centres, paediatricians, physicians, GPs and other medical and para-medical personnel are all involved in the provision of the individual vaccinations.

Vaccination strategy

The two-dose vaccination strategy has been followed in Greece since 1989, with the first dose being given at 15 months of age and the second at 4-6 years of age. In areas with a high measles incidence rate, the first dose can be given at 12 months of age.

Pharmaceutical companies deliver the vaccines to large pharmacies, which in turn deliver them to the normal pharmacies from where insured citizens collect the vaccines and take them to their paediatrician, to the IKA polyclinic, PIPKA, or health centre. The pharmaceutical companies also deliver vaccines to the Ministry of Health and Welfare, which distributes to

¹⁷ Author: Dr Eleni Jelastopulu, Laboratory of Public Health, School of Medicine, University of Patras, Rio Patras.

the different prefectural Departments of Public Health and from there to the health centre and PIPKAs. Gypsies, uninsured citizens, and the very poor get the vaccines free of charge from the health centres and the PIPKAs.

Pharmaceutical companies also make vaccine delivery to large pharmacies belonging to the IKA social insurance company, which then distribute to their regional institutions in the whole country.

There is no invitation or reminder system for vaccination operating in Greece. At the first visit to a paediatrician, parents are informed about all the vaccinations which their children are supposed to get. They are also given vaccination booklets, in which the next vaccination appointment is noted.

Measles vaccination is obligatory according to Greek legislation, and thus parents cannot refuse to have their children vaccinated, e.g. on the grounds that they want their children to acquire natural immunity by getting measles.

The National Immunisation Programme, under which measles immunisation is organised, is financed by the Ministry of Health budget, the social insurance, the EU (especially programmes for minority groups) and NGOs. It is stated by law that all vaccines provided under the National Immunisation Programme be given free of charge to everyone.

Information and education

Normally there are no posters or advertisements calling for parents to take their children for vaccinations. This is only done in conjunction with particular projects or campaigns. Parents are generally informed by paediatricians or by the responsible persons at the IKA institutes or PIPKAs. The department of health promotion and information in the Ministry of Health publishes a brochure with detailed information about the National Immunisation Programme. These brochures can be found at the paediatrician's, health centres and PIPKAs. From time to time information related to the National Immunisation Programme is also given out in the media, e.g. when new guidelines come out or when new vaccinations are incorporated into the programme.

There are plans to establish social-medicine centres, where Gypsies and other minority groups will be informed about vaccinations and where vaccinations will also be carried out. Several organisations are offering training for health professionals involved in immunisation programmes. The Hellenic Centre for Infectious Diseases (KEEL), the National School of Public Health, the Institute for Child Health, professional groups and the medical schools all organise seminars, lectures and congresses for health professionals.

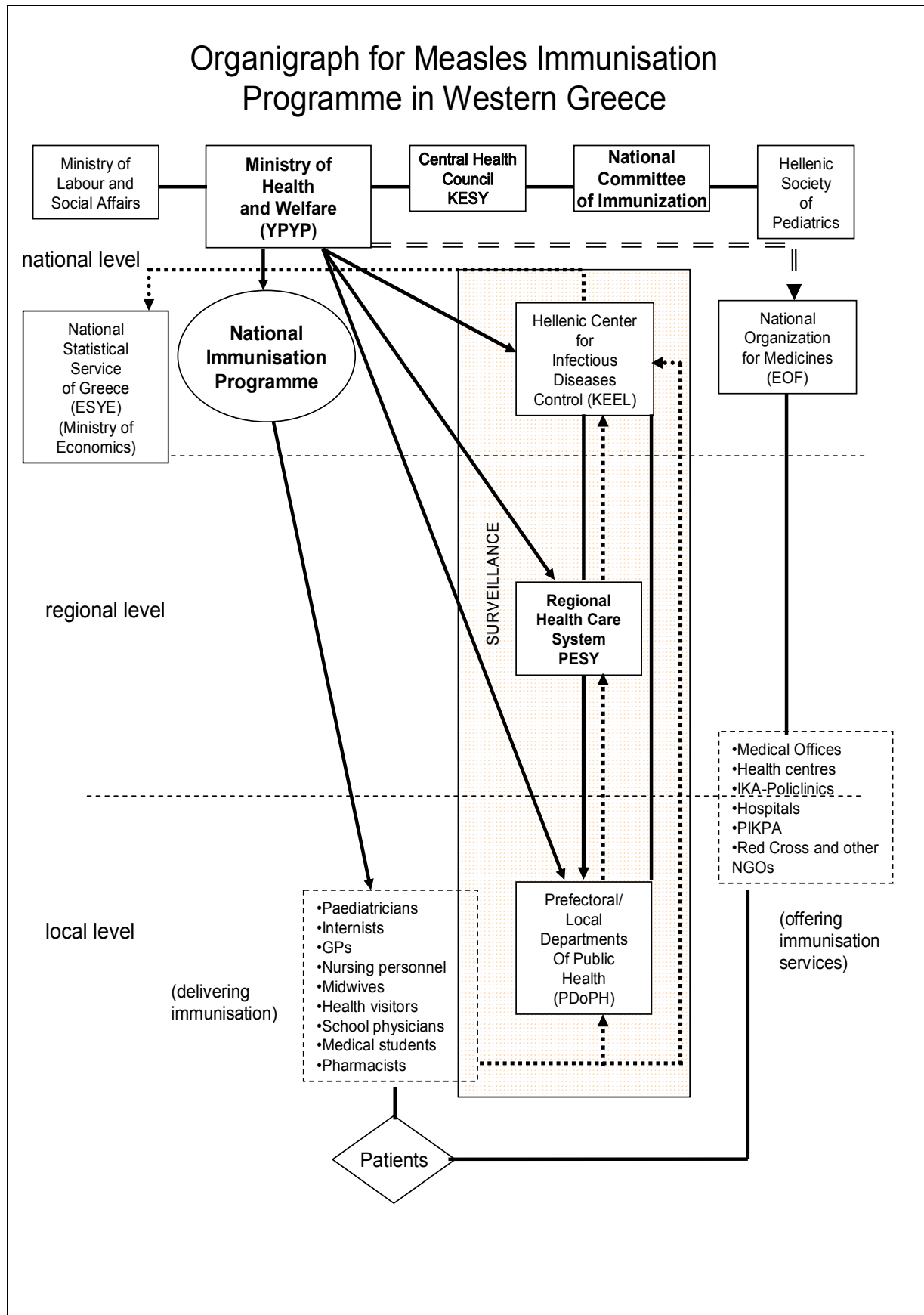
Vaccination documentation/data collection

Vaccination documentation is normally completed by the vaccinating person in the parent-held vaccination booklet. At the IKA and PIPKA vaccination centres, record cards are made for each vaccinated child, and vaccination booklets are also issued. Some paediatricians in private practice also maintain vaccination records, but the majority does not do so. There is also a law stating that health centres should administer vaccination booklets for recording personal details of the vaccinated person, the date and vaccine given, and the next vaccination appointment. Another law, which states that all children should have proof of vaccination (vaccination card) before being admitted to kindergarten or primary school, is also not strictly followed. In addition to that, the majority of minority group children do not go to school and thus their immunisation status cannot be controlled.

Disease surveillance

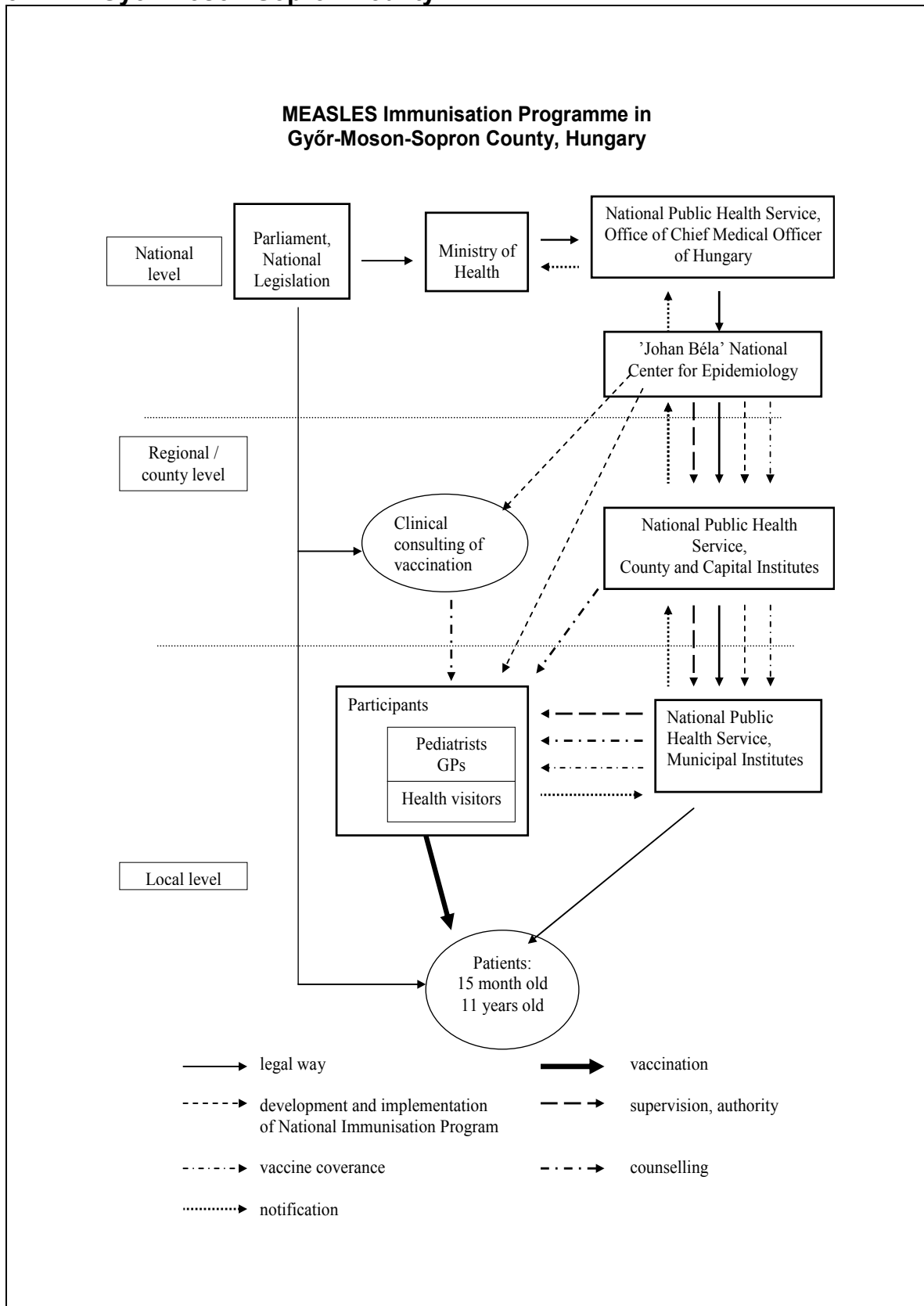
Measles is a notifiable disease in Greece and all paediatricians and physicians country-wide are obliged by law to report each measles case to their respective prefectural Department for Public Health, from where the cases are forwarded to the Hellenic Centre for Infectious Diseases (KEEL). KEEL has developed a detailed form which the doctors can complete and directly report cases. The KEEL, in turn, reports all cases to the Ministry of Health and Welfare's Department of Public Health and to the Minister of Health's office.

Parallel to the registration of the measles cases, serological data from private laboratories is also registered using a special form from KEEL. Hospitalised measles cases directly reported to the Ministry of Health and then to the National Statistical Services of Greece (ESYE). KEEL analyses the collected data using special epidemiological programmes such as EPI-Info. There are also plans to develop new information centres, through which reporting from the physician's practices can be done, as well as establishing a systematic registration method for vaccinations done. The development of a surveillance system for illegal immigrants and refugees is also being planned. ESYE analyses hospitalised measles data according to geographical area, sex, age, treatment success and average stay in hospital. This information is published in monthly bulletins, in the Statistical Yearbook of Greece and the Social Welfare and Health Statistics book. These books are distributed to physicians, paediatricians, lecturers and other interested professionals.



5.1.7 Hungary

5.1.7.1 Győr-Moson-Sopron County¹⁸



¹⁸ Author: Dr Beatrix Oroszi, Public Health and Medical Officer Service, Győr-Moson-Sopron County.

5.1.7.2 Szabolcs-Szatmár-Bereg¹⁹

In Hungary, the Health Act accepted by Parliament regulates – and on the legal basis of this empowerment – the Minister of Health determines the schedule of vaccinations in a regulation.

The Act on Public Health and on the National Public Health and Medical Officers' Service (NPHMOS) gives a special authority to the Service to order vaccinations; to make arrangements needed for the sake of protection; to define the quality, and to procure and store the needed quantity of vaccines.

The detailed task concerning certain vaccinations is declared in the annual Methodological Letter (ML) published by the National Centre for Epidemiology. All Hungarian citizens and in addition any person regardless of his citizenship who has a permission for permanent staying in Hungary, or is a refugee, a hosted, or a petitioner, should be given measles vaccination according to his age. (In Szabolcs-Szatmár-Bereg County the vaccination coverage is 99.88 %).

The first dose of Measles-Mumps-Rubella immunisation is to be given at 15 months of age using trivalent vaccine and viable Polio vaccine in a continuous immunisation framework.

Children should get the second dose at 11 years of age in the course of campaign immunisations. For all children who have missed the obligatory immunisations, it is necessary to make up for it. Paediatricians are liable for checking whether the vaccinations have been made or not at the due age, and make up for the missed shots.

There is an obligation of making up delayed measles vaccination for a person until his 20th year of age.

Vaccination should be given by physicians – unless ML regulates differently – who can be a family doctor; family paediatrician; or in the case of school campaigns vaccination a school doctor. In danger of diseases, people exposed to measles living in the surroundings of a person who is down with measles should be given active immunisation.

We can consider susceptible to measles those children who weren't given active immunisation, or those people who weren't down with measles living without immunisation and with contraindications.

The list of contraindications can be found in the Methodological Letter issued every year by National Centre for Epidemiology. People who are exempt from vaccination should

¹⁹ Author: Dr Marianna Péntes, Szabolcs-Szatmár-Bereg County, Budapest.

be registered both in the vaccination register of the person and in the register of the vaccination circle.

Vaccinations given should be registered as well. Doctors responsible for the vaccination should make a report on continuous, age-dependent compulsory vaccinations monthly and on campaign vaccinations immediately after finishing it to the NPHMOS local institute.

If the vaccination of the child wasn't given by the locally competent family doctor, the data of the vaccination should be reported to the local institute within 24 hours. The total data of the local institutes are sent to the county institute monthly.

The county institutes forward the summed up data of local institutes for the National Centre for Epidemiology annually.

The doctor giving the immunisation should report about side effects, adverse events, accidents due to vaccination to the local institute. They report to the county institute and the county institute immediately reports to the National Centre for Epidemiology.

The county institute should investigate the case and inform the National Centre for Epidemiology Vaccine-Control Department of the results.

Duties of the Citizens:

People bound to be vaccinated are obliged to appear for screening or controlling in the indicated time and place for vaccination or examination if needed.

Their legal representatives are responsible for the appearance of children being under age.

If the person bound to be vaccinated is not able to be present at the indicated time and place of the immunisation for any reason, he – in the case of being under age his legal representative – has to report it immediately to the place pointed out. In this case he will receive a notice of the new date of the vaccination.

If he had been formerly vaccinated somewhere else or he has got a definitive exemption from vaccinations, he is bound to report it and credibly certify it.

Documentation of vaccination should be kept – in the case of being under age by his legal representative – and handed over on occasion of the next immunisation or screening. Lost or damaged documentation can be replaced by the doctor on the basis of the data in the register. Certificates of vaccinations given somewhere else must be obtained by the person or his legal representative.

The children health visitor:

- informs the person to be vaccinated or his legal representative of the aim and importance of the vaccination.
- provides for
 - a register of the people bound to vaccination in her jurisdiction
 - notification of the people bound to vaccination
 - citation for the people missing the vaccination
 - preparing reports of vaccinations
- ensures the storage of the vaccine according to the protocols.
- accounts for the vaccine.

The physician:

- uniquely considers whether the immunisation is practicable or not
- loses no time in reporting side effects, complications due to vaccination
- registers the vaccinations
- supervises the work of the children health visitor.

The tasks of the NPHMOS local institutes relating vaccinations:

- ensures the legal execution of immunisation in its area of competence
- provides the vaccines and auxiliary materials needed for the immunisation
- ensures the distribution of vaccines
- supervises the vaccination registers
- makes reports of immunisation for the county institute
- keeps records of the vaccinations and guarantees their safekeeping for the time fixed in law
- supervises the fulfilment of the vaccinations and keeps checks on the spot
- passes a resolution on the immunisation of the person bound to be vaccinated if he defaults.

NPHMOS county Institute:

- ensures the purchase, storage, distribution and the use of vaccines according to the protocols in its area of competence

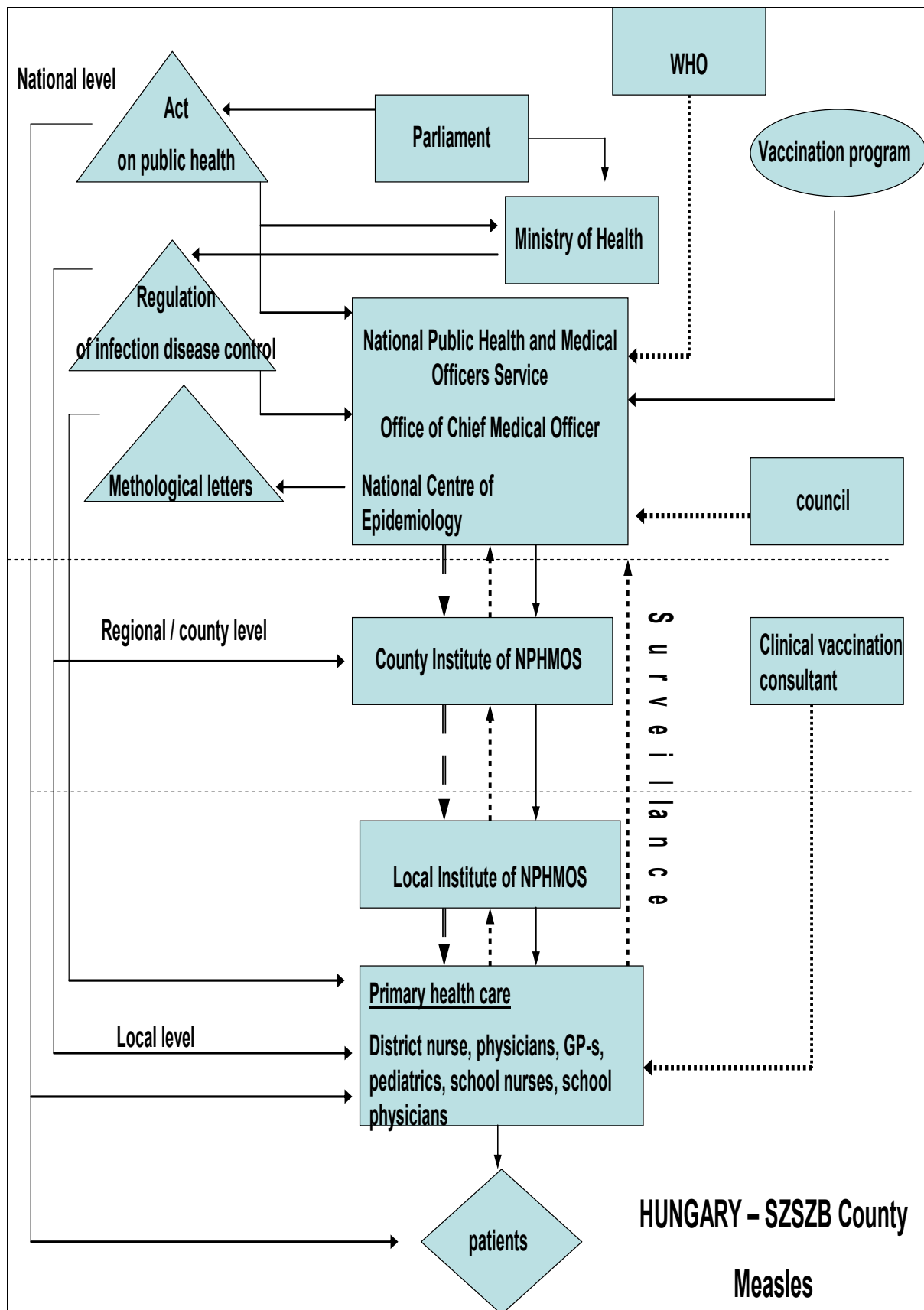
- supervises, analyses, evaluates, summarises and reports the results of immunisation to the National Centre for Epidemiology; takes measures in order to put an end to the detected insufficiencies
- regularly controls the fulfillment of the vaccinations and keeps checks on the spot
- supervises the immunisation work of the local institutes
- checks the activity of immunisation spots
- investigates the cases of side effects and complications due to vaccination.

The National Centre for Epidemiology:

- calculates the required quantity of vaccines for compulsory immunisation on national level; determines the quality and ensures the purchase of them
- publishes the Methodological Letter annually
- analyses the vaccination coverage of the country's population on the basis of the data of county institutes
- controls the vaccination work of the county institutes in its professional supervision activity
- in the case of severe complications or vaccination accidents it investigates on the spot and analyses the vaccine causing side effects or complication in its laboratory.

Office of the Chief Medical Officer

- defines the quality and the quantity of the vaccines in the national health stockpile
- supervises and permits the distribution of the vaccines in the national health stockpile
- in collaboration with the National Centre for Epidemiology it monitors the national immunisation activity; cooperates in the completion of the national vaccine plan and in the preparation of the recommendations for the launching of new vaccinations.



5.1.8 Ireland (Dublin/Mid-Leinster and Dublin/North-East Regions) ²⁰

1. Policy is decided at national government level through the **Department (Ministry) of Health & Children** on the advice of the Immunisation Advisory Committee of the Royal College of Physicians of Ireland (physicians, paediatricians, laboratory and public health specialists). The Irish Medicines Board regulates and advises on vaccines.
2. The **Health Service Executive (HSE)** was legally established with effect from 1st January 2005 as a result of a major structural reform of the Irish health service. It has replaced the Eastern Regional Health Authority and all eleven of the former Health Boards and has also absorbed or taken responsibility for a number of former semi-state health agencies. It has also taken over responsibility for the executive type functions of the Department (Ministry) of Health & Children, which will now concentrate on policy matters. In addition to its policy role, the Department had also been involved in some executive work in relation to immunisation and this will now be the responsibility of the HSE. A number of national directorates have been created, including a **National Hospitals Office**, a **directorate of Primary, Community & Continuing Care (PCCC)** and a **directorate of Population Health**. The detailed sub-structures under the HSE are still evolving.

On its establishment the Chairman of the HSE indicated that “Ireland will have a single, unified health service with devolved and empowered decision making at local level. The regional offices will be responsible for performance management, translating national policies through the local areas and gathering and relaying information on a regional basis. Interaction with local communities and their public representatives will also be a key function. Hospitals and local structures for primary, community and continuing care will report to national directorates. This model of service delivery will bring decision making closer to the patient/client through the Local Health Offices.”

3. Surveillance is conducted by the HSE **Health Protection Surveillance Centre**, (formerly the National Disease Surveillance Centre), which is now part of the Health Service Executive. This Centre also influences policy decisions and acts as an advocate for immunisation through its bulletins and its press releases on disease trends. Infectious Diseases Regulations backed by legislation require mandatory reporting of cases

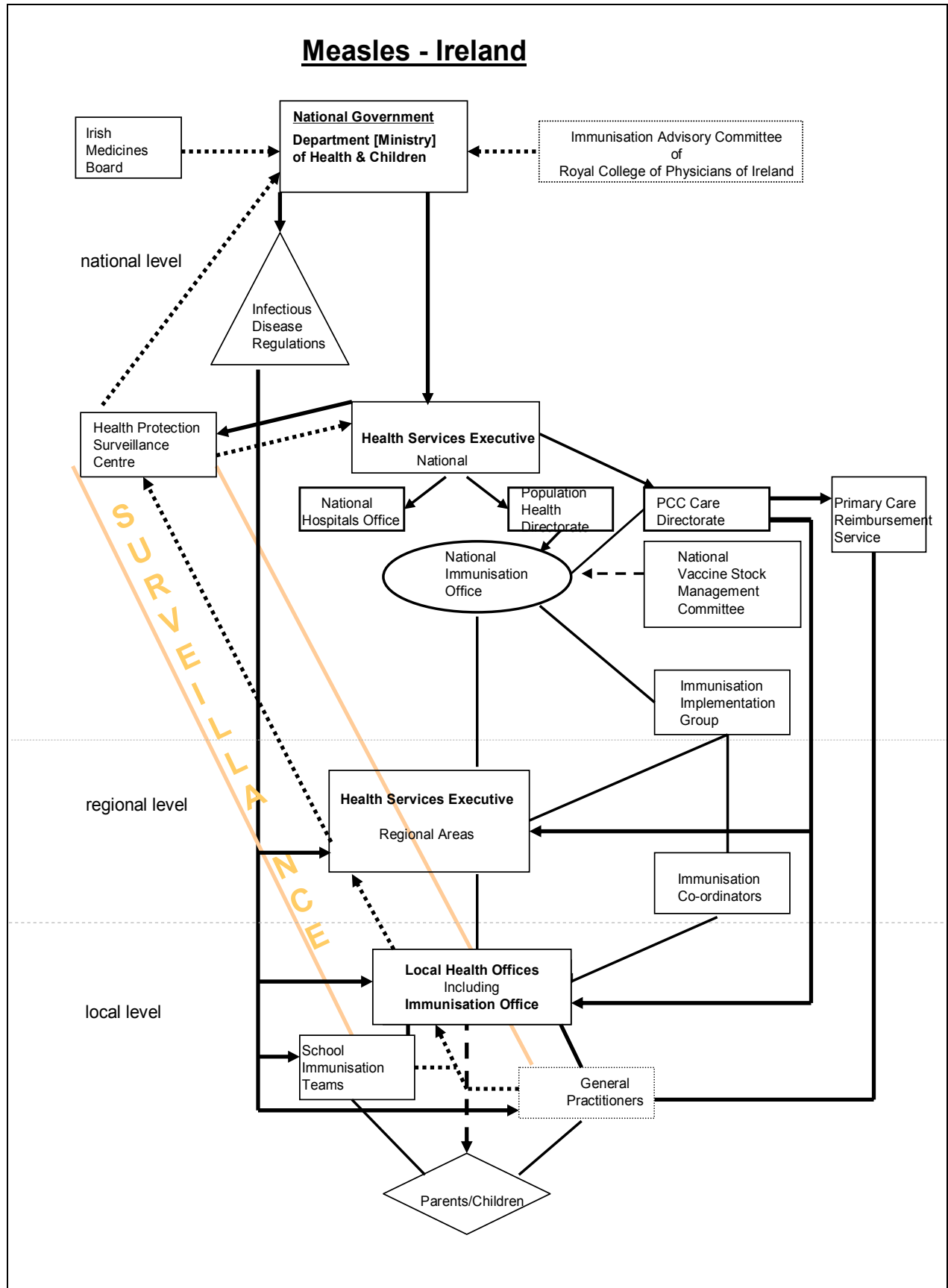
²⁰ Author: Kieran Hickey, Health Service Executive, Dublin.

of measles and this is done mainly by GPs to local public health departments and thence to regional level and to the national surveillance Centre.

4. The HSE has established a **National Immunisation Office** under its Population Health directorate. This office is responsible for production of information for parents and health professionals, vaccine procurement, distribution and supply chain management and IT systems development. It organises an annual national conference on Immunisation, public information campaigns and promotions such as a campaign to promote MMR vaccination during European Immunisation Week. It is developing a training programme for health professionals. It produces and supplies resource material to HSE Local Health Offices. It also organises the bi-monthly meetings of the **Immunisation Implementation Group** whose membership consists of the **Immunisation Co-ordinators** from each of the former Health Board areas. This Group and its members are important links for action through regional and local levels. Each Local Health Office has an Immunisation Office within it with a designated telephone contact number for the public. The National Immunisation Office also plays an important role through the **National Vaccine Stock Management Committee** in organising the procurement and distribution of the MMR vaccine and in ensuring proper monitoring of vaccine quality including storage temperatures.

General Practitioners are independent contractors for the provision of immunisation services. Their contracts were with the former Health Boards and will now be with the HSE. They are now paid for immunisation services through the **HSE Primary Care Reimbursement Service**.

General Practitioners are primarily involved in administering the first dose MMR vaccine to children at age 12-15 months. The second dose of MMR vaccine to children at age 4-5 years is primarily administered by HSE School Immunisation Teams.



5.1.9 Italy

5.1.9.1 Emilia-Romagna²¹

Since 1978 health care in Italy is guaranteed through the National Health Service (SSN) that provides prevention, treatment and rehabilitation services to all citizens and which is financed through tax revenues. The 21 Italian Regions are autonomous for health services organisations and management, even though they follow common rules and guarantee to every citizen equal services in the whole country (basic benefit package). The co-ordination among the Regions is guaranteed by the State/Regions Conference, in a framework of shared decisions.

Primary and hospital care is provided by the National Health Service with a network of Local Health Units that can also refer to private structures for some services. Moreover, every citizen is granted a general practitioner paid per capita; children up to 14 years of age are referred to a paediatrician.

Measles vaccination policy in Italy and Emilia-Romagna

The first indications by the Health Ministry were in 1979 and referred to measles prevention in Italy through active immunisation of children aged 2 or more. Vaccination is free of charge since 1995.

The activities in the Regions took place at different moments and vaccination coverage was then inadequate (even less than 50%) in many areas of the country for many years. In 2003, average coverage reached about 77%, but we also suffered some serious epidemic episodes which pressed towards a national plan for measles (and congenital rubella) elimination, coordinated by the Health Ministry and the National Institute of Health (ISS).

In Emilia-Romagna, measles vaccination is free of charge and the campaign started in the late 80s. In many areas of the region, it covers not only babies aged 13-15 months, but also susceptible children up to 10 years of age. In 1996, to improve and enlarge vaccination coverage, the second vaccine dose was added. The regional coverage rate is one of the highest in Italy (in 2004 it was 93% under 24 months of age) but it still does not reach the 95% value which is considered necessary to avoid the autochthonous disease transmission. Moreover, mass immigration from low-coverage areas underlines the importance of an active monitoring of the susceptible population.

²¹ Author: Dr Luisella Grandori, General Direction for Health and Social Politics, Bologna.

Organisational structure

The National plan for measles and congenital rubella elimination was prepared by the Regions' technical table and was agreed between the Health Ministry and all Regions on November 13, 2003. The coordination of the planned actions is guaranteed by a national group led by the National Institutes of Health and with contact persons at a regional and local level (Health Unit). The National plan includes training activities, information to families, and periodic progress verification of process and result indicators. Goals and activity programmes are agreed with the different professional groups involved (paediatricians, general practitioners, hospital and university doctors). Training at local level is realised through models and didactic aids prepared at national and regional level.

A national campaign for family education was planned by the Regions' technical table in collaboration with public health and paediatric scientific societies. Information materials for families, television commercials, advertisements on the major national newspapers were prepared.

A banner on the website of the Health Ministry gives information on the disease, the vaccine and the proposed vaccination procedures; organisations, institutions, newspapers, scientific societies can copy it on their websites.

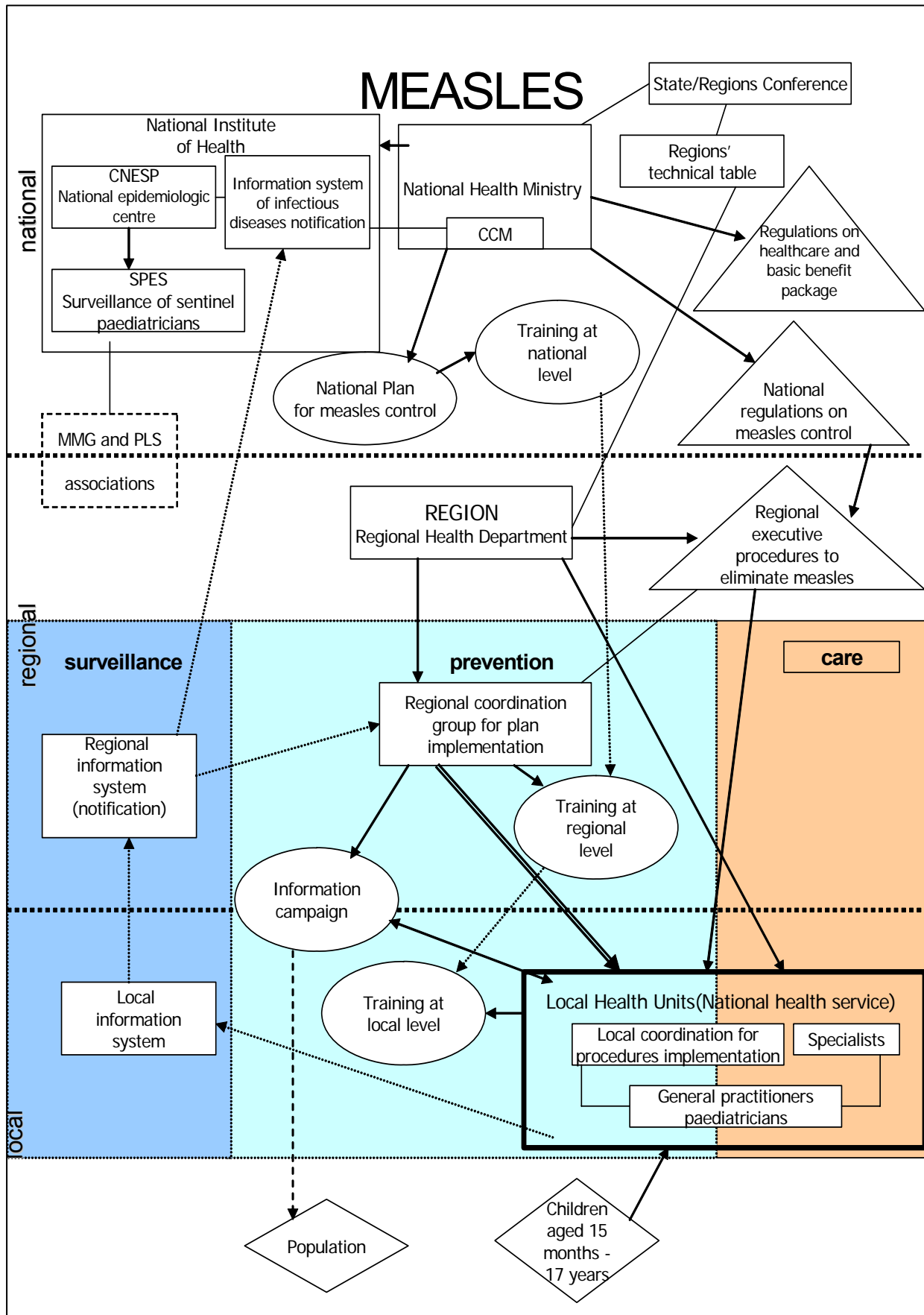
Disease surveillance is conducted in two ways:

1. compulsory notification of cases come from physicians to Public Health Departments of the Local Health Units, which transfer information to the corresponding regional services and, then, from the regional information system to the national one;
2. surveillance system based on sentinel paediatricians, coordinated by ISS.

Vaccination coverage is controlled in two ways:

1. the data collected from the Local Health Units are transmitted to the regional information systems and then to the national one;
2. periodic national sample surveys, coordinated by ISS, are carried out in collaboration with the regional health systems (already done in 1998 and 2003).

The monitoring of planned actions and results is realised through systematic collaboration between local, regional and national levels.



5.1.9.2 Sicily²²

Measles Health Management Programme

- 1) Prevention and strategies programmes are defined and issued at the national level by the Health Ministry through agreements with the scientific associations and the National Federation of Family Paediatricians.

The Prevention Department is in charge of health co-ordination, supervision and intervention and also of the information to citizens and health personnel. With the passing of Law 138, 2004 ("Urgent interventions for confronting public-health hazards"), the *Centro Nazionale per la Prevenzione e il Controllo delle Malattie* (CCM – Italy's National Centre for Disease Prevention and Control) has been established at the Ministry of Health. The main objective of CCM is that of active prevention through both the promotion of healthy life styles and screening and of confronting a variety of health emergencies. CCM has been created as a network of existing institutions and experts: the activities of CCM are coordinated with those of the Regional Health Authorities and with national institutions and organisations (ISS – Italy's National Health Institute; University research centres; Associations involved in healthcare and in public and private research). Following the Agreement of March 23rd, 2005 (State-Regions Conference) Regional Authorities have to bring into action National Prevention Plan objectives, intended to improve the effectiveness and the efficacy of prevention programmes at regional level and to lower National Health Service costs. CCM will coordinate with Regional Health Authorities for surveillance and active prevention programmes. The main areas of concern of the National Prevention Plan, which will last three years, also include: vaccination plan, prevention of complications in diabetes and cancer screening.

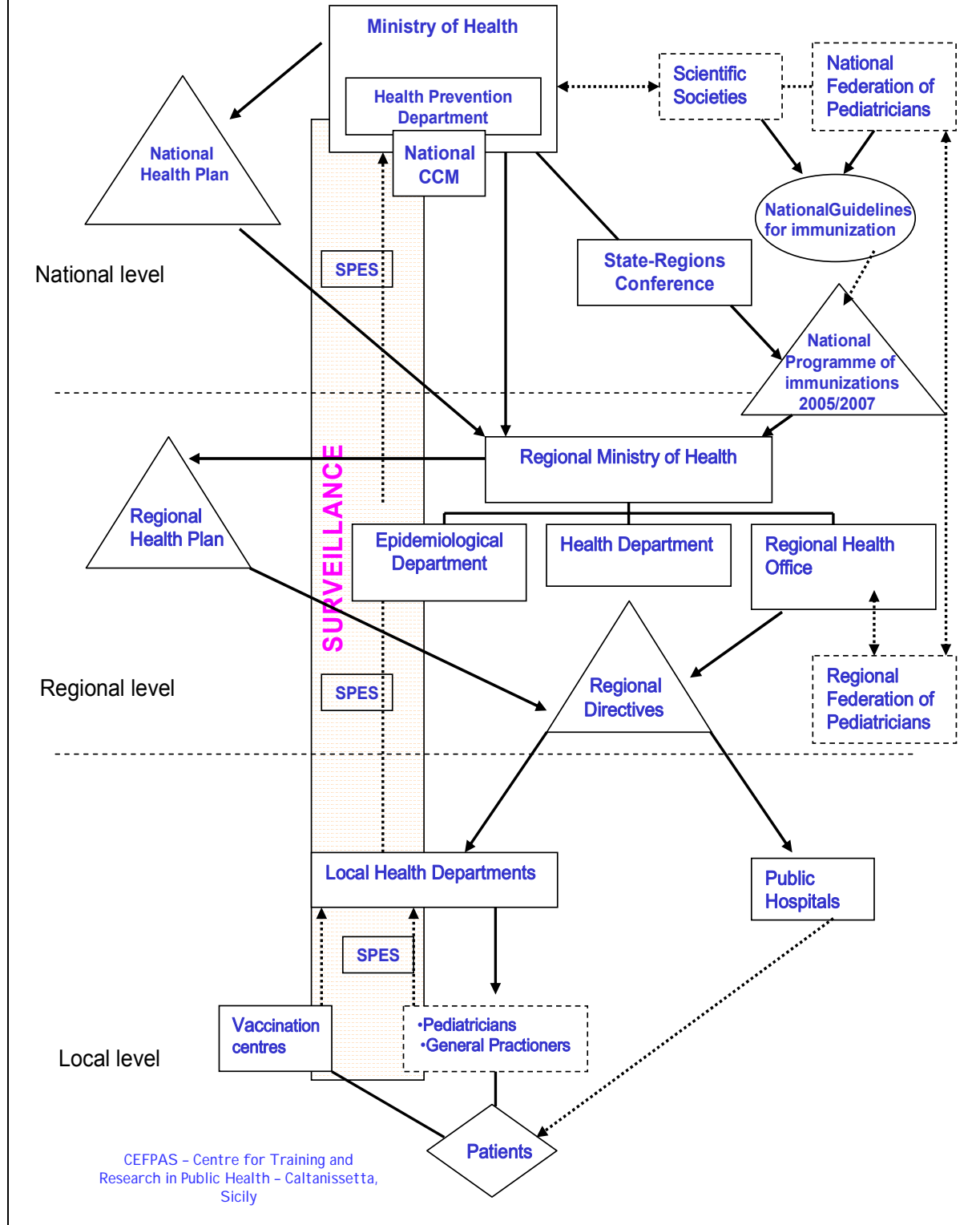
Until now, the Italian situation has been characterised by strong differences among the regions as far as vaccination, disease frequency and sensitivity of surveillance systems are concerned. Vaccination is free and uses a combined Measles, Parotitis and Rubella vaccine (MPR), in all regions.

In 2003, the State-Regions conference established the agreement on the national health plan 2003/2007 for the eradication of measles and of congenital Rubella, by defining the objectives, the vaccination and surveillance strategies and the necessary actions to achieve those objectives.

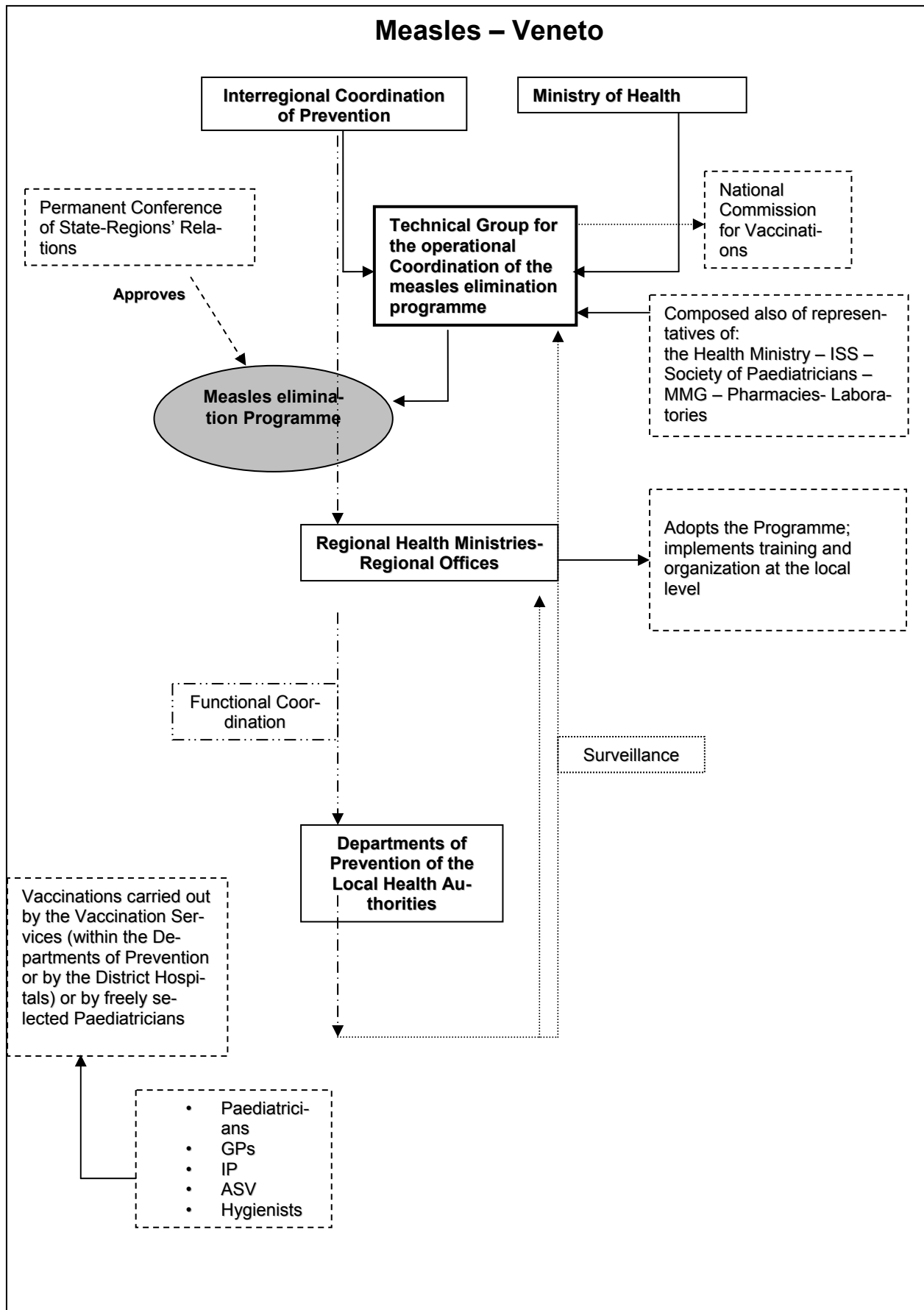
²² Author: Daniela Falconeri and Danilo Greco, Centre for Training and Research in Public Health Caltanissetta (CEFPAS).

- 2) The Sicilian Region has a “Special Statute”. The Sicilian Regional Assembly issues and adopts national laws. The Ministry of Health is a government authority and it is the institutional body that addresses, coordinates and defines the lines of the programme in the field of population health through decrees and Regional laws. In particular, the Regional Health Plan adopts the national directives, and explains the organisational strategies and the objectives to be achieved.
- 3) The Local Health Organisations (LHO) and the Public Hospitals must also guarantee, among the other Essential Levels of Assistance, the recommended and necessary vaccines. Vaccine Services, Family Paediatricians and GPs, promote and administer the vaccine MPR in order to guarantee an adequate coverage of the target population.
- 4) The epidemiological surveillance is carried out directly by Health Personnel (doctors). The vaccine services Data Banks record the newly notified cases of measles and give information about the extension of the vaccination to the population. This information is sent to the Epidemiological Department that delivers them to the Health Prevention department. Since the year 2000 a Paediatricians network (Sentinel Surveillance Paediatricians) at national level has been created with the responsibility for the evaluation of the trend of children’s diseases and the impact of vaccination in the prevention programmes.

Organigraph for Measles – Sicily



5.1.9.3 Veneto ²³



²³ Author: Fabio Perina, Veneto Region – Departement of Health and Social Services, Venice.

5.1.10 Lithuania (Kaunas)²⁴

The main document that regulates the epidemiological control of communicable diseases in Lithuania is the Amendment to the Law of Prevention and Control of Communicable Diseases in Humans. In order to increase human resistance to communicable diseases, the greatest attention is devoted to immunoprophylaxis. Taking into consideration the guidelines of the health policy for the European region “Health XXI” purpose 7 “The Reduction of Communicable Diseases” provided by the WHO, a National programme of immunoprophylaxis is being implemented in the country as approved for the year 1998 to 2005. The first programme of this kind was launched in Lithuania in 1992. The purpose of the National programme of immunoprophylaxis is to decrease the rate of morbidity, mortality and disability caused by tuberculosis, diphtheria, tetanus, Haemophilus influenza-B-type infection, hepatitis B, whooping cough, measles, rubella, mumps and poliomyelitis. The main purpose of this programme is to vaccinate the greatest possible number of children at the earliest possible time, i.e. to create a high level collective immunity among children. Currently, the WHO is implementing the strategic plan of Measles and Congenital Rubella Syndrome for the European Region with the aim to stop the spreading of the local type of measles virus and warn against the disease with Congenital Rubella Syndrome (<1 Congenital Rubella Cases for 100.000 live newborns). Such is also the plan of epidemiological surveillance and vaccination for year 2003 through 2007 approved for Lithuania. The main principles of the plan for measles liquidation initiative prepared by the WHO for the European Region are: a great range of vaccination with the first dose of measles vaccine, whereas the second dose of vaccine should be given to children before they start school. Children get their first dose of (MMR) combined vaccine against measles, mumps, and rubella in Lithuania when they are 15-16,5 months old, whereas, as of year 2002 in Lithuania, the second dose of (MMR) vaccine is already given to children at the age of 6 or 7. The plan of epidemiological control and vaccination of measles and congenital rubella for Lithuania includes the following: organisation and implementation of additional vaccination campaigns against measles and rubella; strengthening of the system of the epidemiological surveillance of these diseases by carrying out the exhaustive epidemiological examination of each case of measles and the laboratory confirmation of the diagnosis.

- Vaccination against measles, according to the calendar of children’s prophylactic vaccination of the Republic of Lithuania, is financed by the Government. The expenses involved by vaccination against the diseases are not included in the list approved by the Ministry of

²⁴ Author: Orina Ivanauskiene, Kaunas Public Health Center, Kaunas.

Health, and vaccination of persons leaving for foreign countries where immunoprophylaxis of the incoming persons is obligatory, are not covered by the Government. The immunoprophylaxis expenses of adults are covered by the Government, municipalities, employers and/or by the inhabitants themselves. These expenses can be compensated according to the Law of Health Insurance, as well as according to the order stipulated by the Ministry of Health, and the epidemiological situation.

- Vaccination cannot be carried out by individuals themselves. Prophylactic vaccination is carried out by state and private health care institutions in their vaccination rooms, or by medical staff invited by the administration of an institution at their workplace. Children, in agreement with the calendar of prophylactic vaccination of children of the Republic of Lithuania, are vaccinated in their chosen primary health care institutions. Only those juridical and physical persons who have obtained a license for the practice of primary and public health care activity stipulated by the Ministry of Health can be privately involved in immunoprophylaxis. Vaccination is allowed among community nurses when they have a state approved certification that confirms their completion of the course of vaccination fundamentals, when the physician of the area is present. Facts about vaccination are recorded in the personal illness history of a person, as well as in the journal and the passport of vaccination, or the data are entered into a computer data-base, if such is available. Vaccines are prohibited to be sold at pharmacies. Free trade of vaccines would violate the principle of “the cold chain” as only enterprises involved in drug trading have permission to supply the immunological preparations to those primary and public health care institutions that have licenses for performing immunoprophylaxis.

The National Level

- **The Government** approves the mandatory state programmes while carrying out the management of prophylaxis and control of communicable diseases; it also establishes institutions of management that implement the strategy of prophylaxis and control of communicable diseases.
- **The Ministry of Health** implements a state strategy based on the competence it has while carrying out the management of prophylaxis and control of communicable diseases; prepares state mandatory and target programmes of control and prophylaxis of communicable diseases, as well as controls their implementation; it also issues statements that stipulate the order of prophylaxis and control of communicable diseases.

- **The State Public Health Surveillance Service with the Ministry of Health** controls public health centers in counties, in respect as to how they perform their coordinating activities in territories while carrying out the epidemiological surveillance of communicable diseases.
- **The Center of Communicable Disease Prevention and Control** (at the State Public Health Surveillance Service with the Ministry of Health) is a central institution that coordinates all the activities connected with immunoprophylaxis in the country: designs strategies of immunoprophylaxis and sets up projects of national programmes for prophylactic vaccination; organises their implementation; cooperates with the WHO and corresponding European institutions on the issues related to the launch of immunoprophylactic programmes and their implementation; organises the centralised procurement and distribution (and delivery) of vaccines necessary for the national programme, as the vaccines financed by the Government (including MMR) are supplied to primary health care institutions after they have placed an order with them; consults persons who carry out prophylactic vaccination on technical skills of performing the vaccination as such, as well as on medical contra-indications, on issues of applying protective vaccination methods, and provides information to society; estimates and analyses the quality of the performed immunoprophylaxis; organises the scientific research of estimation of the immune feedback of population to the registered immunological medications; coordinates, analyses and, in the event of necessity, adjusts vaccination according to: the effectiveness of immunoprophylaxis; side effects to injections and complications; contraindications of prophylactic vaccination.
- **Vilnius University Faculty of Medicine Children's Clinic Centre of Paediatrics (Vilnius University Children's Hospital)** organises the courses of professional advancement in the field of immunoprophylaxis; consults on issues of performing vaccination; vaccinates children with relative contra-indications to vaccination; cures some more problematic contra-indications after the vaccination.
- **The Training Center of Nurses** organises courses for social nurses in the field of immunoprophylaxis.
- **The laboratory of the Lithuanian AIDS Center** is one of the most modern serology laboratories in Lithuania. A variety of tests on HIV/STI, opportunistic infections, virus infections, etc. (tests on measles too) are available.

The County Level

- **The County Governor's Administration** organises the drafting and implementation of mandatory state and special purpose programmes of prophylaxis and control of communicable diseases; organises the drafting and implementation of special purpose programmes of prophylaxis and control of communicable diseases; analyzes, how the mayors of municipalities implement the prophylaxis and control of communicable disease, within the scope of their competence.
- The immunoprophylaxis within the territory of the Republic of Lithuania at the state, municipalities, and private health care institutions is coordinated by **Public Health Centers** within counties. These institutions in the counties, and their branches in the districts too (at the local level) are responsible for the activities listed below:
 - estimation of the effectiveness of immunoprophylaxis and the range of prophylactic vaccination within administrative units of a territory, i.e. the number of vaccinated children since the date of a registered outbreak of a disease in a certain age group;
 - control (not less frequent than twice a year) of transportation and storage of immunological preparations, and of the regime of decontamination of vaccines;
 - organisation of estimation of human immune system by applying serological methods and prophylactic vaccination according to epidemiological indications (together with primary health care institutions);
 - filling out statistical and analytical forms about morbidity (which is affected by immunoprophylaxis) according to the data of epidemiological research presented by primary and public health centers, and presentation of the forms to the Center of Communicable Disease Prevention and Control in the due order;
 - evaluation of the statistical reports on prophylactic vaccination submitted by primary health care centers, summarisation of them on the county's or territory's behalf and presentation to the Center of Communicable Disease Prevention and Control.

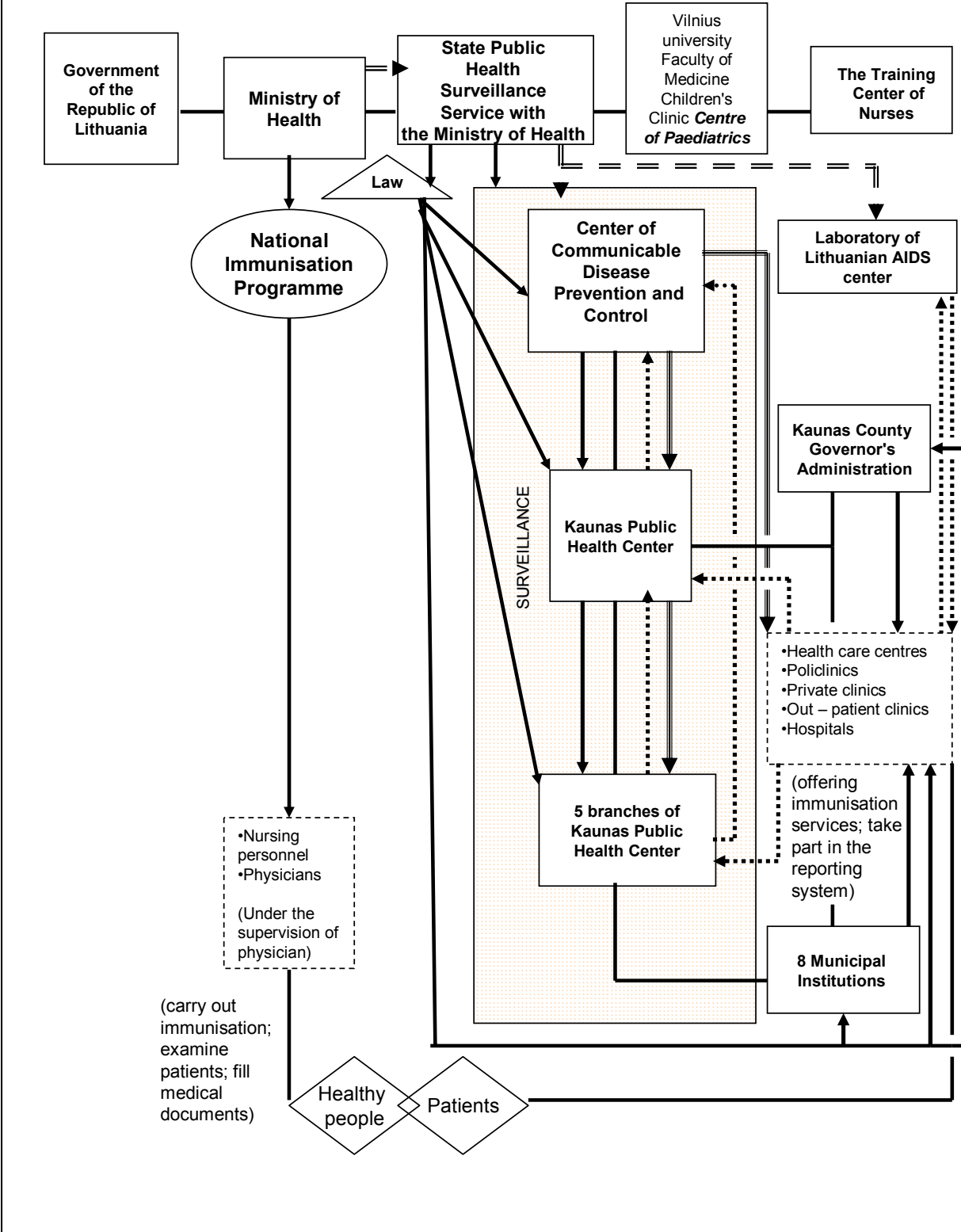
The Local Level

- **Municipal Institutions.** The Council of the municipality hears the municipality mayor's annual accounting on the course and results of implementation of the organisational measures plan of the prophylaxis and control of communicable diseases; approves the special purpose programmes of municipalities regarding prophylaxis and

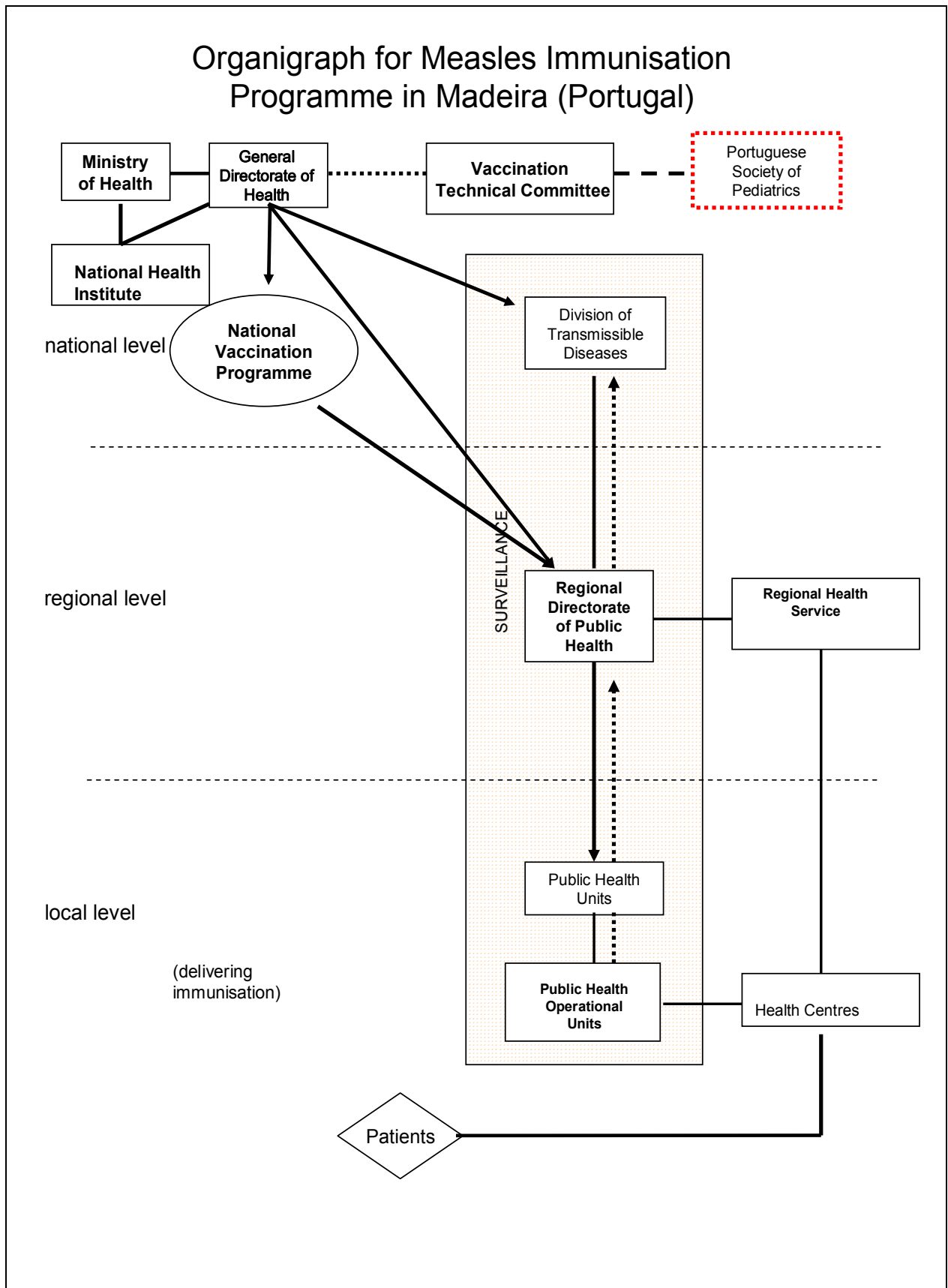
control of communicable diseases; following coordination with the chief of a public healthcare institution, approves the regulations of the sanitary control of the municipality; upon coordination with the Ministry of Health, approves when necessary in its own area more stringent requirements of prophylaxis of communicable diseases, than those according to the hygienic norms.

- Every state or private health care institution, by the order of the head, appoints qualified professionals and/or forms divisions that organise and coordinate all provisions connected with the immunoprophylaxis in children and adults with the aim to ensure “the cold chain” of transportation and storage of immunological medication, and to supply the necessary means of anti-shock, disinfection and vaccination. The responsibility of those professionals is also to arrange and ensure accountability of vaccination by installing a computer programme; they confirm vaccination plans; they foresee the need for immunological medications, single-use syringes and vaccination passports, and, in agreement with the established order, submit requests for the above-mentioned means to the centre of prophylaxis and control of communicable diseases; they ensure the timely presentation of reports on prophylactic statistical vaccination and its range; they control the registration of cases of the side effects of vaccination; they fill out the reports and present the information according to the order established by the Ministry of Health.

Organigraph of Measles in Kaunas / Lithuania



5.1.11 Portugal (Madeira)²⁵



²⁵ Author: Ana Clara Silva, Direcção Regional de Planamento e Saúde Pública, Funchal.

5.1.12 Russian Federation (Chuvash Republic)²⁶

The Ministry of Health and Social Development of the Russian Federation is the state executive body at the national level, the Ministry of Health of the Chuvash Republic at the regional level, and the Municipal Department of Health at the municipal level, involved in developing the state policy on measles prevention and regulation of related laws.

Epidemiological Control and Surveillance (related to measles as well) at the national level is provided by the Federal Service of consumer rights protection and well-being. At the regional and municipal level the above-mentioned responsibilities are provided by the territorial departments and municipal units of the Federal Service of consumer rights protection and well-being.

The Federal Service of consumer rights protection and well-being operates through the Federal Health facilities, namely Centers of Hygiene and Epidemiology (in the Chuvash Republic – Center of Hygiene and Epidemiology of the Chuvash Republic). The terms of reference (TOR) for the Centers is to provide reporting and registration, working with the federal data base of social-epidemiological monitoring, organisation of SanEpid expert examination and related SanEpid activities, including disinfection.

At the national level, the Federal Service of consumer rights protection and well-being works in cooperation with the Moscow Scientific Research Institute of epidemiology and microbiology named after Gabrichevsky which helps to organise methodology and scientific support in measles control. It also monitors the morbidity level, inoculation rates for measles, does epidemiological surveillance on measles, typing and study of measles strains, provides creation and support of collection of strains of measles virus and organisational work on prevention of measles. In order to fulfill this task, the interregional centers were organised in the territory. The Chuvash Republic works in partnership with the Nizny Novgorod regional measles control center.

The system of record of measles cases and rates of vaccination has several levels. Each case of measles is subject to the record at the site, having the note sent urgently to the territorial unit of the Territorial department of the Federal Service of consumer rights protection and well-being. The Federal Service creates an overview report on the region (Chuvash Republic). Monthly and in the end of year it reports to the Nizny Novgorod regional measles control center and The Federal Service of consumer rights protection and well-being.

²⁶ Author: Vera Barieva, Medical Information Analysis Center, Cheboksary.

Vaccination against measles is done with regard to the National calendar of prevention inoculations and is provided at the primary care facilities. At the facilities there is an office and a designated professional providing registration, filling out forms and developing annual plans for vaccination. Vaccination is done by the authorised medical staff, having had special training in the field. Quarterly and in the end of year the report on vaccination is submitted to the territorial unit of the Territorial department of The Federal Service of consumer rights protection and well-being and then by municipalities to the Territorial department central office. This office in turn submits the overall republican report to the Nizny Novgorod regional measles control center.

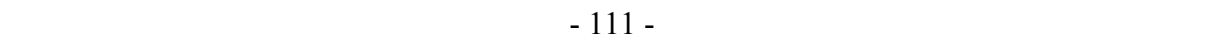
The work on measles prevention is organised with regard to the **Federal laws** “SanEpid well-being of the population”, “Immunologic prevention of infectious diseases”.

The main guidelines and activities on eradication of measles and reduction of morbidity are defined in the special **Programmes**, namely the Federal targeted programme “Vaccine-based Prevention”, the programme of elimination of measles in the Russian Federation by 2010, the National plan of actions in implementation of the measles elimination programme in the Russian Federation. At the regional and municipal level special programmes were developed adapted for the local specifics.

The state **system of security control** of immune biological drugs including the vaccine against measles includes certification process and further control of quality in relation with the Federal laws “Certification of products and services”, “About drugs”, the Ruling of the Cabinet of the Russian Federation “On the state control of the medical immune biological drugs”.

The National body of the medical immune biological drugs control and the central body of certification of the medical immune biological drugs at the same time is the State Scientific Research Institute of standardisation and biological drugs control named after Tarasevich. It provides surveillance for all organisations and industries which have to do with the production and supply of the medical immune biological drugs.

In health care facilities the state control of quality of the drugs to be used is organised by the Territorial Department of the Federal Service of consumer rights protection and well-being.



5.1.13 Sweden (Västra Götaland) ²⁷

Measles is a very rare disease in Västra Götalandsregionen. In 2000, 1 case was diagnosed, in 2002 2 cases were diagnosed and no cases in 2001, 2003 or 2004. This is due to an efficient immunisation programme that traditionally has had a very high coverage rate with 95-98% of children in the programme. However, since the late 90ies, the coverage rate has declined in a number of geographical pockets, leading to an efficient coverage rate around 90-95% in these areas, in some cases even lower.

Local level

Primary Health Care organisation organises the Child Health Care and Maternal Health Care at the local level. There is a direct collaboration between Child Health Care centres, Maternal Health Care centres and Health care centres and Hospitals at the regional level via Child Clinics and Obstetric Clinics. The local level has the main responsibility to maintain and deliver vaccination programmes according to a specific schedule, where vaccination against measles is one of the immunisations offered.

Regional level

The immunisation programme is running as collaboration between local acteurs within Primary Health Care organisation and hospital clinics. The surveillance part of the organisation is run by the Regional Unit for Infectious Diseases Prevention and Control. This unit is working with prevention and reducing risks for the spreading of contagious diseases, through tracking transmitters, information, educational initiatives and research. The unit has the regional responsibility to implement and maintain measures as defined in the Act of Health Care and Act on Disease Control.

National level

The National Board of Health and Social Welfare has the overall national responsibility that the population has an efficient protection against contagious diseases. The Board organises and coordinates the work against contagious diseases run by different authorities and administrations. The Board also organises and coordinates initiatives against large scale outbreaks larger parts of the country. It is normative for the regions and county councils, through its

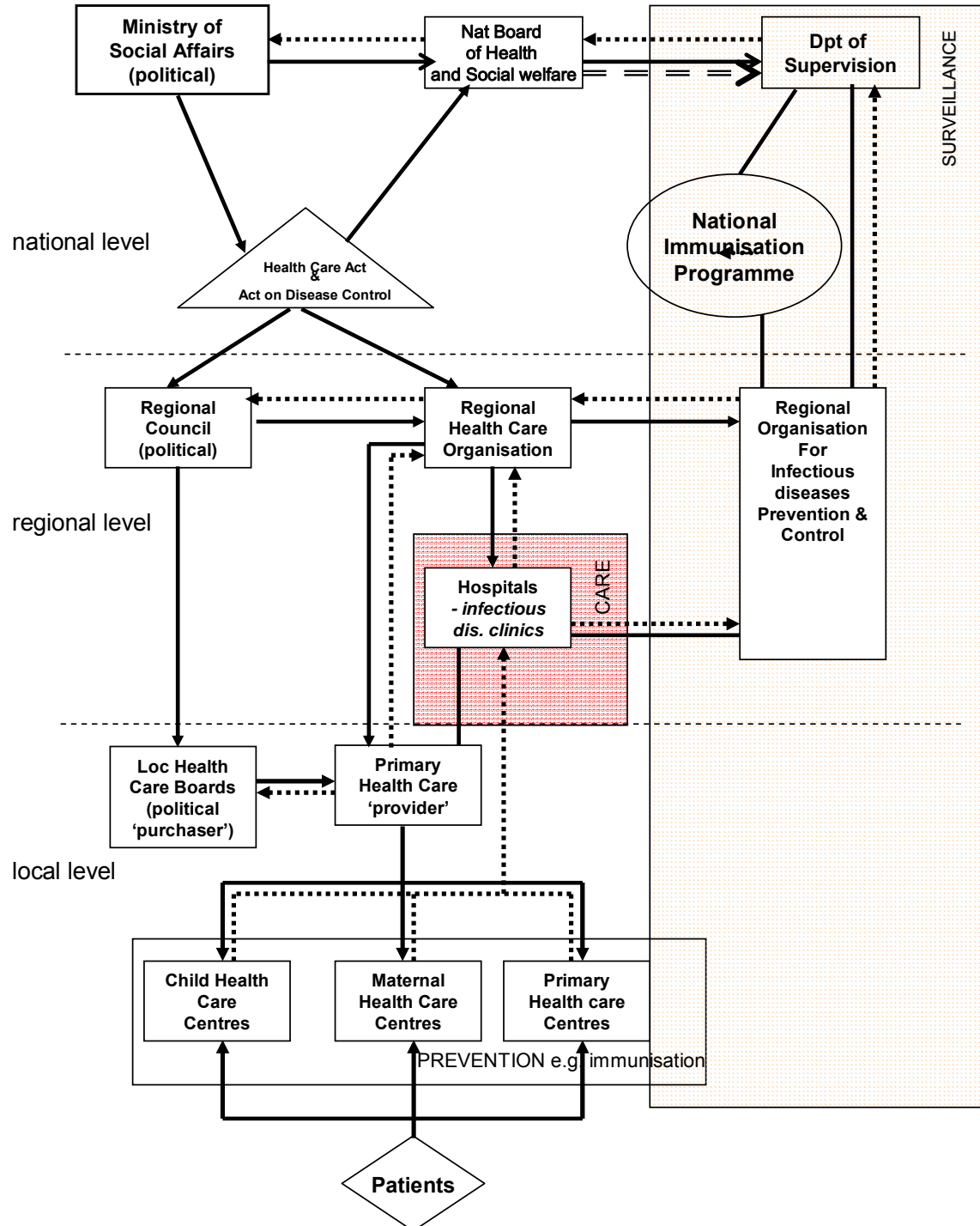
²⁷ Author: Dr Göran Henriksson, Folkhälsokommitténs kansli Västra Götalandsregionen, Mariestad.

regulations and guiding principles of how to interpret and apply the legislation for the health care sector.

Resources

As with all resource allocation to health care this is a matter of negotiation between the ‘purchaser’ and ‘provider’. However, the Act on Health Care and Act on Disease protection and control restrict the purchaser’s and the provider’s possibilities to organise measles management in other ways than is prescribed from the national level.

Organigraph for Measles Management in Västra Götalandsregionen



5.1.14 Switzerland (Ticino)²⁸

Surveillance

The control of transmissible diseases lies primarily within federal competence (national), through the Federal Law on Epidemics. The application of the Federal Law on Epidemics regarding the control of transmissible diseases lies primarily within the competence of the Swiss Federal Office of Public Health, which depends on the Federal Department of Home Affairs.

In conformance with the Federal Law on Epidemics the Swiss Federal Office of Public Health, together with the Cantons, has to take the measures required to fight transmissible diseases caused by agents which are pathogenic for man. In the Ordinance concerning the declaration of physicians and laboratories the observations which are subject to declaration are specified, as well as the criteria and times of declaration; when supplementary declarations are necessary this is also specified.

As far as measles is concerned, it is subject to compulsory declaration on the part of physicians and laboratories. Physicians declare in the case of a clinical suspect case defined by the triad: 1. fever; 2. maculopapular rash; 3. cough, rhinitis or conjunctivitis.

Laboratories declare every time analyses enable them to show up the measles virus (cultures, genome, serology, etc.). The declarations are to be made to the Cantonal Office of Public Health and to the Swiss Federal Office of Public Health. The declarations of measles must be made within a week of diagnosis. Furthermore, for every measles case physicians will receive a supplementary form to be filled in by the Cantonal Officer of Public Health.

On the basis of the regional or national epidemiological situation of measles (e.g. in case of an epidemic outbreak) the Swiss Federal Office of Public Health as well as the Cantonal Office of Public Health can undertake the actions deemed necessary on the basis of the Federal Health Law (e.g. targeted information campaigns, vaccinations of the contacts of the measles patients).

Vaccination

The vaccination against measles is part of the National Immunisation Programme; the latter is worked out by the Federal Committee for Vaccinations in collaboration with the Swiss Federal Office of Public Health and with Swissmedic (Swiss Agency for therapeutic products).

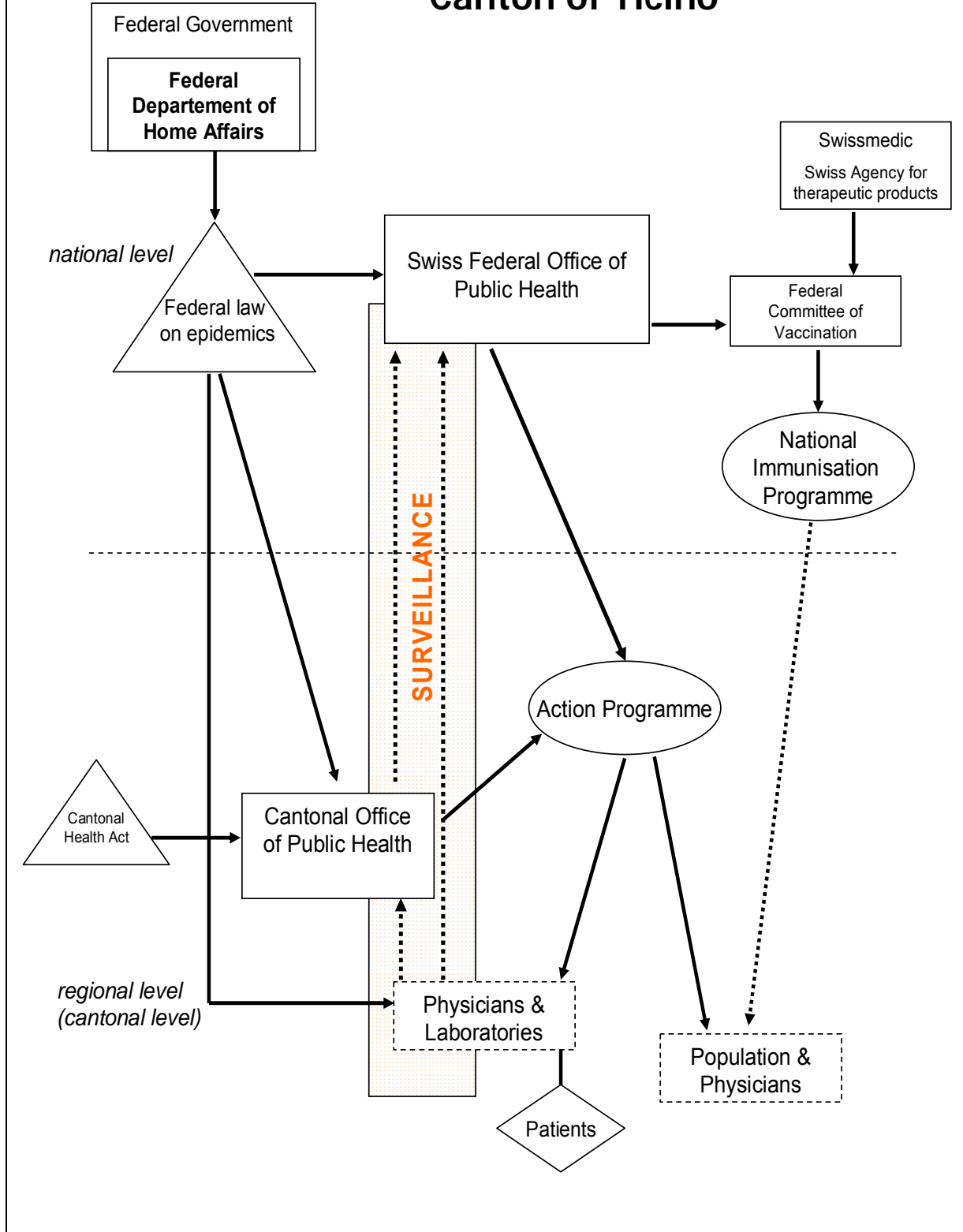
²⁸ Author: Dr Andrea Bordoni, Istituto cantonale di Patologia, Locarno.

The immunisation programme is regularly updated following the development of new vaccines, the evolution of knowledge regarding the effectiveness and safety of vaccines, the changes in the epidemiological situation in Switzerland and the international recommendations within the ambit of the WHO.

The vaccinations are not compulsory in Switzerland, although recommended (N.B. however, on the basis of cantonal laws, some Cantons can request that certain vaccinations be compulsory; in Ticino no vaccination is compulsory).

Regarding measles vaccination, in particular two doses are recommended. At the age of 12 months and between 15 and 24 months; a vaccination “catch-up” (a total of two doses with at least a one-month interval) is recommended for each person under 30 who has not been vaccinated; people between 30 and 40 years of age require one dose only. For people over 40, probably already immune, a vaccination is no longer necessary.

Measles & Immunisation Programme in Switzerland, Canton of Ticino



5.1.15 United Kingdom (England)²⁹

1. National level measles vaccination policy decisions are made by the **Department of Health (DoH)** and informed by the **Joint Committee on Vaccination and Immunisation (JCVI)**, the **Health Protection Agency (HPA)** and laws such as **The Public Health Act 1984**.
2. The **JCVI** was established in 1963 as an independent advisory body ‘to advise the Secretary of State for Health on matters relating to communicable diseases, preventable and potentially preventable through immunisation. The JCVI review current policy and advise on future vaccination policy and immunisation schedules. The information used for decision making by the JCVI comes largely from the **Health Protection Agency (HPA)** and the Medicines and Healthcare products Regulatory Agency (MHRA).
3. The **Department of Health** sets out immunisation policy for England in the document ‘Immunisation Against Infectious Diseases’, or otherwise known as the ‘**Green Book**’. The ‘Green book’ provides information regarding immunisation against infectious diseases. The current edition was published in 1996 and has been updated to reflect developments over the past 9 years. The Green book includes statistical information relating to the incidence of disease, and the current vaccination schedules.
4. **Immunisation Co-ordinators** operate at a regional/local level (covering roughly 2 **Primary Care Trusts (PCT)** areas or around 500.000 people) are employed as part of **Health Protection Units (HPU)** and are responsible for co-ordinating immunisation policy for those PCTs.
5. **Primary Care Trusts (PCTs)** employ the primary care staff – **GPs, practice nurses, health visitors, school nurses** – with direct public contact and who promote and ensure vaccination uptake in the general population. PCT’s are responsible to their host **Strategic Health Authorities** who in turn are responsible to the DoH.

²⁹ Author: Paul O’Connell and Angela Iverson, University of Brighton.

6. The DoH contracts **private firms** to **manufacture** and **distribute** MMR vaccinations **directly** to administering GPs. The MMR vaccines used in the UK since 1988 were manufactured by GlaxoSmithKline (GSK), Merck and Aventis Pasteur MSD.
7. Records concerning vaccinated children are held by local **Child Health Record Units** who provide this information to the **Health Protection Agency (HPA)**. The HPA is an independent body established to protect the health of the population of England. This includes monitoring and preventing infectious diseases, these roles are carried out by the Agency's Centre for Infections. The HPA provides information to the JCVI that supports decision making regarding national policy.

5.1.16 Discussion³⁰

Mintzberg and Van der Heyden (2000) introduced the organigraph as a new approach to charting how organisations work. They considered that in a time of new and often complex organisation forms, the traditional organisation chart depicting traditional management hierarchies in a vertical chain of command does not necessarily give an adequate illustration of the way an organisation operates, what parts connect to one another, how processes and people come together, what information has to flow where.

An organigraph is intended to map processes in order to understand critical interactions, what relationships exist, how information spreads through the organisation and so demonstrate how the organisation works.

Four components were assigned to the organigraph:

a set: organisations can be seen as a set of items such as people and machines that form a collection, group or portfolio, often barely related to each other but sharing common resources – facilities, funds, overall management. A professional service firm for example operates as a set with a group of professionals each working almost exclusively with their own clients.

a chain: consists of items/groups that connect in an orderly operation, a progression like an assembly line. *Chains* are linear, they promote standardisation, they systematize an operation and can be controlled. *Chains* can show a connection between different events which when combined, create a business process.

a hub: is a co-ordinating centre for process activities where people, things or information come together. A *hub* acts as a central checkpoint and depicts movement to and from one focal point. A *hub* can be a person, such as a manager or a football coach, a building or a machine such as a computer. A core competence in an organisation could be regarded as a *hub*.

In a health service context a hub could also be a nurse co-ordinator for patient care rather than a doctor or hospital administrator.

a web: numerous hubs connected in a network can represent a *web*, which can also be regarded as different “nodes” - people, teams, computers or whatever else – that communicate together without going through a central co-ordinator. Any complex project or set of activities can be seen as a *web*. A *web* can characterise a range of activities, more often than not,

³⁰ Author: Kieran Hickey, Health Service Executive, Dublin.

creative, innovative or developmental in nature, where various people talk to and collaborate with each other in either informal or team settings. Open – ended communication and collaboration are features that energise a network.

The more complex the organization the more complex the organigraph will be. Organigraphs illustrate relationships and processes. An organization is not restricted to one type of organigraph. There is no single correct organigraph. Instead there can be many types of organigraph.

The authors of the organigraph considered that: managers of a *set*, allocate; managers of a *chain*, control; managers of a *hub*, co-ordinate; managers of a *web* link it all and energise. They also drew a distinction between the set and the chain, which they considered to be two rather conventional components not unlike the traditional “boxes” in an organisation chart, and the hub and the web, towards which there is a growing propensity in organizations of today. Organigraphs do not eliminate “boxes” altogether but do introduce new components which the authors called *hubs* and *webs*.

Organigraphs in Ben II RHM

As already indicated, the purpose of the Ben II RHM project in seeking organigraphs was to provide overviews of the organisation of the regional health management systems and programmes for the tracers of breast cancer, diabetes (type II) and measles. The aim was to depict the relationships of the different decision-making bodies to each other as well as the flow of actions within the health management process. This is essential because it is not only the outcome of regional health management that is important but also an understanding of how it is organised. As we have seen from Mintzberg and Van der Heyden, organigraphs are not just diagrams but maps, and serve to describe the interaction between people and information flow. For an optimal comparability of all organigraphs, we asked all project members to use “basic forms for the organigraphs” and “different kinds of arrows for different functional connections” as detailed in par 4.2.

The use of organigraphs in Ben II RHM has a very broad focus. As well as looking within individual organisations Ben II RHM has also been seeking to look at the relationships between organisations at the different levels and how various organisations function within an overall health management system at all levels, national, regional and local; also to look at the flow of actions within the health management process of planning, organising, delivering and monitoring of preventive, treatment and care services for the three tracers, measles, breast cancer and diabetes. It is not always possible to get such a comprehensive picture from the

organigraphs and programme descriptions received and the discussion that follows is limited by this constraint.

Organigraphs and Programme Descriptions for Measles

All 19 of the participating regions submitted organigraphs for measles. Programme descriptions were received from 16 regions the exceptions being, Győr-Ménfőcsanak (HU), Veneto (IT) and Madeira (PT). Whilst the organigraphs can give an overview of the health management system, the programme descriptions can give a number of more detailed insights into the system.

The existence of two chains, from and to national level, can be seen in 12 of the 19 regions, Varna Oblast (BG), Moravia-Silesia (CZ), Western Greece (EL), Győr-Ménfőcsanak (HU), Szabolcs-Szatmár (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Kaunas (LT), Madeira (PT), Chuvash Republic (Russian Federation), Västmanland (SE), Ticino (CH), England (UK). In these regions the organigraphs and programme descriptions show one chain through which there is downward transmission from national Ministry level to regional and local levels, of a measles immunisation policy or programme, including vaccination schedules decided by the Ministry nationally, and another chain through which there is upward transmission of surveillance data to national level.

Different organisational arrangements are shown in Upper Austria (AT), Flemish Community (BE), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), regions.

The federal government agrees the national immunisation programme with the states or regions in Upper Austria (AT). The Flemish Community (BE) participates each year in an inter-ministerial conference at which the Federal and Community health ministers agree an immunisation schedule. In Germany there is no national immunisation plan but the two participating German regions draw up their own action programmes and targets. In doing this, the two regions adopt the recommendations of the national expert advisory institution, STIKO, without modification. In Italy all regions now agree the national plan with the Ministry through the aegis of the State Regions conference. The Austrian, German and Italian regions do show an upward *chain* from local through regional to national level for surveillance data but the Flemish region does not show such a *chain*. The reference framework for measles includes a national/regional immunisation plan with defined targets, also a law on notification of infectious diseases and also refers to a goal of improving measles immunisation surveillance.

Given the inherent complexity of health management systems in general, one would expect to find a number of *hubs* and *webs* in most of the regions' systems. The organigraphs and programme descriptions for measles from the regions show one or more *hubs* at national level.

The reference framework includes implementation of WHO guidelines on measles immunisation.

The most common hub at national level is a national public health institute or centre or a national committee that acts as a centre of expertise and that provides scientific advice for the formulation of the national/regional immunisation programme, usually based on WHO guidelines. There may also be direct input from national scientific institutes or from medical associations. A *hub* of this type at national level is shown by 16 regions, and 3 regions, Upper Austria (AT), Veneto (IT), and Vastra Gotaland (SE) do not show such an organisational arrangement.

Some national ministries have also established focal points, i.e. *hubs*, at national level for the co-ordination of the immunisation programme or the giving of advice and support to the regions. The format for this may be a national committee or group, representative of various stakeholder interests from national and regional levels, but it can also be a national institute or service centre within or closely associated with the Ministry or national responsible authority. Some may be involved in organising public information campaigns or in producing authoritative information and education material for health professionals and for parents, activities that are in line with the measles reference framework. This type of *hub* can be identified in the organigraphs and programme descriptions of the Flemish Community (BE), Moravia-Silesia (CZ), Western Greece (EL), Győr-Ménfőcsanak (HU), Szabolcs-Szatmár (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Kaunas (LT), Chuvash Republic (Russian Federation), Vastra-Gotaland (SE), Ticino (CH), England (UK) regions. In Madeira (PT), the Vaccination Technical Committee may play such a role through the General Directorate of Health but this is unclear as there is no programme description.

A third type of *hub* occurs at the national and regional levels in the surveillance *chain* referred to above. At national level it is the centre to which surveillance data are sent, usually from a corresponding hub at regional level. It may be a department or agency of the ministry or an associated institute or centre for disease prevention and control. The correlation and publication of data on vaccine uptake or on incidence of measles is an important role that underpins some of the provisions of the reference framework. Such a *hub* at both national and

regional levels can be seen in 18 of the 19 regions. The Flemish Community (BE) does not show such a hub at national level and only refers to surveillance and notification of measles cases up to regional level. Of the other 18 regions, it seems that 17 report surveillance of all measles cases up to national level. However, Upper Austria (AT) states that national hospital measles incidence data only are collected but not ambulatory data as a total surveillance system for measles cases does not exist at present.

Other types of *hub* are also apparent at regional and local levels. These can be grouped according to their focus.

The reference framework for measles identifies good practice requirements for quality assurance through evaluation of programmes, for serological surveys and for the prevention of new infections in the event of a measles outbreak. Some *hubs* at regional level act as centres of expertise and advice, for example, regional public health institutes in Moravia-Silesia (CZ) and North Rhine-Westphalia (DE). The state health association is shown by Saxony-Anhalt (DE) as providing expert input at regional level. Another interesting hub is shown by Győr-Ménfőcsanak County (HU) and Szabolcs-Szatmár (HU), in the form of a clinical vaccination consultant at regional/county level who gives advice to those implementing the vaccination programme at local primary health care level. In Sicily (IT), the regional federation of physicians is shown as providing advice. There is a regional organisation or centre of expertise for infectious disease prevention and control shown in Västra-Götaland (SE).

There are a number of provisions in the reference framework for measles to policies and interventions underlying the achievement of the required levels of coverage with the 1st and 2nd dose of measles vaccine, e.g. call/re-call systems, identification of non-immunised children or persons, immunisation of marginal or lower socio-economic population subgroups.

A number of *hubs* are focused on implementation. The vaccine board of Flanders (BE), representative of all vaccinators, discusses implementation of the immunization programme. The regional inspectorate for public health prevention and control in Varna Oblast (BG) has since 2005 operated a special software programme for detection of people in need of immunization by their GPs. In Saxony-Anhalt (DE), an immunization-working group representative of all institutions and associations dealing with immunization works with the Ministry at regional level implement the health target of achieving proper immunization status in more than 90% of the population through the initiation of target group specific pilot projects. These projects can give rise to other hubs at local level since any of the participants in this working group can contribute by running a pilot project at that level. The programme descrip-

tion from Szabolcs-Szatmar (HU) describes what seems to be the significant role of children's health visitors who work at local level under the supervision of physicians, act as hubs at that level. In Dublin/Mid-Leinster and Dublin/North-East (IE), immunisation co-ordinators at regional level act as hubs and in addition to relating upwards as members of the immunisation implementation group at national level, they also work with the immunisation offices within the local health offices which form another set of *hubs* at the local level. The organigraph for Emilia-Romagna (IT) shows that there is a regional co-ordination group for implementation and that this relates to another hub for local co-ordination within each local health unit. The organigraph for Veneto (IT) also indicates that there is functional co-ordination at these two levels linked to the co-ordinating *hub* at national level. The Kaunas (LT) region indicates that the primary health centers at regional level play a strong role in co-ordinating the immunisation programme. In England (UK), immunisation co-ordinators operate as *hubs* at a regional and local level.

Finally, a number of *webs* or collaboration networks can be discerned in the organigraphs and programme descriptions.

At national level there is collaboration between the relevant department of the Ministry, or the national authority responsible for public health, and different actors such as state/regions conferences, expert committees or agencies, public health institutes, professional or industry associations. This collaboration takes place in deciding on national policy or in monitoring or co-ordinating the national immunisation programme. One or more such webs can be seen at national level in 14 of the 19 regions, Upper Austria (AT), Flemish Community (BE), Varna Oblast (BG), Moravia-Silesia (CZ), Western Greece (EL), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna, Sicily and Veneto (IT), Kaunas (LT), Chuvash Republic (Russian Federation), Madeira (PT), Ticino (CH) and England (UK).

A similar type of *web* at regional level can be seen in Upper Austria (AT), where the regional health authority and the health insurer work together to set targets for the region including a target for the elimination of measles and also co-operates with the state medical council, representing physicians, to implement the immunization programme. Also in North Rhine-Westphalia and Saxony-Anhalt (DE), the regional State Health Conference in which all health care actors are involved, fixes health targets for the prevention of measles. This gives rise to other webs shown at local level in NRW where Local Health Conferences translate the targets into action. In Saxony-Anhalt (DE), the immunization-working group at regional level extends to form a network with the pilot projects at local level. A *web* between regional and local levels through collaboration between co-ordination *hubs* at both levels is shown by Dub-

lin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Veneto (IT), and England (UK). Vastra-Gotaland (SE) also describes a web between regional and local levels when referring to collaboration between specialist clinics at regional level and primary health care centers at local level.

The organigraphs and programme descriptions reflect very well the complexity of the health management system that can involve so many different organisations and actors at the different levels, national, regional and local.

The programme descriptions along with the organigraphs show that in Varna-Oblast (BG), Moravia-Silesia (CZ), Győr-Ménfőcsanak (HU), Szabolcs-Szatmár (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Kaunas (LT), Madeira (PT), there is a single health authority from national to regional to local level. In some of these regions the programme descriptions indicate that the downward chain incorporates relatively strong control and clear-cut legal requirements or directives for regional and local health services, for health professionals and for citizens relating to the implementation of the immunisation programme. In other regions the health management chain may be more diffuse and the legal requirements such as obligatory immunisation less stringent. However, whilst the regions in the former category are all amongst those that have achieved the highest measles vaccine uptake, some regions in the latter group e.g. Flemish Community (BE), North Rhine-Westphalia (DE) and Emilia-Romagna (IT) have also achieved relatively high uptake rates, so further investigation of the organisational approach by these regions may prove beneficial to other regions with the more diffuse management systems.

5.2 Breast Cancer

5.2.1 Austria (Upper-Austria)³¹

The Federal Government is responsible for legislation, formulating health policy and general directives. The State Government, assisted by the Health Authority is responsible for carrying out directives and implementing laws in policies.

There is no centralised decision making or implementation of health promotion activities, basically due to the federal structure of the country.

Screening

The Ministry of Health and Women, the Austrian National Health Insurance and the National Medical Council create a new basis for Health Screening Examinations (Vorsorgeuntersuchung Neu/VU-NEU; 2005). Professional breast examination became part of the health screening examinations and a Mammography Screening will be offered to women up to 40 years of age every two years.

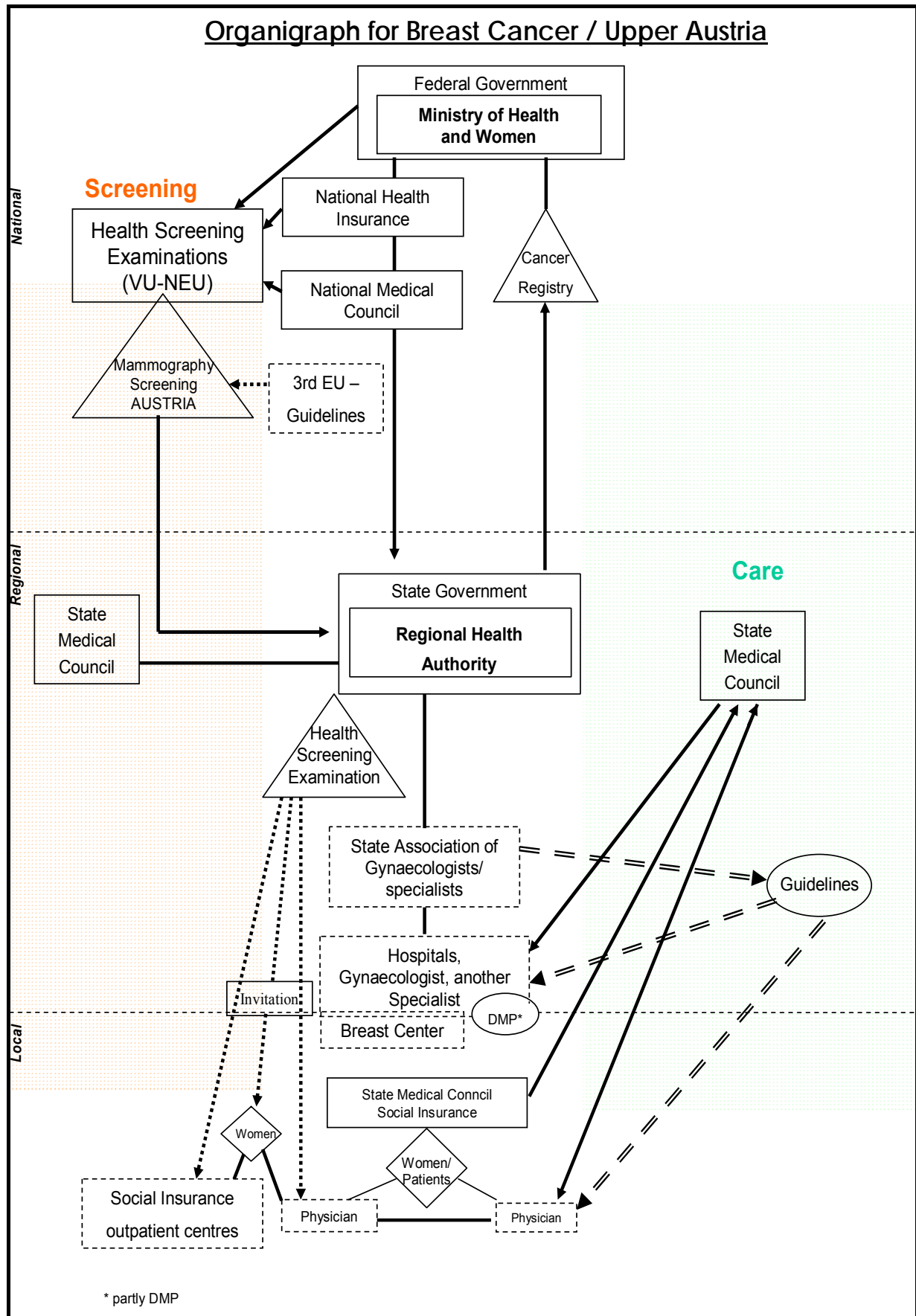
Preventive and screening activities are offered by public health offices, social insurance outpatient offices and physicians in ambulatory care (General Practitioner; Specialists). The Austrian Ministry of Health and Women plans to implement a nation-wide mammography screening programme which will be run in accordance with the third EU-Guidelines for Quality Assurance in Mammography-Screening.

Care

Women with Cancer on suspicion will be transferred to Breast (Cancer) Centers in hospitals. One of the Breast Centers (according to the guidelines of the European Society) takes the initiative to get the EUSOMA certification by the end of the year 2005.

Based on screening examinations and findings of pathology, surgeons, oncologists and radiooncologists create a treatment concept for women with breast cancer. (Cooperation and breast cancer management programme).

³¹ Author: Dr Sabine Pöstelberger, Krankenhaus der Barmherzigen Schwestern, Linz.



5.2.2 Belgium (Flemish Community)

Which institutions/organisations have the main responsibility for health management at the local, regional and national level?

- The Flemish Community is responsible for the prevention in general and the organisation of breast cancer screening in particular.
- The federal government is responsible for organising and financing care, and for financing the mammographys for screening.

Which further institutions/organisations are involved and how do they relate to each other?

- The five centres for screening are responsible for inviting the women from the target group, the second readings of the mammographies, the quality assurance of the mammographic entities and the follow up of women with abnormal screening results. They also form a consortium which is responsible for the registration of all data of the screening programme.
- The mammografic entities are radiologists or radiological services which are recognised by the Flemish Community. They perform the mammographies and the first reading of these.
- The 'Logo's' are a network of locoregional organisations active in prevention that cover the whole Flemish region. They work together with the centres for screening in sensibilisation of the target group at a local level, in order to increase participation.
- Also GPs and gynaecologists can recruit women for screening. They are also responsible for follow up of the women with abnormal screening results.
- A Flemish Working Group on Breast Cancer screening, involving all actors mentioned above, as well as the mutualities and the Flemish League against Cancer, acts as an advisory organ for the Flemish administration and minister on this matter of breast cancer screening.
- The database used to invite women is a database from the federal health insurance institute.

Which laws regulate health management?

- Decree of 21 November 2003 concerning preventive health care.
- Decision of the Flemish Government of 2 February 2001 concerning the recognition of mammographic entities and regional screening centres for breast cancer screening, adapted on 28 May 2004.
- Ministerial decision of 7 March 2001 ratifying the guidelines, cited in article 16, 1° en 3°, of the decision of the Flemish Government of 2 February 2001 concerning the recognition of mammographic entities and regional screening centres for breast cancer screening.

Who is responsible for the surveillance and how is it conducted?

The Flemish administration of Health Care is responsible for the surveillance of the programme. This is performed using the evaluation of the data set delivered by the centres, through the consortium. The European guidelines for quality assurance in mammography screening are followed as much as possible. The quality control of the mammographic entities is done by the screening centres on the basis of registration of data and evaluation of the screening mammographies. In future, the screening centres themselves will be evaluated by an independent international organisation (e.g. the European reference centre EUREF in Nijmegen, the Netherlands). At the same time, the data development in the Flemish Cancer Registration Network is followed up. The Federal government has commissioned the Scientific Institute for Public Health to evaluate the programme for breast cancer screening in the different communities.

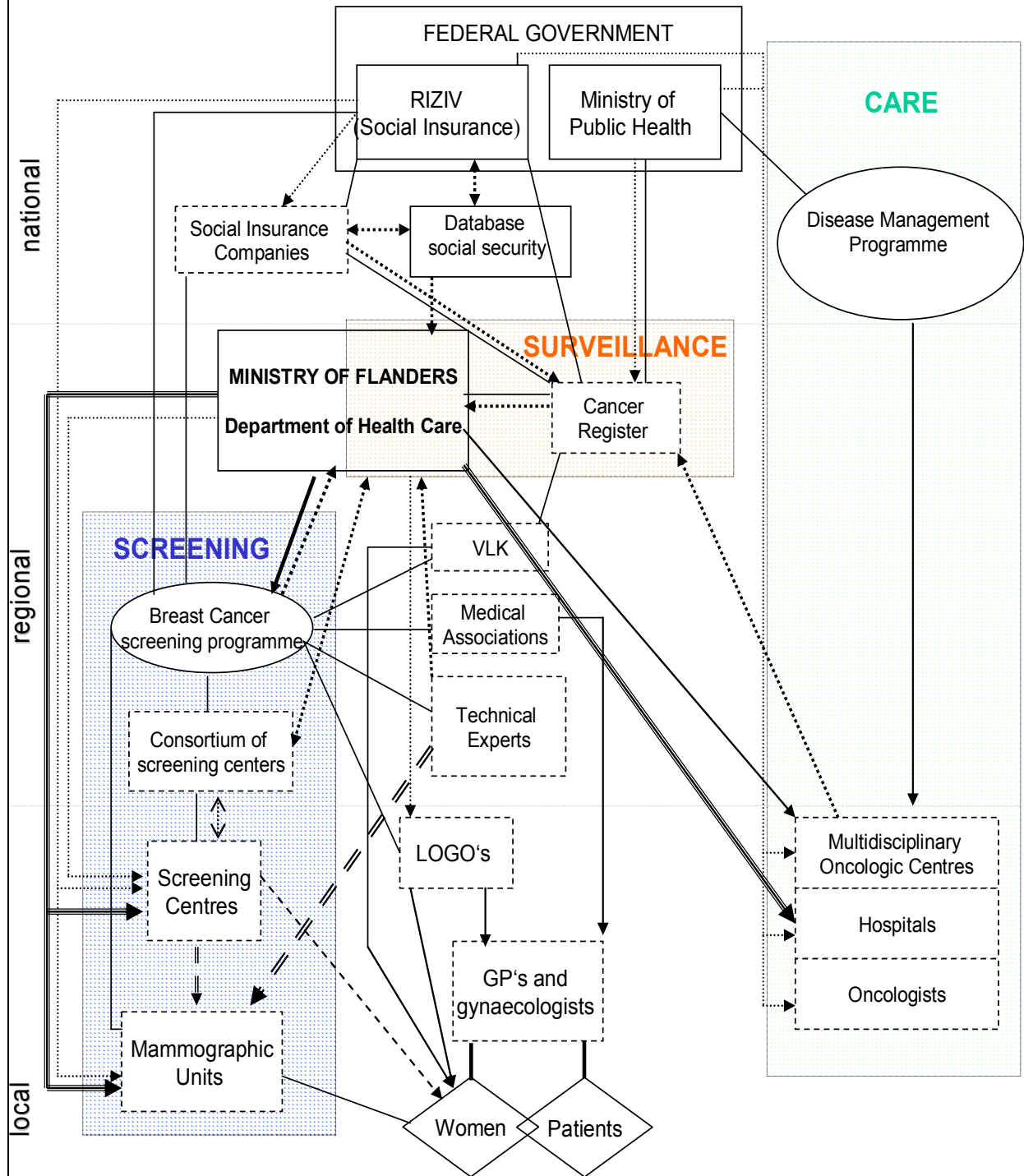
Do registries exist? If so, how do they work?

For the purpose of the breast cancer screening, the Flemish administration of Health Care selects the women in the target population from the general population database; this selected data set is then provided to the screening centres. The process of screening and follow up in case of an abnormal screening result is registered for each woman, as well as the data of the next screenings. The screening centres register this through web-based application (Heracles), which is managed by the consortium. The data are delivered to the Flemish administration of Health Care after coding by the consortium. In future, these coded data will be linked to the data in the cancer register.

Are there campaigns/action programmes of major importance?

At the local and regional level the Logo's are working together with the screening centres sensibiliseringsacties. The 'Flemish Ligue against Cancer' (VLK) organises from time to time mass campaigns, also involving other actors like women organisations. The Flemish Administration is also working on a website on breast cancer screening which will be more user-friendly for the general public. At the moment, the existing website (www.borstkankeropsporing.be) is merely focused on.

Breast Cancer – Flemish-Community



Flanders; April 2005

5.2.3 Bulgaria (Varna-Oblast)³²

The Ministry of Health attaches high priority to the prevention and treatment of diseases of great social importance, such as neoplasms.

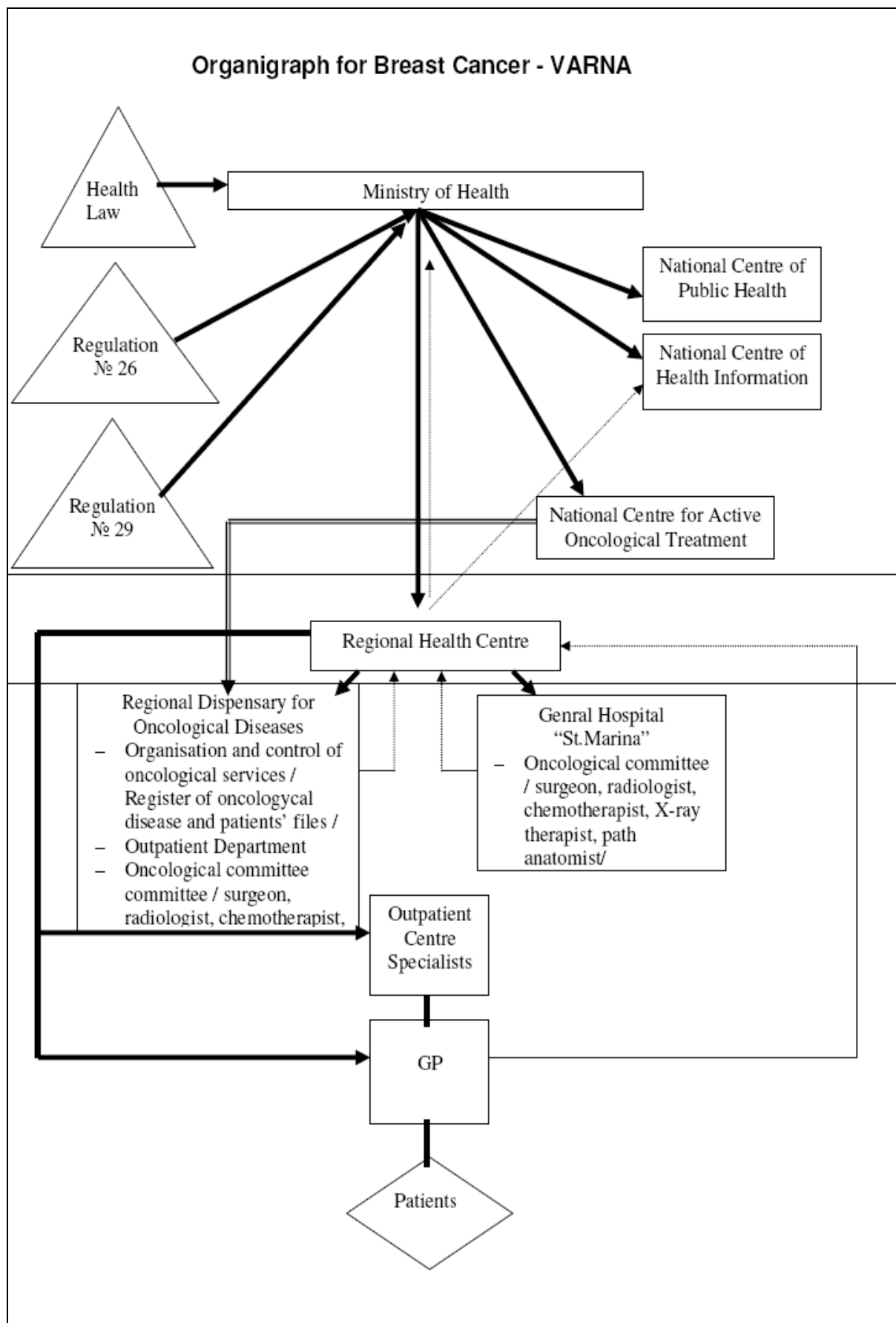
The Ministry of Health has developed and implemented a “National Strategy and a Working Programme for Preventive Oncology Screening in the Republic of Bulgaria 2001 - 2006”, which has been approved by the Council of Ministers. One of the main health policy priorities of this programme is the development of the National Health Strategy – “Better Health for a Better Future of Bulgaria”. It is aimed at achieving a stable trend of decreased morbidity, disability, and mortality rates, which will guarantee improved health of the population.

Neoplasms are amongst the diseases of greatest social importance, having a substantial impact on the population’s health. 20,000 people in Bulgaria annually die of neoplasms. Causing 14% of all deaths in Bulgaria, they take a second leading position as a cause of death, following the coronary-heart diseases.

The main goal of the National Programme for Preventive Screening of Neoplastic Diseases is to increase the proportion of cancer cases found and treated in pre-clinical or earlier stages, and to subsequently decrease the death rates by 30%. It is also aimed at increasing the culture and health knowledge of the population; to educate women about the risks, consequences, and possibilities for treatment; to establish a stable practice of systematic surveillance and investigation by the general practitioners; and to educate the society as a whole for the methods of cancer prevention.

In correspondence with the National Programme, for breast cancer control for instance, educational modules are developed and training courses are organised for general practitioners, lab-technicians and pathologists. Mammography screening tests are organised and can be carried out not only during the campaigns, but throughout the whole year.

³² Author: Dr Diyan Dimov, Surgeon-oncologist, “Dr Marko Markov” Regional Oncology Dispensary, Varna.



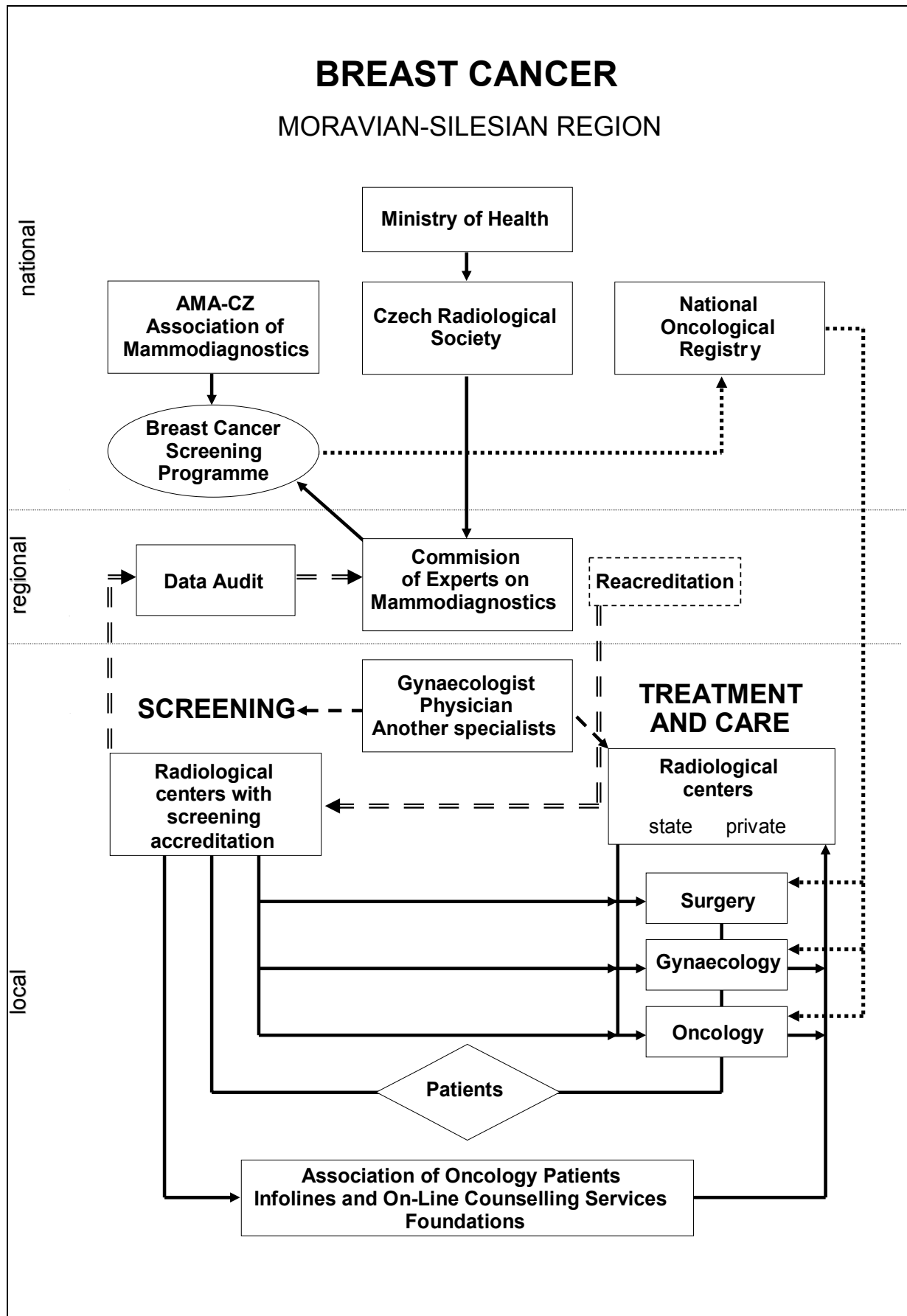
5.2.4 Czech Republic (Moravia-Silesia)³³

The breast cancer prevention policy started as part of the “Oncology preventive programme” in the seventies. It was based on the methodological guideline (Výnos ministerstva zdravotnictví a sociálních věcí ČSR o dispenzární péči o nemocné s přednádorovými stavy a novotvary a povinné hlášení novotvarů č. 3/1989 Věst. MZSV ČSR (reg.) v částce 19/1988 Sb.). After 1990, some changes were made to this oncology strategy and breast cancer screening and treatment became more independent. The prevention of breast cancer is based on the national health prevention policy. The role of the regions is more oriented towards promotion and technical support. The Medical Society and some NGOs support this policy by sciences or supporting information activities for citizens.

Prevention: All women aged 45-69 have free access to screening programmes – these are examinations by gynaecologists or GPs and mammography. There are a lot of specialised centres for breast cancer prevention located in large cities (as part of hospital or outpatient polyclinics). Campaigns promoting prevention measures are continuously being carried out in the region and in the whole country. Reporting is an obligatory part of cancer prevention.

Treatment: Diagnostics and prevention are linked to specialised units for breast cancer therapy (common part of surgery dept. or gynaecological dept.). These units provide oncological, psychological, sociological, and plastic surgery support for patients. The health insurance mostly covers all treatment. The regions are responsible for registration and quality control to share this responsibility with health insurance companies.

³³ Author: Dr Helena Sěbakova, Regional Public Health Authority, Ostrava.



5.2.5 Germany (North Rhine-Westphalia)³⁴

With approximately 51,100 new cases a year, breast cancer is the most frequent type of cancer among women in Germany (Reference Centre for Mammography in Münster 2007). For the detection of breast cancer, breast examinations are carried out throughout Germany in accordance with the guidelines of national professional associations and in accordance with the German legislation on early cancer detection. The examinations are offered to all women aged 30 years old and older and include palpation of the breast and lymphatic nodes as well as an instruction for the conduct of breast self examination.

As part of the concerted actions against breast cancer, the government of North Rhine-Westphalia (NRW) promotes breast self examination through the programme “Tactually Safe” (“Sicher Fühlen” in German). The main component of the programme is the organisation of informative seminars. In the seminars, members of the regional medical association inform women on the detection of breast cancer and show them how a self examination should be carried out.

As part of the programme, information about the self examination steps is available in informative brochures and printed materials like special cards for the bathroom walls. In addition, the women could obtain information from the internet portal of the programme (www.sicherfuehlen.de). In the portal, the steps of a self examination are graphically shown and the public has access to a video of a woman performing a self examination.

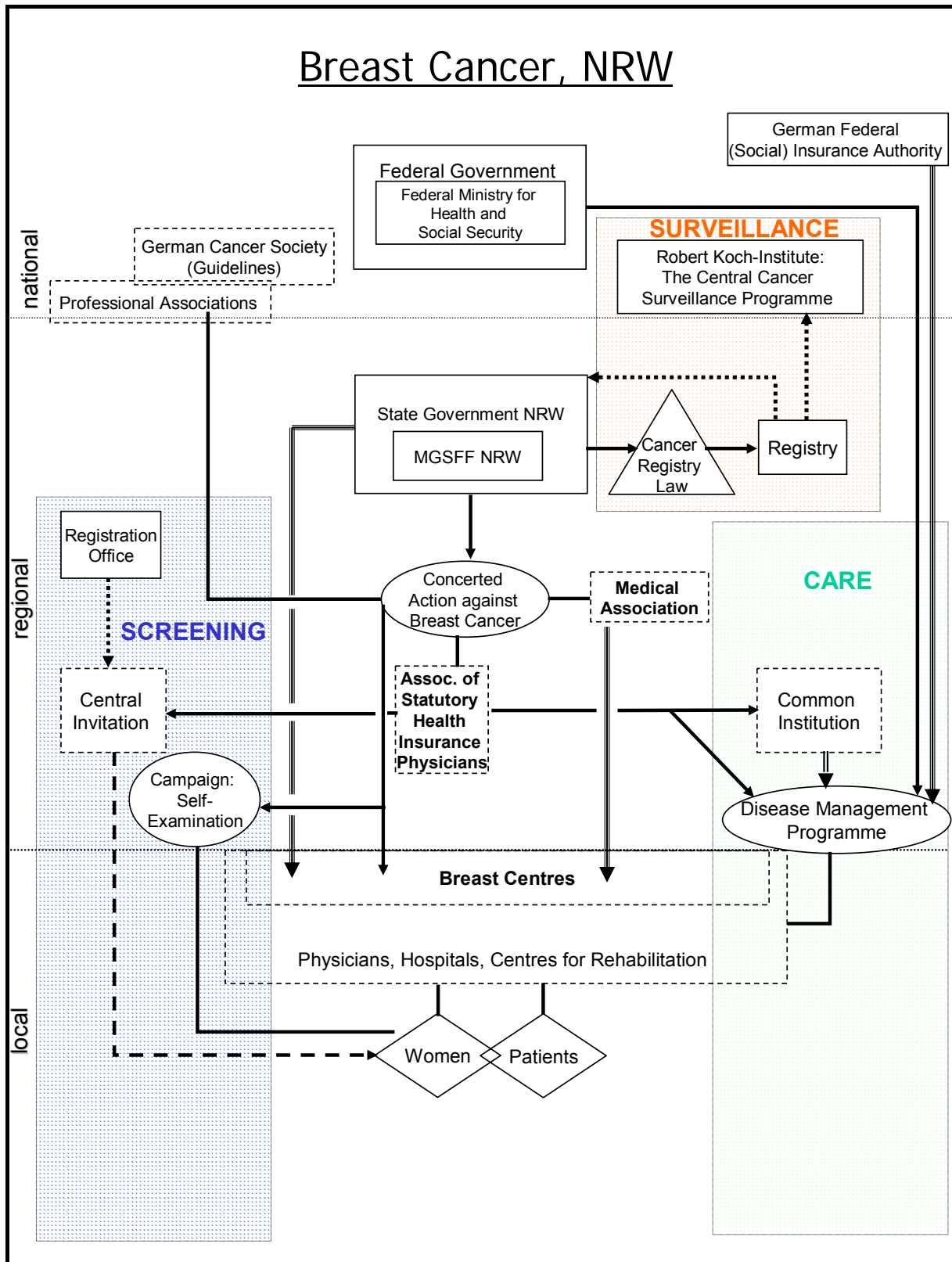
With regard to the mammography screening, in June 2002, the German government implemented nationwide the quality-assured Mammography Screening Programme. Women in the age group between 50 and 69 years receive an invitation for a quality-assured mammography. The programme, which is based on the European Guidelines for Quality Assurance in Mammography Screening (EUREF), comprises about 10 million females and has a recall rate of two years (Reference Center for Mammography in Münster 2007).

To improve the quality of care, breast cancer was included in the German Disease Management Programme (DMP) in 2003. North Rhine-Westphalia was the first German state to organise highly qualified and specialised breast centres intended to offer integrated health care to breast cancer patients.

In addition to a patient-centered multidisciplinary network, the programme is aimed at improving the quality of patient care. The patient is guaranteed treatment according to state-of-the-art standards of evidence-based medicine. The main objectives of the breast cancer

³⁴ Author: Ixhel Escamilla MPH, Institute of Public Health North Rhine-Westphalia, Bielefeld. Organigraph author: Dr Peter Schröder-Bäck, Institute of Public Health North Rhine-Westphalia, Bielefeld.

disease management programme are the improvement of the quality of treatment and rehabilitation; the provision of detailed information and consultation for surgery throughout treatment and rehabilitation; and the empowerment of breast cancer patients.



5.2.6 Greece (Western-Greece)³⁵

Structure, Organisation and Management of the Breast Cancer Screening Programme in Western Greece

The Ministry of Health and Social Solidarity (YPYKA) is responsible for legislation, formulating health policy, planning health promotion and prevention programmes and issuing general directives. The first law regarding the organisation of the anticancer fight was implemented in 1959. Although the law regulated the establishment of anticancer centres and the organisation of committees of anticancer fight in all prefectures of Greece as well as the control of anticancer fight programmes, only little advances were made in this direction.

One of the main institutions, which are involved in the organisation and management of breast cancer prevention and screening, is the Hellenic Cancer Society (HCS). The Hellenic Cancer Society was set up 45 years ago with the aim to inform, provide preventive care, early detection, therapy and rehabilitation of the Greek population and organises various activities in the field of breast cancer screening. The society distributes general and specific information brochures, which inform women about breast self-examination, clinical examination by the doctor and mammography. These brochures are distributed to hospitals, health centres, gynaecologists and other relevant organisations, institutions, and agencies. The Hellenic Cancer Society also organises many information events with discussions and video clips. Strictly speaking, no professional breast examination or breast self-examination programmes exist in Greece. However, there are individual initiatives from different organisations or clubs, which, through the distribution of information, encourage women to attend regular, preventive care examinations and also inform about breast self-examination.

Currently, a programme, which involves the clinical examination of women from certain population groups by medical teams, is being organised by the Association of Volunteers Against Cancer together with the Hellenic Association of Women with Breast Cancer and the Oncology hospital “Metaxa”. Mammography screening programmes have not yet been implemented within the Greek National Health System, neither at national, nor at regional level. Breast cancer screening, including mammography, is carried out at some breast centres or breast clinics which are located in public hospitals, but not in a systematically organised way.

In 1989, a pilot mammography-screening project was started by the Hellenic Society of Oncology (HSO) in two prefectures in Greece, one of them (Ilia) in Western Greece, under the European programme “Europe Against Cancer”. The project ran for 10 years and invited

³⁵ Author: Dr Eleni Jelastopulu, Laboratory of Public Health, School of Medicine, University of Patras, Rio Patras.

women in the age group 40-64 years. The HSO further developed the programme and extended it to more regions and prefectures, including one more prefecture in Western Greece (Aitolokarnania).

The following programme description mainly refers to the Greece Against Cancer programme, which is run similarly to its predecessor programme, Europe Against Cancer.

Organisation of programmes

The Hellenic Society of Oncology and the Hellenic Anti-Cancer Institute carried out the Europe against Cancer programme and are now running the Greece Against Cancer programme. They have formed an organisation called the Hellenic Foundation of Oncology, which organises and implements mammography screening programmes in the whole of Greece. In Western Greece, a mammography-screening programme was first introduced in the prefecture Ilia in 1989 as part of the pilot project Europe Against Cancer. In the prefecture Aitolokarnania, the programme is running since 2001. Screening is done in mobile units, which are stationed at various places in the prefectures (towns and villages) for a certain period of time. A mini-bus service is run together with the mobile screening service for the transportation of women who live in far outlying areas. A period of 4-5 months is required to prepare the programme and inform the public before screening is done in any particular area. The local authorities assisted with the organisation and planning of the programme by offering rooms in which local offices of the HSO could be housed and made it possible for the mobile units to be stationed at particular points by providing electricity, water and telephone lines. In Ilia, the mobile unit was stationed at 25 points within the prefecture. The programme employs two surgeons, two computer specialists, two drivers, four radiographers and a further twelve persons who help with administrative work. Furthermore, 3 surgeons, seven radiologists, two cytologists, a radiation physician and an epidemiologist are employed on a part-time basis. The Greece Against Cancer programme is mainly financed by the Hellenic Foundation of Oncology and run according to the European Guidelines for Quality Assurance in Mammography Screening.

Screening strategy

The programme invites women aged 40-64 years every two years. Demographic data from the National Statistical Service of Greece and from voters' registers were entered into an electronic database at the HSO's main office and used for the invitation of women in the target population. Every woman who attends the screening programme has to complete a question-

naire covering information about the personal medical history and the family's history of breast cancer. Two-view mammography is done at every visit and the mammograms, together with the questionnaire, are sent to the HSO main centre in Athens on a weekly basis. Only women who attend the initial screening round are invited for the next round.

Dissemination of results

Mammography is carried out by radiographers and radiologists. The mammograms are independently read by two experienced radiologists in Athens. In case of disagreement in the diagnosis, a third reading is organised in which 5 persons (including the two radiologists concerned) participate. When a mammogram is positive, the woman is invited for further assessment to the point where the mobile unit will be stationed at that time. A medical team comprising a surgeon, a radiologist and a cytologist will clinically examine her. Should surgical biopsy be necessary, the woman is referred to the reference centre (University Hospital Rio, Patras, Western Greece), or to the breast clinic at the oncology hospital in Athens. Women who are not willing to go to the reference centres, to which they have been referred, are given copies of their examination and result documents, so they can go to a hospital of their choice.

Information and education

Before screening is done in any area, numerous information events are organised, not only by the HSO but also by local authorities and churches. For instance in the prefecture Ilia, the bishops initiated a memorandum to be read at the end of each church service to encourage all women to take part in the screening programme. The points where the mobile unit will be stationed are also published out in the newspapers, television and radios. Professionals involved in the screening programme are informed about new developments and guidelines through special further training courses, seminars, medical journals as well as congresses.

Programme related projects/campaigns

The HSO and other organisations such as the Red Cross and women's organisations arrange many information campaigns for the public in the areas where screening programmes are being implemented.

Programme monitoring and evaluation

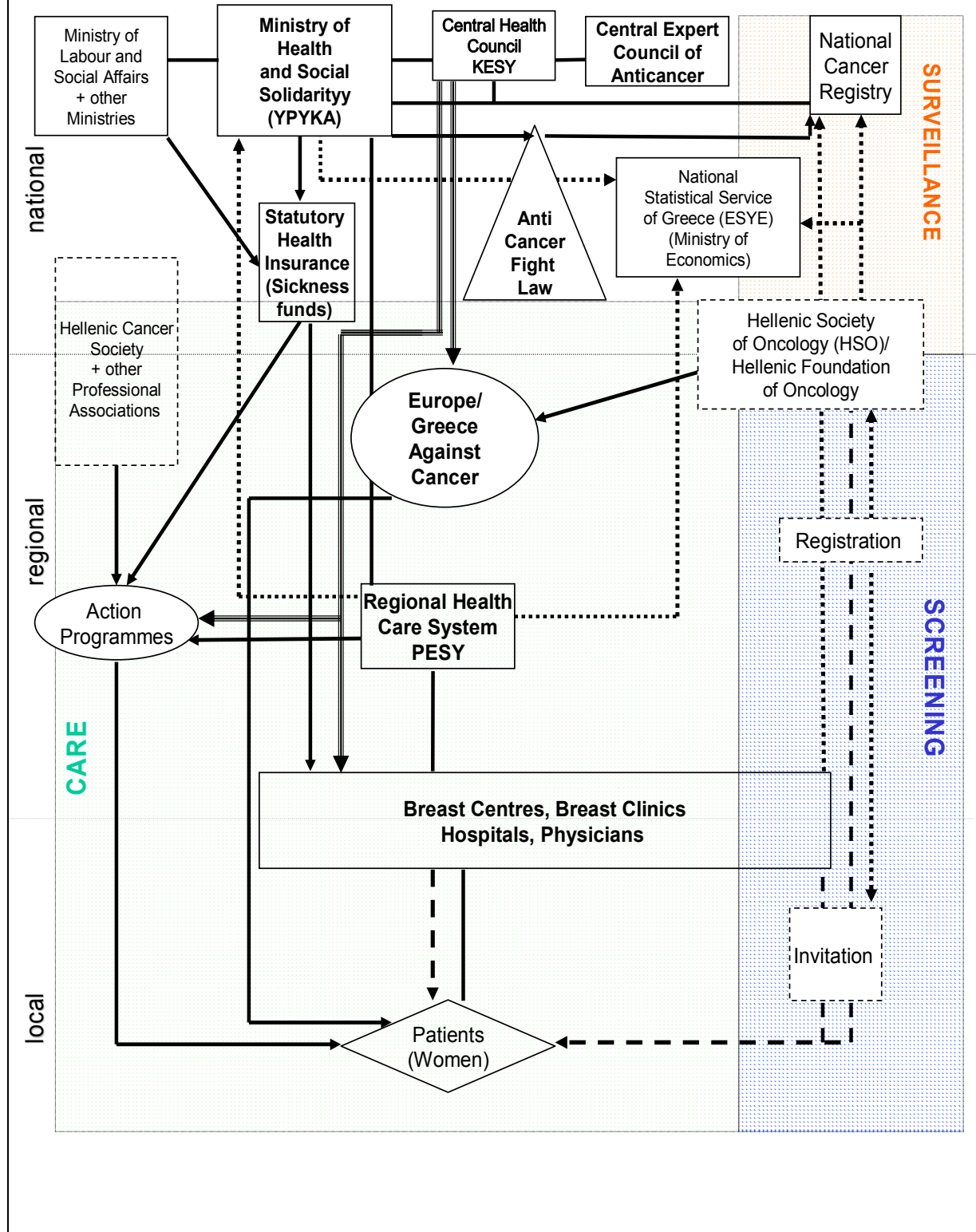
Data on different aspects of the programme such as numbers of women invited, the numbers attending, referrals for further assessment, cancer detection rate and interval cancers are collected. The HSO evaluates its programme by participating in the programme “Quality assurance programme for mammography screening with mobile units”, where different aspects of the screening programme including the invitation system and the information dissemination are looked at. The programme is also annually evaluated by the European Network of Reference Centres for Breast Cancer Screening (EUREF).

The radiographers maintain a daily ‘suitcase protocol’ as quality control of the mammography units and dark rooms.

Disease surveillance

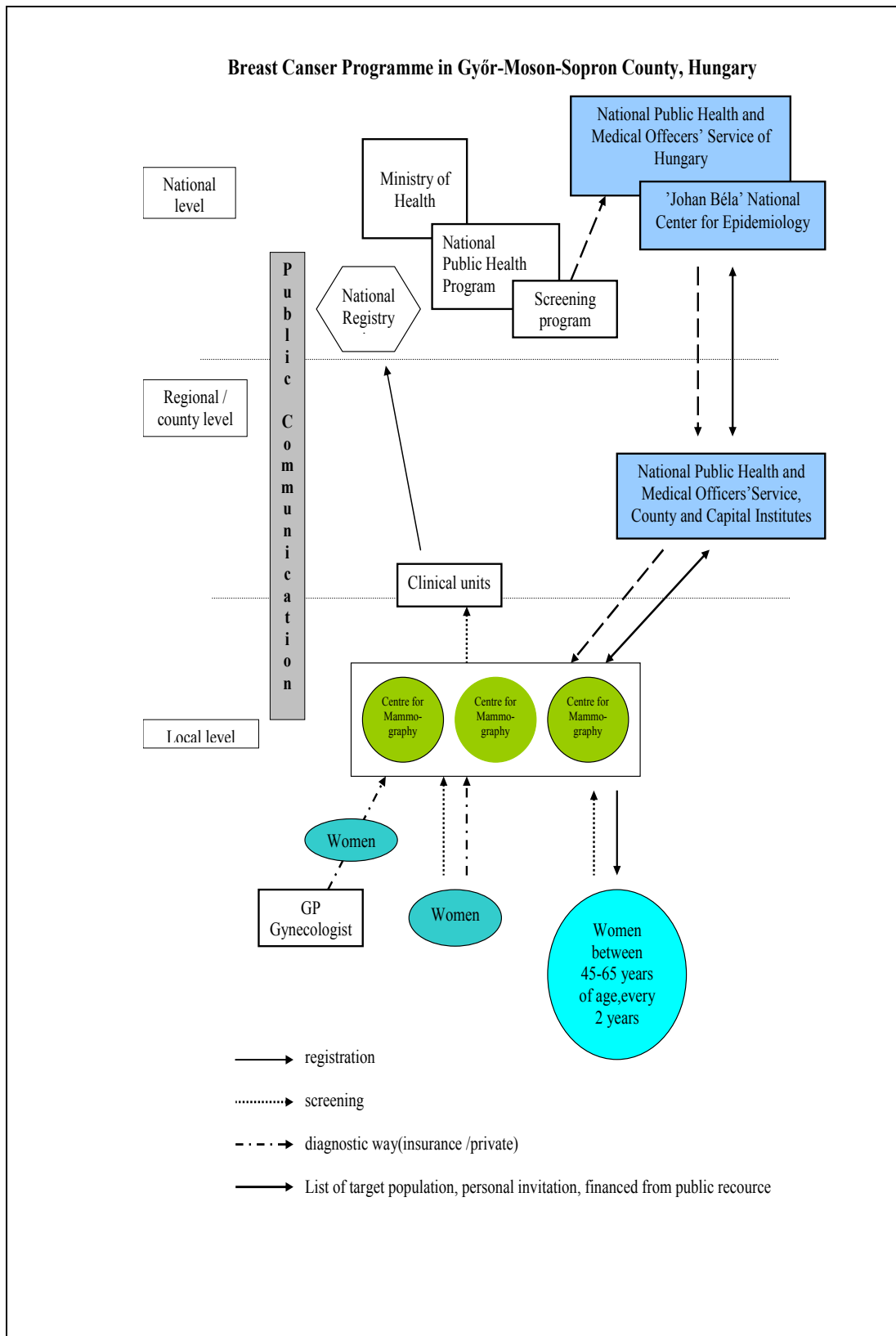
The Greek cancer registry was established in 1990 within the Ministry of Health and Welfare’s Central Health Council (KESY). Clinic based registers also exist at the University Hospital Rio in Patras and at the general hospital Agios Andreas also in Patras, Western Greece. Data from the HSO organised Greece Against Cancer Programme are forwarded to the Greek cancer registry, where it is analysed and published.

Organigraph for Breast Cancer Screening in Western Greece



5.2.7 Hungary

5.2.7.1 Hungary (Győr-Moson-Sopron County)³⁶



³⁶ Author: Dr Erzébet Bazsika, Public Health Institute, Győr-Moson-Sopron County.

5.2.7.2 Hungary (Szabolcs-Szatmár-Bereg)³⁷

National Level

The National Health Insurance Fund hands over the data of women to be screened (women 45-65 years of age, who haven't attended screening for the past two years) to the National Public Health and Medical Officers' Service monthly. The data are entered by the Office of the Chief Medical Officer into their computer network. The County Institutes can connect to this system.

The National Health Insurance Fund pays only to those screening sites which have entered into contract in the framework of a tender procedure invited by the Office of the Chief Medical Officer for the screenings.

Quality control is ensured by the Breast Workgroup of prominent professionals appointed by the Office of the Chief Medical Officer. They qualify the work of screening sites by monitoring and assessing the monthly, quarterly reports; technical quality control radiographs (sensito-densitometria; breast-phantom tests).

Hospitals report on patients with cancer to the National Cancer Registry monthly. The Registry is maintained by the National Institute of Oncology due to the recommendations. The Cancer Registry on the base of the collected data informs the Office of the Chief Medical Officer on the territorial distribution of morbidity.

The Breast Workgroup communicates with the screening sites through the Office of the Chief Medical Officer and the County Institutes.

Before starting screenings the Health Societies had compiled standard protocols and principles by professions and screenings for the care of patients on the base of their professional experiences.

Regional (mostly county) and Local Level

In our country the organised screenings of the population are run on territorial bases by family practitioners' districts. The list of women for personal invitations – if necessary “call and re-call” system – is provided by the Screening Department of National Public Health and Medical Officers' Service County Institute.

The professionals of the County Institute organise meetings for the designed districts' family practitioners, nurses, children health visitors, healthcare professionals, Red Cross activists, and representatives of NGOs in 4-5 weeks before screenings. Here are delivered the

³⁷ Author: Erzsébet Varga, National Public Health and Medical Officer's Service Szabolcs-Szatmár-Bereg County, Budapest.

lists of women to be invited for screenings to the family practitioners and children health visitors' services. Having checked they send these lists to the competent Local Institutes. The collected lists are forwarded to the Centers of Mammography.

The Screening Department of National Public Health and Medical Officers' Service County Institute sends the list of women to be invited for the screening sites in three weeks before screening by (security packed) e-mail, or through the National Screening System. The screening sites send the invitations for the patients in 8-10 days before the day of screening.

The screening sites inform the Screening Department of the partial results of the screenings regularly. The Screening Department monitors the partial results. When the partial results do not meet the requirements, the department takes a more increased part in organising screening. The screening sites send the lists of participants / non-participants, and the results of screenings for the family practitioners through the County Institutes monthly. The Screening Department of the County Institute provides the participants ratio of family practitioners districts for the local institutes.

Centrally operated, financed from public resources mammography is to be repeated bi-annually on the base of principles published by the Office of the Chief Medical Officer in the women 45-65 years of age.

Considering this and adapting ourselves to different local conditions, with the help of: physicians, nurses, children health visitors working in primary health care system; NGOs; local governments the Screening Department of the County Institute organises the screenings leaning on the work of local institutes.

The Screening Department of the County Institute monitors the daily, weekly results of the screenings and evaluates the attendance rate of family practitioners districts', settlements and local institutes.

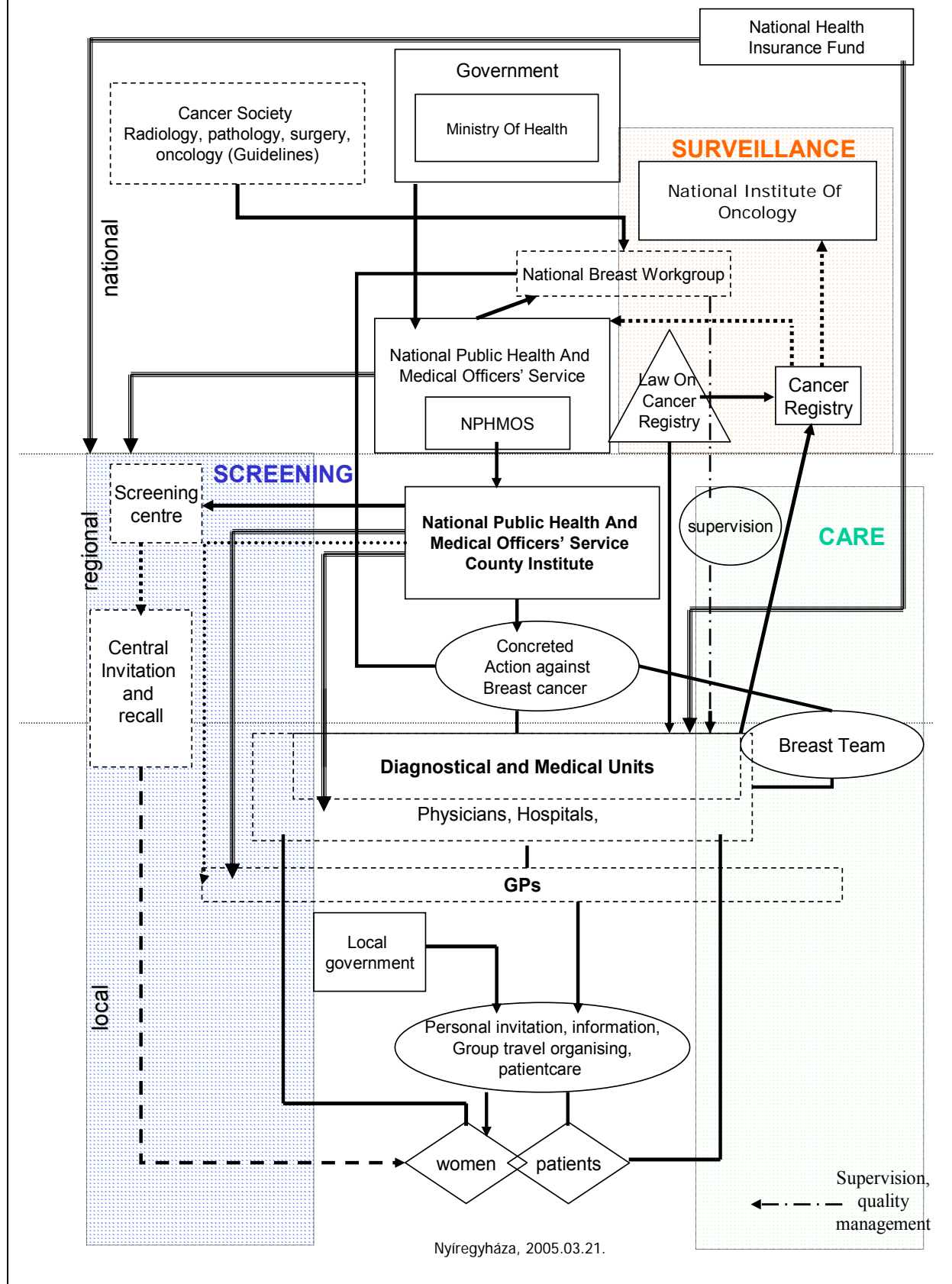
The screening sites are bound to report on screenings in a statistical form given by the Office of the Chief Medical Officer monthly and quarterly. These reports are forwarded to the Office of the Chief Medical Officer by the County Institute according to schedule.

The Office of the Chief Medical Officer reports to the Screening Department on their screening activity and on the postage to be financed by the Office of the Chief Medical Officer monthly and quarterly in a given time and format. The screening sites report wrong data monthly (data of dead or gone away patients, "unknown" or returned letters).

The Screening Department sends a report to the Office of the Chief Medical Officer monthly on the screening activity, on wrong data and on technical quality control radiographs;

and quarterly on the therapeutic activity for women with detected cancer in a given by the Office of the Chief Medical Officer time and format.

Breast Cancer Screening (Szabolcs-Szatmár)



5.2.8 Ireland (Dublin/Mid-Leinster and Dublin/North-East Regions)³⁸

1. Policy in relation to breast cancer screening is decided at national government level through the **Department (Ministry) of Health & Children**, e.g. the timing of the final rollout of the national programme now due to be achieved in 2007.
2. The **Health Service Executive (HSE)** was legally established with effect from 1st January 2005 as a result of a major structural reform of the Irish health service. It has replaced the Eastern Regional Health Authority and all eleven of the former Health Boards and has also absorbed or taken responsibility for, a number of former semi-state health agencies. It has also taken over responsibility for the executive type functions of the Department (Ministry) of Health & Children, which will now concentrate on policy matters. In addition to its policy role, the Department had also been involved in some executive work and this will now be the responsibility of the HSE. A number of national directorates have been created, including a **National Hospitals Office**, a **directorate of Primary, Community and Continuing Care (PCCC Care)**, and a **directorate of Population Health**. The detailed sub-structures under the HSE are still evolving. On its establishment the Chairman of the HSE has indicated that “Ireland will have a single, unified health service with devolved and empowered decision making at local level ... The regional offices will be responsible for performance management, translating national policies through the local areas and gathering and relaying information on a regional basis. Interaction with local communities and their public representatives will also be a key function. Hospitals and local structures for primary, community and continuing care will report to national directorates. This model of service delivery will bring decision making closer to the patient/client through the Local Health Offices.”

The HSE is responsible for the delivery of all hospital and primary care services for breast cancer patients with the exception of those primary treatment services provided directly by the BreastCheck programme to those patients diagnosed as a result of the mammography-screening programme.

3. The **National Cancer Registry**, governed by a Board set up by legislation, conducts surveillance. This Board and the National Cancer Registry is expected in the future to report to a new body, the **Health Information and Quality Authority (HIQA)**, which has also been more recently legally established under the health service reform

³⁸ Author: Kieran Hickey, Health Service Executive, Dublin

programme. HIQA will not be responsible to the new HSE, but will report directly to the Minister and Department of Health & Children.

The role of HIQA will be to:

- develop, set and monitor quality standards for the delivery of health and personal social services
- assure, measure and improve the delivery of health and personal social services through accreditation programmes, information systems and health technology assessment;
- and having regard to available resources for provision of health and personal social services, promote practices that evidence has shown produce high quality and best possible outcomes.

4. The Breast Screening programme has been organised and delivered by a statutory body, originally the National Breast Screening Board, which was established in 1998 as a joint Health Board initiative. The Board was not subsumed into the new HSE but was re-established following the abolition of Health Boards and became a national statutory body reporting directly to the Minister and Department of Health and Children.

The first Board initiated a national screening programme named **BreastCheck** in February 2000 and under Phase 1 of this programme free breast screening was offered to women aged 50-64 in Health Board areas in the Eastern/North Eastern/Midland region. This area now comprises two new regions under the HSE, i.e. Dublin/North-East and Dublin/Mid-Leinster. There was a partial extension of BreastCheck in 2004 to the south-east area which is now part of the new HSE Southern region and Government approval has been given for Phase 2 which will involve the full expansion of BreastCheck nationwide.

The expanded service is projected to commence in 2007 and two new clinical units (with static and mobile screening units) are planned to supplement the two existing units in Dublin. One of these hospital based units will be in Cork to serve the HSE Southern region and the other in Galway to serve the Western region.

BreastCheck has its own dedicated budget, funded directly by the Department for Health & Children. It is managed from a Central Office in Dublin and has a Chief Executive and support staff. It currently has two Screening Units, each of them located on the campus of a major teaching hospital, one on the north side of

Dublin and the other on the south side. They each have associated mobile units, which provide screening in local areas. BreastCheck has arrangements with the two host hospital specialist units to provide beds and operating theatres for patients referred from its screening service. Following surgery, women are referred to hospital symptomatic breast services for follow-up and further treatment, if required. BreastCheck employs its own staff, including Consultant medical staff, e.g. Surgeons and Radiologists who are attached to the breast units at the two host hospitals.

BreastCheck is responsible for all aspects of the programme

- Compiling of Population Register
- Scheduling and issuing appointments for screening
- Issuing result letters to women and their GP's
- Inviting women to triple assessment clinics where appropriate.
- Organising hospital admission and surgery where appropriate.
- Recalling women for screening every two years.

BreastCheck has developed its own computerised information system and employs an Epidemiologist as well as a Statistician and also a Communications Manager and a Health Promotion Officer. A Clinical Director is responsible for each of the Clinical Units. There is an emphasis on quality assurance in line with EUREF guidelines and data is published annually. Breastcheck published its own guidelines for Quality Assurance in Mammography Screening in 2000 and a revised edition was published in 2003. BreastCheck has set a number of performance parameters against which it measures its performance and the results are published. One such parameter was a target of 70% rate of acceptance of invitation to the screening programme by eligible women, i.e. participation rate. Rates in excess of this target have been consistently achieved.

External evaluation has shown that the BreastCheck programme is performing to a high standard. A consumer research report on women's experiences was positive. A womens charter was drawn up setting out BreastCheck's commitment to detailed standards of service in the following areas:

- In the screening process

- If recall is required
- If breast cancer is diagnosed

Under the charter (<http://www.breastcheck.ie/screening/charter.html>), women are encouraged to tell Breastcheck what they think, especially if the declared standards of service have not been met. In addition to published guidelines to breast screening for women and their families, supplemented by a video and CD Rom, BreastCheck has published an Information Package for Primary Health Care Nurses and an Educational Package for General Practice, in 2004. For all BreastCheck publications, including annual reports, please see <http://www.breastcheck.ie/publications/>.

For the screening process a computerised database generates a letter of invitation to each woman in the target age group. A woman can check her registration or register on line if necessary. The invitation will be to attend either the central static unit or one of the mobile units for the screening examination.

If recall is required, this will be to an assessment clinic provided by BreastCheck at one of the two host hospitals. If there is a positive diagnosis, treatment options will be explained and arrangements made for admission for treatment by specialised trained staff at the specialist unit of the host hospital.

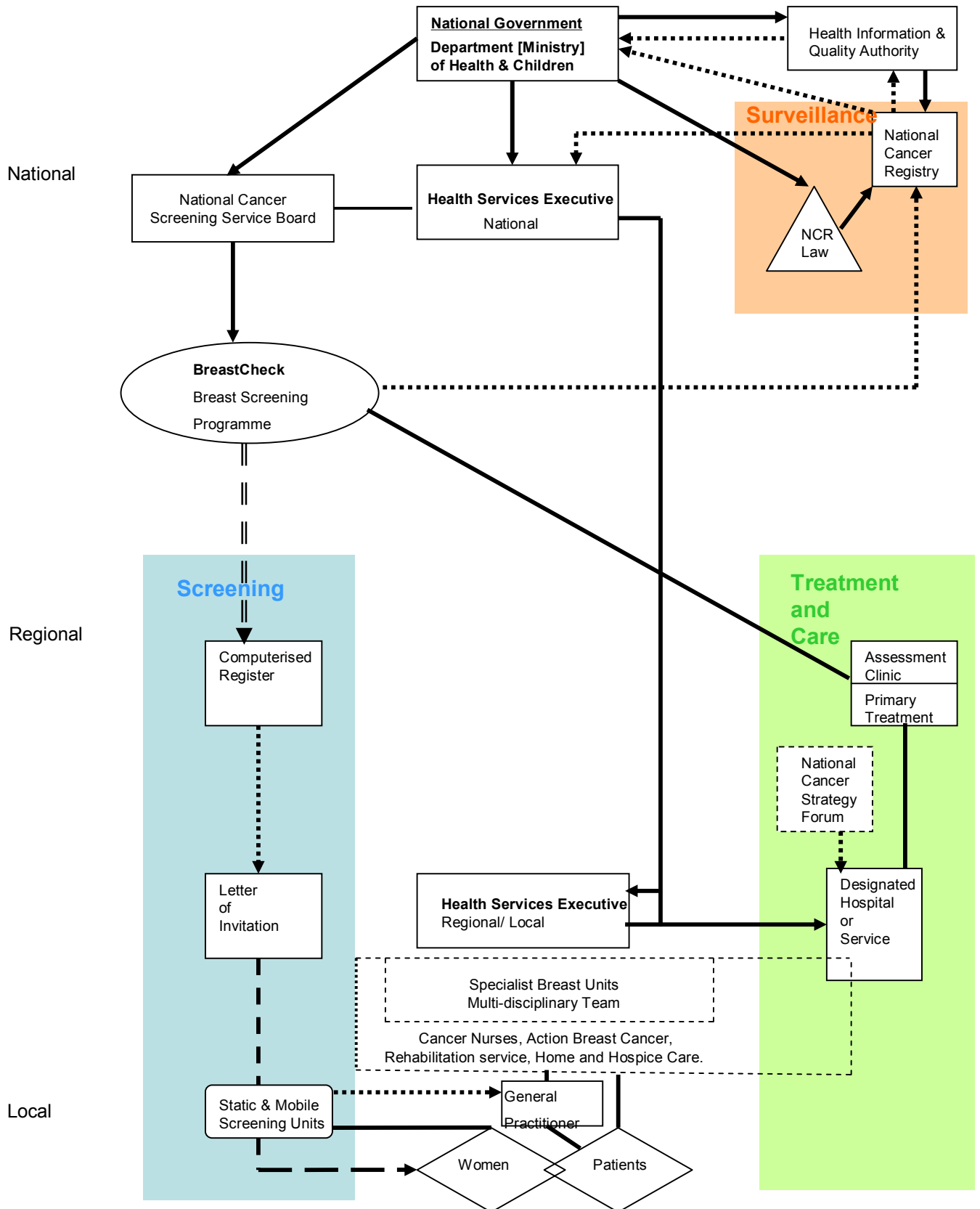
There has been some discussion about admission policy as there is a number of Specialist Breast Units to be developed in selected hospitals throughout Ireland not all of which will have consultant and other staff funded by BreastCheck. The National Cancer Strategy Forum will make recommendations as a result of these discussions.

The organisation of BreastCheck is seen as a model of excellence within the Irish Health service. The governance, quality assurance and business models developed by BreastCheck have been recognised as key to the success of the programme thus far. The Minister for Health and Children decided in 2007 to establish a National Cancer Screening Service to take forward the expanded BreastCheck programme, an existing pilot Cervical Screening programme and a proposed future Colorectal Screening programme.

The existing National Breast Screening Board was expanded and forms the Board of the new organisation under the title of the National Cancer Screening Service Board.

5. The HSE's national Hospitals Office and directorate for Primary, Community and Continuing Care are ultimately responsible for the provision of the designated hospital or other service required by a woman with a positive diagnosis of breast cancer. As shown on the organigraph, this may be in a hospital Specialist Breast Unit or in a service at community level.
6. Action Breast Cancer is a support service of the Irish Cancer Society – see <http://www.cancer.ie/action/>.

Breast Cancer - Ireland



5.2.9 Italy

5.2.9.1 Italy (Emilia-Romagna)³⁹

Since 1978 health care in Italy is guaranteed through the National Health Service (SSN) that provides prevention, treatment and rehabilitation services to all citizens and which is financed through tax revenues. The 21 Italian Regions are autonomous for health services organisations and management, even though they follow common rules and guarantee to every citizen equal services in the whole country (basic benefit package). The co-ordination among the Regions is guaranteed by the State/Regions Conference, in a framework of shared decisions.

Primary and hospital care is provided by the National Health Service with a network of Local Health Units, that can also refer to private structures for some services. Moreover, every citizen is granted a general practitioner paid per capita; children up to 14 years of age refer to a paediatrician.

In 1996 the Health Ministry (National Oncological Commission) indicated among its priority goals the implementation of organised screening programmes on the population, developed by each Region and covering the whole country, and it prepared intervention guidelines and operative protocols.

The 1998-2000 National Health Plan included screening programmes for early detection of breast and cervix cancer in the national basic benefit package, and some Regions have already started local programs.

Following the recommendations issued by the Council of the European Union (Official Journal of the European Communities, December 16, 2004) and approved by the European Parliament, the Italian law n. 138/2004 funds Regions for their activities of population screening for cervix, breast and colon-rectum cancer (€ 10.000.000,00 in 2004; € 20.975.000,00 for 2005; € 21.200.000,00 for 2006). European recommendations also include procedure for quality assurance, results monitoring and health professionals training.

In addition to SSN structures, in Italy there are also qualified scientific institutes for cancer research and treatment, directly funded by the Health Ministry.

The Health Ministry has recently created also a Centre for Diseases Control (CCM): with the technical support of the National Screening Observatory (ONS). The CCM has to assist, evaluate and check screening programmes already implemented or which are being implemented by the Regions.

³⁹ Author: Dr Naldoni Carlo, Dr Priscilla Sassoli, General Direction for Health and Social Politics, Bologna.

Some scientific associations are interested in these topics – in particular the Italian Group for Breast Screening (GISMa), with a role of quality promotion, scientific investigation and research on screening programs.

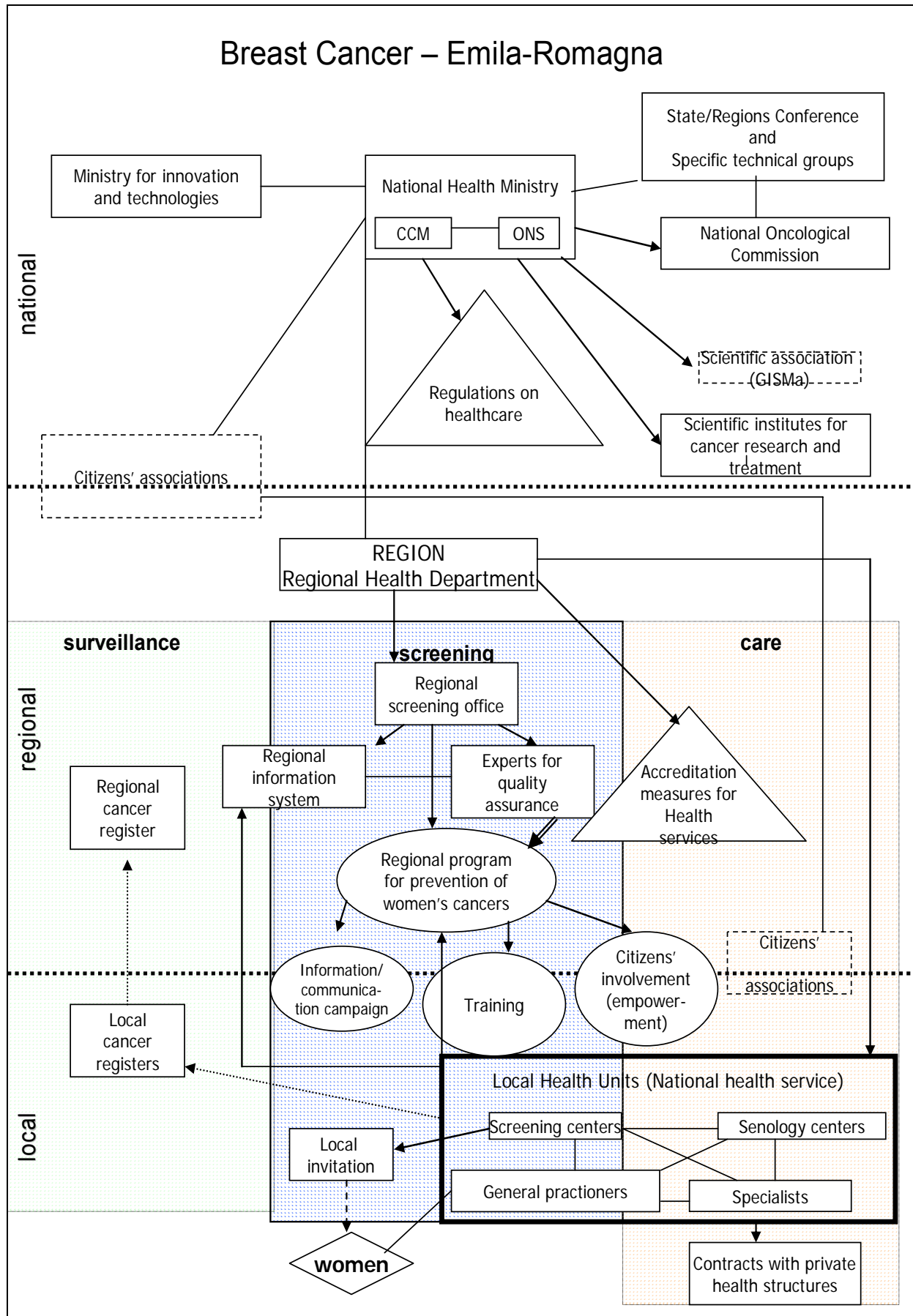
Also some Citizens' Associations at national, regional and local levels play an important role to support and help screening and care activities; in particular, the Italian League against Cancer and Europa Donna (Europe Woman) are to be remembered.

In the 80s and 90s some Italian Regions had already started screening programmes at a local level. Among them, Emilia-Romagna is in the forefront: since 1996 it has developed organised screening programmes on the population (breast and cervix cancer, and now also colon-rectum cancer) as public health interventions on the whole regional territory. They are financed and coordinated by the regional government through the Regional Office for Screening. Programmes are offered free of charge. They are monitored through data collection by the Screening Centres; the Local and Regional Cancer Registers offer information on case incidence, prevalence and outcomes. Moreover, according to the regional programme for cancer prevention, the Region has to promote information and communication campaigns and training initiatives for the health professionals involved that will then be developed by the Local Health Units.

The screening programme for breast cancer involves women aged 50 to 69 every second year with a very large compliance. If mammography reveals alterations, the woman is invited to undergo all the necessary examinations till diagnosis and in case treatment. For this reasons, in each Local Health Unit there is a Screening Centre that coordinates the activities and directly controls and manages the entire diagnostic-therapeutic course.

Breast cancer is the most common cancer in women and the most frequent cause of death. The standardised rate mortality in Emilia-Romagna was 33.8 out of 100.000 in 2002. Actually 83 women out of 100 with breast cancer are still alive after 5 years.

The regional programme also includes program's quality and health, that will be developed through control and clinical audit and with educational initiatives following inspection of sentinel events. Process and outcome indicators permit the control of development and goals attainment. These indicators mainly consider women's participation, diagnostic capacity of the program, program's efficiency, that is its organisational standards and its capacity to reduce mortality for this pathology using conservative therapies as frequently as possible.



5.2.9.2 Italy (Sicily)⁴⁰

- 1) Prevention and strategies programmes are defined and issued at national level by the Health Ministry through agreements with the scientific associations and National cancer Institutes.

The Prevention Department is in charge of Health co-ordination, supervision and intervention and also of the information to citizens and health personnel.

With the passing of Law 138, 2004 ("Urgent interventions for confronting public-health hazards"), the *Centro Nazionale per la Prevenzione e il Controllo delle Malattie* (CCM – Italy's National Centre for Disease Prevention and Control) has been established at the Ministry of Health. The main objective of CCM is that of active prevention through both the promotion of healthy life styles and screening and of confronting a variety of health emergencies. CCM has been created as a network of existing institutions and experts: the activities of CCM are coordinated with those of the Regional Health Authorities and with national institutions and organisations (ISS – Italy's National Health Institute; University research centres; Associations involved in healthcare and in public and private research). Following the Agreement of March 23rd, 2005 (State-Regions Conference) Regional Authorities have to bring into action National Prevention Plan objectives, intended to improve the effectiveness and the efficacy of prevention programmes at regional level and to lower National Health Service costs. CCM will coordinate with Regional Health Authorities for surveillance and active prevention programmes. The main areas of concern of the National Prevention Plan, which will last three years, also include: vaccination plan, prevention of complications in diabetes and cancer screening.

Regarding this last issue, National cancer institutes work in support of the Prevention Department in order to elaborate guidelines for the surveillance, screening and care of cancer in collaboration with the Patients' associations and the Scientific societies.

The Agency for Regional Health Services is an Institution placed at National level in support of the combined work between the State and the Regions. It helps to reach agreements on the Disease management programme defined by the regions.

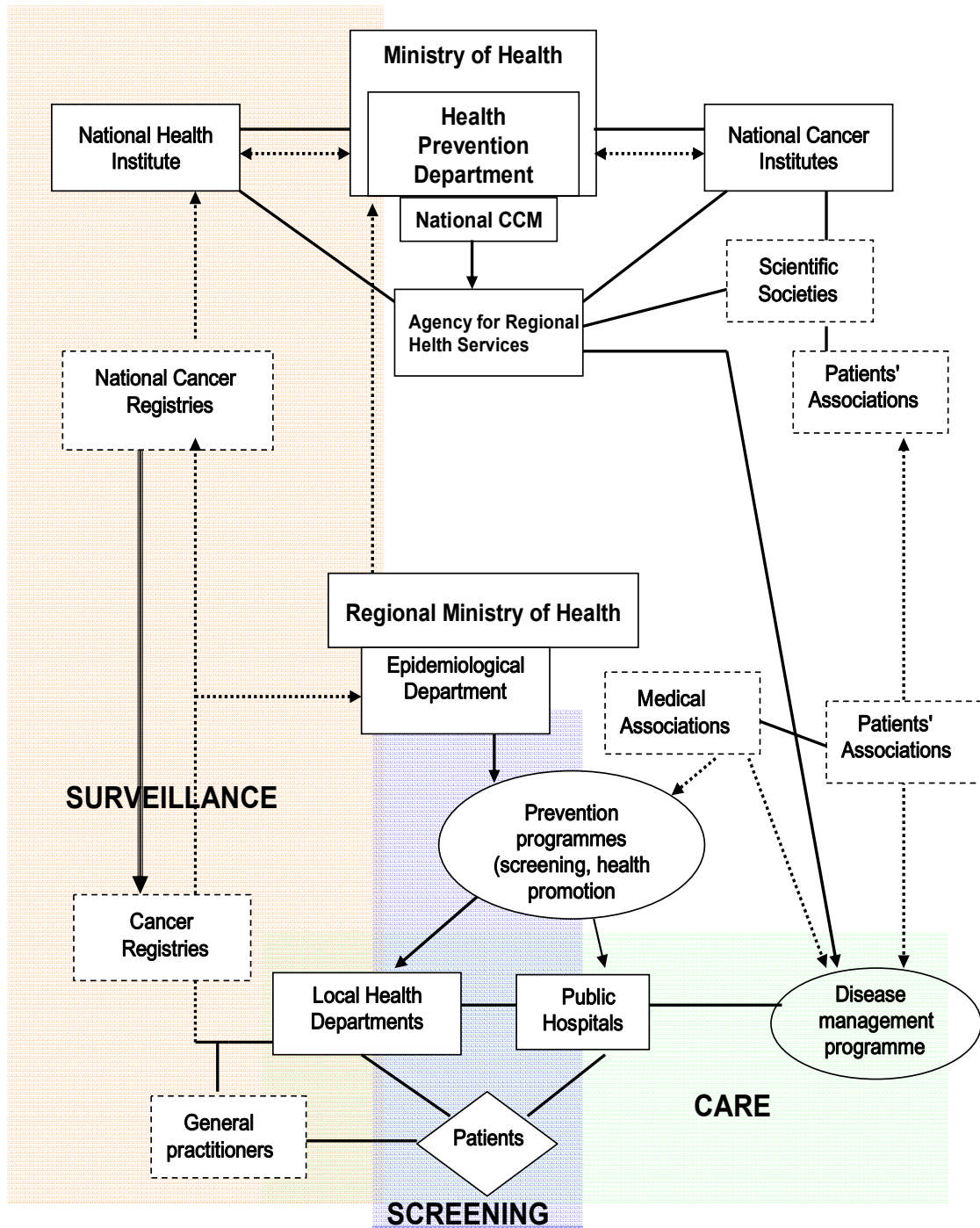
- 2) The Sicilian Region has a "Special Statute". The Sicilian Regional Assembly issues and adopts national laws. The Ministry of Health is a government authority and it is

⁴⁰ CEFPAS – Centre for Training and Research in Public Health, Caltanissetta, Sicily.

the institutional body that addresses, coordinates and defines the lines of the programme in the field of population health through decrees and Regional laws. In particular, the Regional Health Plan adopts the national directives, and explains the organisational strategies and the objectives to be achieved.

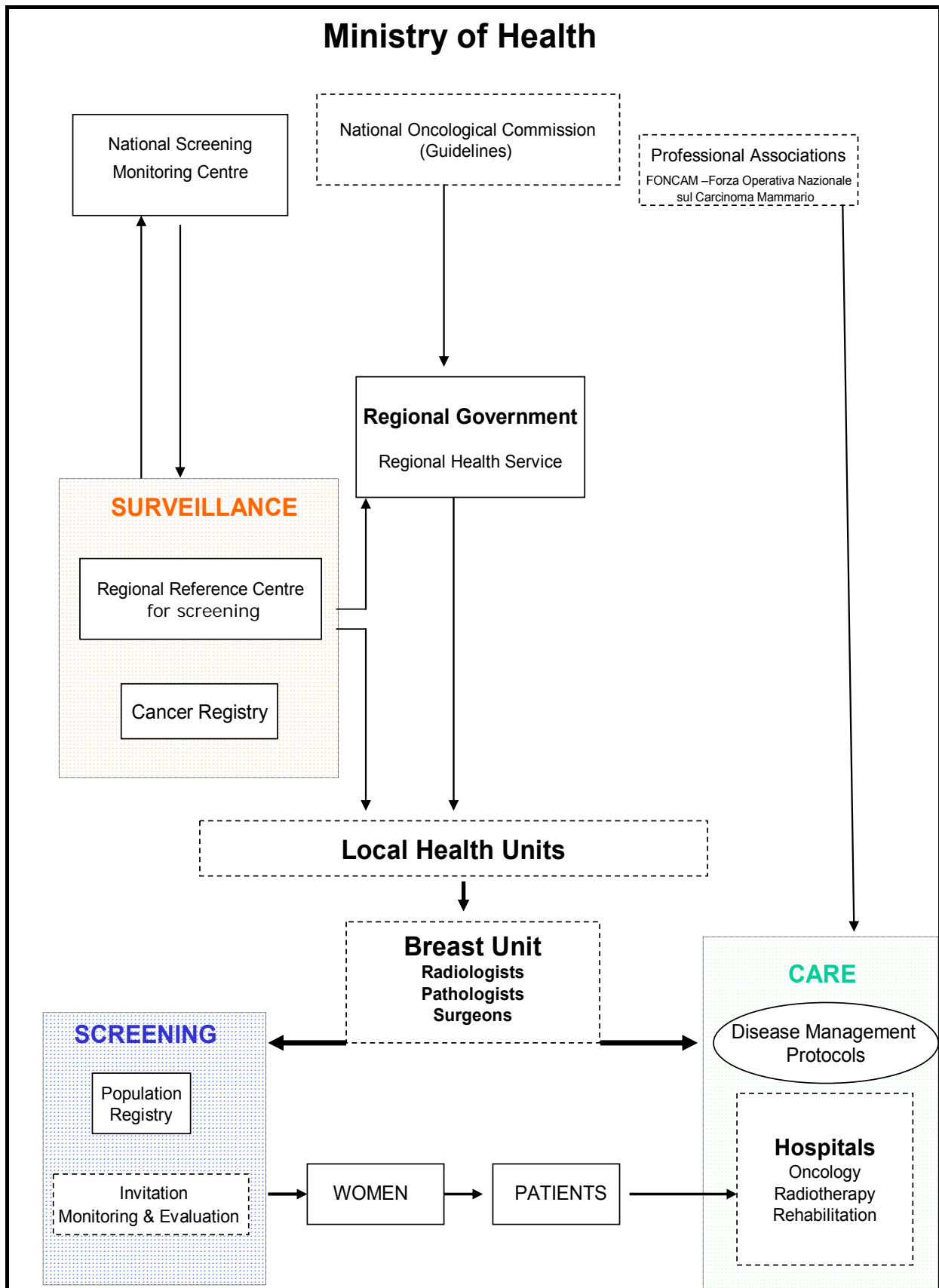
- 3) The Local Health Organisations (LHO) and the Public Hospitals must also guarantee, among the other Essential Levels of Assistance, the surveillance, the screening and care of breast cancer.
- 4) The epidemiological surveillance is carried out directly by LHO and Public Hospitals through the cancer registries. The new cases and all the other information relevant for breast cancer surveying are recorded at National levels in the National Cancer registries after the notifications come from the local registries and the Regional epidemiological department.
- 5) The diseases management programme elaborated in collaboration with the Agency for Regional Health Services, the Patients' association and the Medical association, represents the guidelines for the screening and the care of the patients affected with breast cancer.
- 6) In Sicily the screening programme is offered for free, every two years, to women between 50-69. These women are those taken from the database including the people assisted by the Region. The invitation is sent by the Local Health Organisations (Management Screening Centre). The GPs receive the list of their own patients invited to the screening programme and give them all the useful information for a fully conscious participation to it. Women resulted positive to the mammography are invited to undergo further examinations.
- 7) As far as the financial issue is concerned, the Italian law n. 138/2004 finances the infrastructures, the equipment and the technology, the computer system and other kind of informative systems and the training activities addressed to the health professionals. The activities linked to the screening programme (see above) are included in the Essential Levels of Assistance.

Breast Cancer - Sicily



CEFPAS - Centre for Training and
Research in Public Health - Caltanissetta,
Sicily

5.2.9.3 Italy (Veneto)⁴¹



⁴¹ No description. Author: Fabio Perina, Veneto Region – Department of Health and Social Services, Venice.

5.2.10 Lithuania (Kaunas) ⁴²

The Health Ministry of the Republic of Lithuania is the executive power institution of Lithuania. In its activity, the Health Ministry is conformity to the law, to Lithuanian Republic Constitution and is following all law statements, documents adopted by Lithuanian Parliament, its following Lithuanian international treaties and President's decrees, Lithuanian Governments decisions and Prime Minister's orders.

The main task of the Ministry of Health is to take care of population health, to strengthen and promote health.

By Health Minister's order Nr. 40 a three level oncological aid system was established and regulated on January 30, 1992.

The Role of family physicians is of great importance: they must have good knowledge of malignant tumours, development, treatment complications, principles of pain killing. They participate in prophylaxis programmes and inform women about them.

In case of emergency, oncological patients are sent to oncological centers (like Kaunas University of Medicine Oncology Hospital). There special and qualified malignant tumours diagnostics and treatment is applied. Surgical, radiation and medicine ways of treatment are applied there.

Patients with complicated situations are sent to the third level (academic) centers: like the Oncology Institute of Vilnius University or Kaunas University of Medicine, Oncology Clinic.

The Oncology Clinical hospital was established in 1997. It has an oncology department (40 beds), a radiation department and a department of chemotherapy day center. Good treatment results are achieved in cooperation with other surgical and therapeutic clinics. Patients having breast, prostate, organs of digestive, central nervous system, female genital organs malignant tumours are treated using chemotherapy, radiation and surgical methods.

By the Lithuanian Republics order Nr. 352, in 2002 Lithuanian State Educational Oncology Center was reorganised to Vilnius University Oncology Institute with clinic and its function is to perform fundamental and applied sciences research work to create conditions for qualification of research workers and specialists, to propagate science knowledge in public; to render health care services. One of the practical tasks is female health check (genitals and breast cancer diagnostics). Another sphere of Institute research is improvement of early cancer diagnostics and new technology methods.

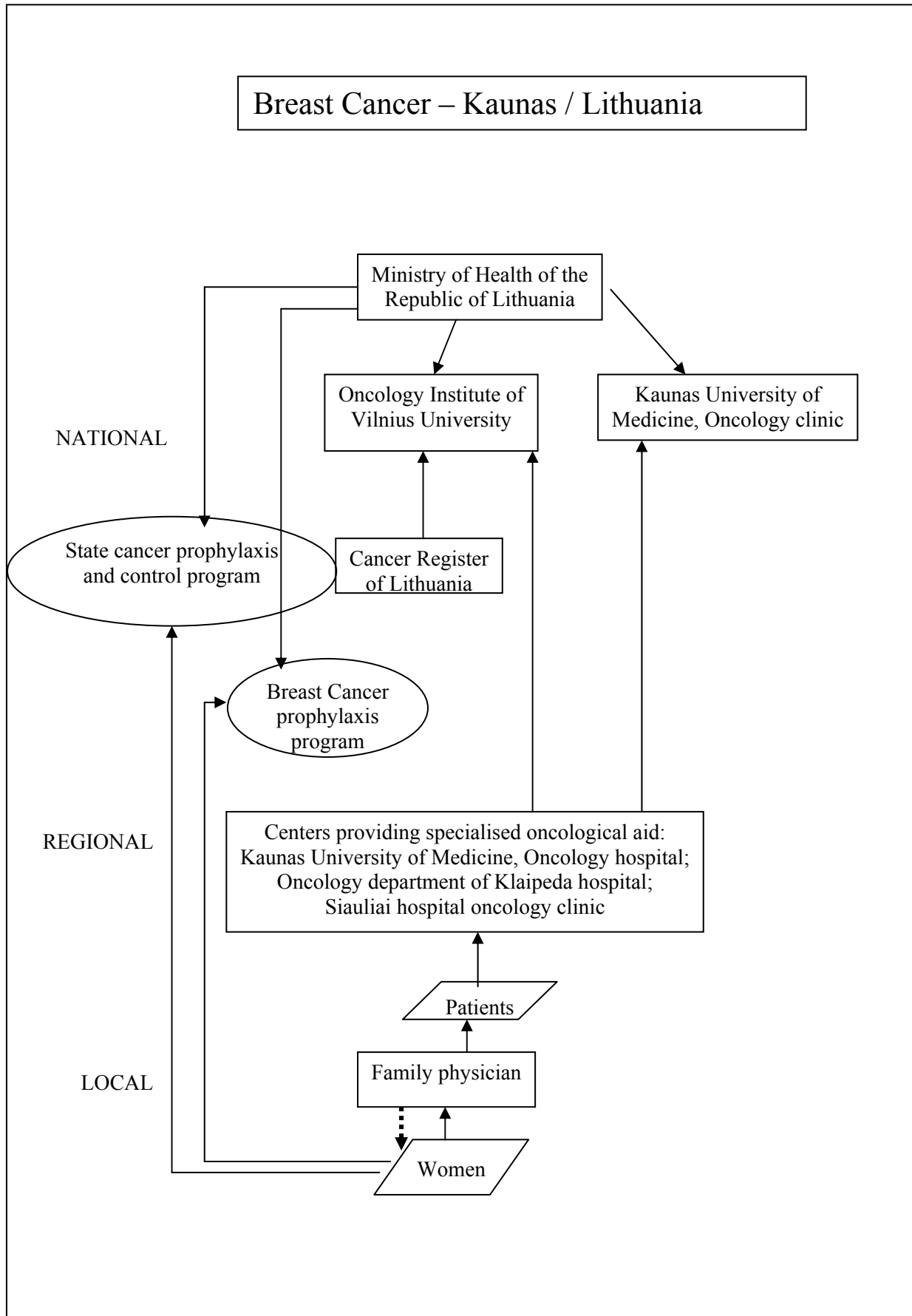
⁴² Author: Evelina Daugeliene, Kaunas Public Health Center, Kaunas.

Rehabilitation after combined cancer treatment is of great importance, programmes to improve oncology patients' life are created. Obligatory Health Insurance Fund compensates prophylaxis programs. One of them is breast cancer prophylaxis program.

The Government of the Republic of Lithuania approved a cancer prophylaxis and control programme for 2003-2010 years. It aims to diminish mortality rate, disablement from oncology diseases.

The programme is prepared with regard to WHO recommendations. The programme gives instructions how to solve oncological problems. They involve cancer prevention, early oncological diseases diagnostics, family physicians training, public education and effective treatment. Ministry of Health of the Republic of Lithuania controls and organises the program.

Cancer Register of Lithuania is established in 1957. Since 1993 Cancer Register has been member of International register association. Cancer Register is a small unit collecting data about malignant tumours and mortality from them. It has information about oncological diseases since 1978. Cancer Register participates evaluating, planning and organising health care services. Scientific reports, information work activities are included into Register's plan. Since 1994 Cancer Register of Lithuania has been publishing issue "Main oncological aid results in Lithuania" based on the statistic data.



5.2.11 Russian Federation (Chuvash Republic) ⁴³

The Ministry of health and social development of the Russian Federation is the body responsible for the development of the state policy and regulation of laws in the prevention of breast cancer at the national level, having the Ministry of health of the Chuvash Republic at the regional level and the municipal health care authority at the municipal level responsible for the issue.

The main functions of the Federal service of surveillance in health care and social development are the quality control of medical care in breast cancer (including prevention), state registration and quality control of medical equipment and drugs used in the treatment and prevention of breast cancer, licensing and funding of the Federal targeted programs.

The Moscow Scientific Research Oncology Center named after Gertsen provides scientific and methodology support of breast cancer prevention. It organises the elaboration of the unified Federal information methodological materials, protocols of cancer treatment (including breast cancer), gathering, overview and assessment of the regional statistics on breast cancer risk factors, morbidity and mortality from breast cancer, comprehensive assessment of the epidemiological situation in breast cancer prevalence and development of the targeted programmes of prevention of breast cancer, provision of highly specialised oncology medical care at the Federal level.

The Association of Oncology and Radiology of the Russian Federation organises seminars, scientific conferences, participates in the development of the methodologies on breast cancer prevention, assists in spreading positive national and international experience of breast cancer treatment. It works in collaboration with the regional Association of Oncologists and Radiologists of the Chuvash Republic.

The republican oncology dispensary is a leading oncology care facility in the Chuvash Republic. It includes the Republican mammological center, responsible for the prevention and treatment of breast cancer.

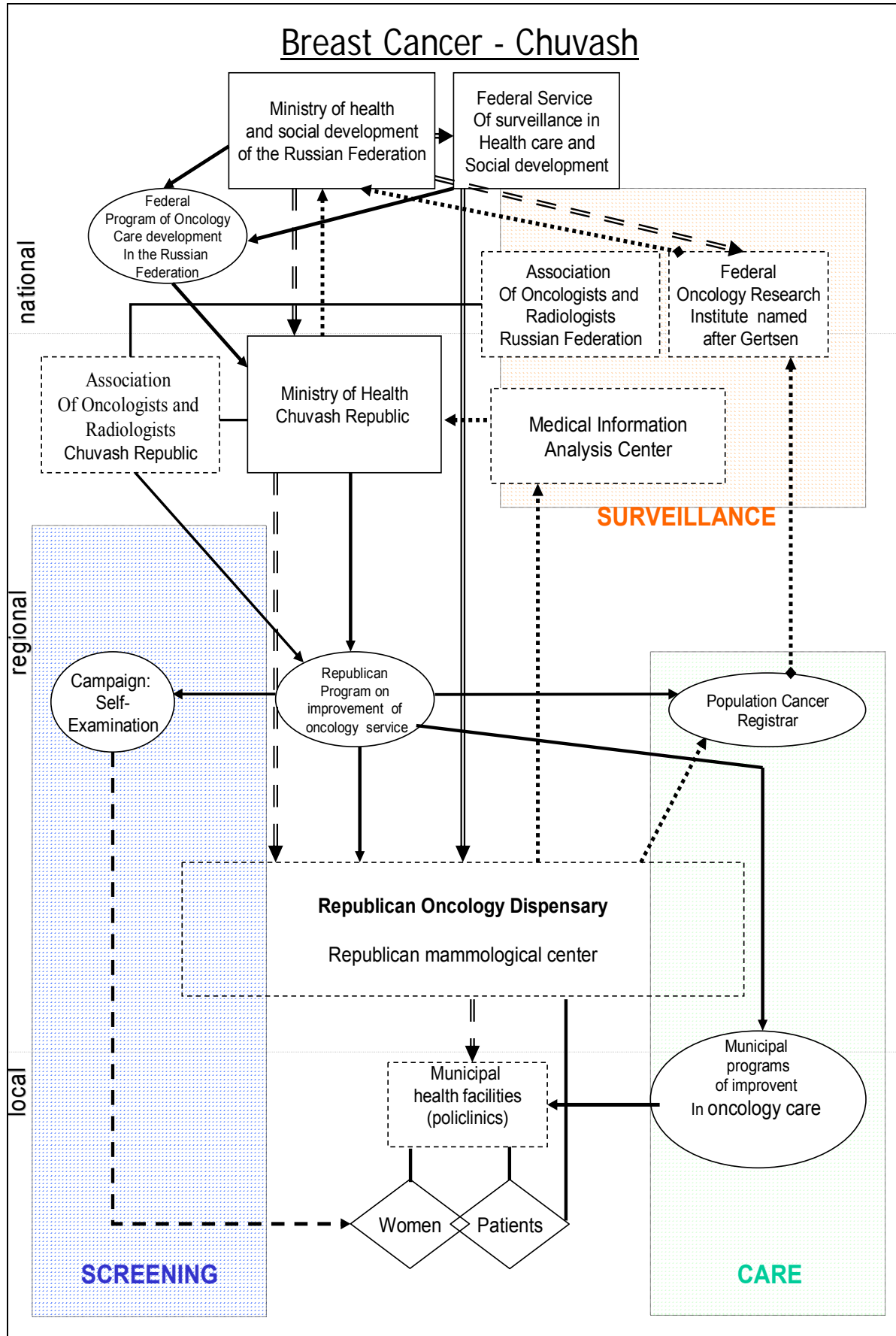
The main functions of the center are the following:

- Epidemiological analysis of breast cancer prevalence at the regional and municipal levels, statistic reporting on the epidemiology of breast cancer.
- Organisation and support of the Cancer Registry which includes all breast cancer cases (passport data, date of diagnosis, progress of disease, stage of treatment)
- Development and implementation of the *Republican breast cancer prevention programs*

⁴³ Author: Igor Dolgov, Republican Oncological Dispensary, Cheboksary.

- Treatment and rehabilitation of breast cancer patients based on the protocols of treatment of breast cancer approved by the Ministry of Health and social development of the Russian Federation
- Control of work in the municipal health care facilities on the prevention and early detection of breast cancer
- Gathering and analysis of screening organised at the municipal (local) level.

At the local level (regions and cities of the Republic) within the framework of the municipal breast cancer prevention programmes nurses, midwives and physicians provide screening for breast cancer. Having detected a nodular structure in the breast, the patient is sent to the mammological center of the Republican Oncology Dispensary where the comprehensive diagnostic process is organised. Since 1995, the WHO training programme on self examination of the breast has been implemented at the primary level (polyclinics, women's consultations, feldsher's stations, general practitioners).



5.2.12 Sweden (Västra Götaland) ⁴⁴

Local level

Patients enter the system either because they have palpated a resistance in the breast or that such a resistance is discovered en passant by the physician, or via the extensive screening programme which has been running since many years in the region. When a suspected resistance is discovered, the patient is referred to a hospital clinic for definitive diagnosis. The role of local level health care is mainly to be an important part of the screening organisation.

Regional level

This organisation is run by the regional health care organisation and is divided into the hospital clinics and in the ambulatory screening units which are visiting the communities following a defined schedule. Women are invited to visit either these units or the hospital based units for a mammography investigation. Any suspicious tumour or suspected x-ray pattern is referred to a specialised surgeon for further investigation comprising a clinical investigation and a fine needle biopsy. Practically all cases are managed at the regional level, within surgical wards.

National level

The national Board of Health and Social Welfare has a supervisory function. It has the responsibility to supervise, to coordinate guidelines, and to promote the regions/county councils to provide care in accordance with the Health Care Act.

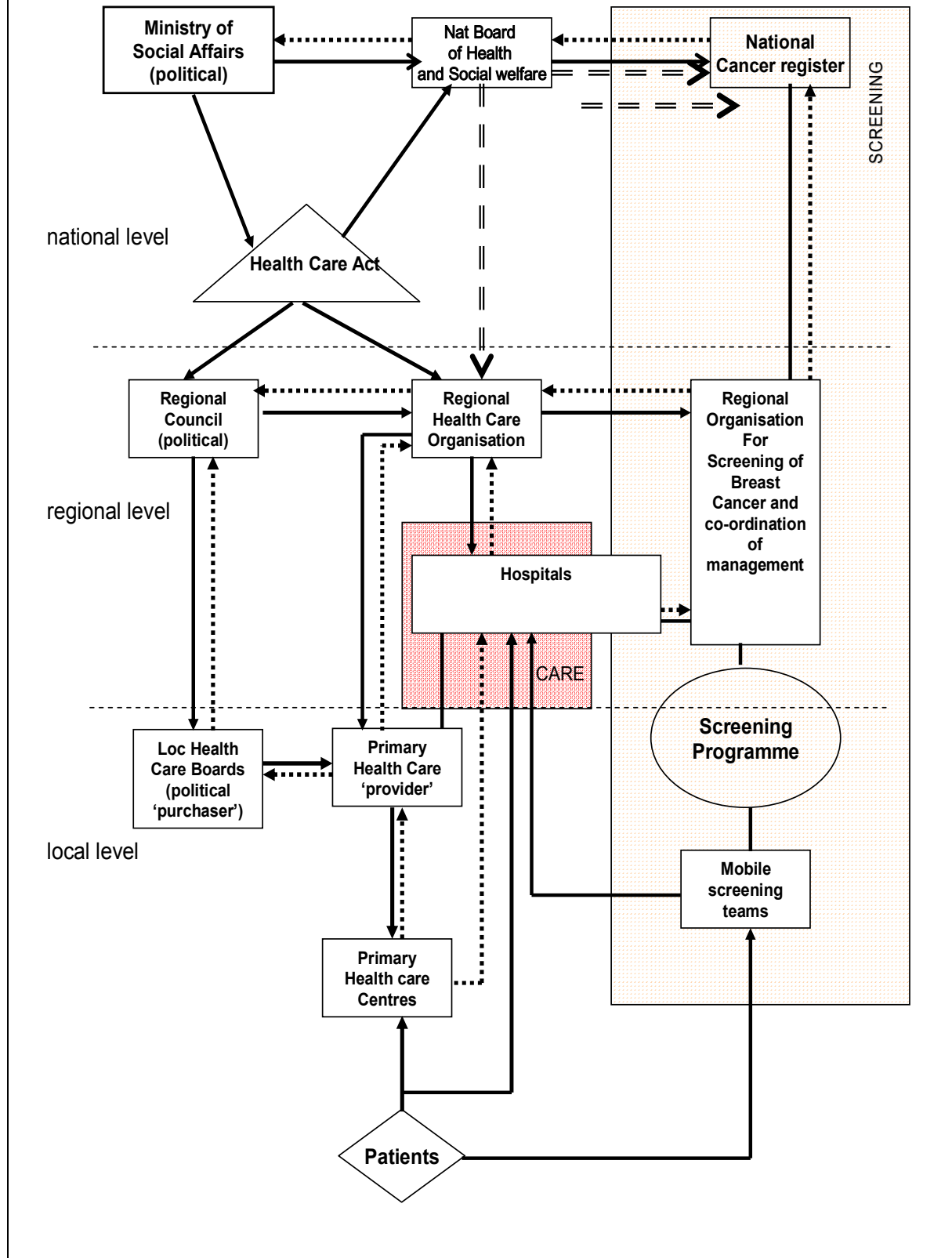
The National Board runs the cancer register, which aims to follow the development of all cancer, regional differences and trends in different parts of the country. This is also a basis for different Quality Assurance initiatives.

Resources

As with all health care delivery in Sweden, the organisation is decided at the regional level within the framework of the Act of Health care. It is financed via taxes, which are also decided by the regional council and to a small extent via patient fees.

⁴⁴ Author: Dr Göran Henriksson, Folkhälsokommitténs kansli Västra Götalandsregionen, Mariestad.

Organigraph for Breast Cancer Management in Västra Götalandsregionen



5.2.13 Switzerland (Ticino)⁴⁵

At national level

The Swiss Conference of Cantonal Ministers, together with the Swiss Federal Office of Public Health and Oncosuisse (Swiss Federation against Cancer, Swiss Cancer League) have worked out the programme 2005 - 2010 against cancer, which lays down the objectives and guidelines for the fight against cancer at national level.

Considering the high degree of political and administrative decentralization, the working out of the legal bases for the fight against cancer in Switzerland is delegated to the 26 cantons, which develop their own health policy and autonomous experiences in health promotion and prevention. This autonomy also concerns social, education and fiscal policy and territorial organisation.

The Swiss Institute for Applied Cancer Research (SIAC) represents the three major domains of patient-oriented cancer research:

- Epidemiological study of cancer frequency, research on risk factors and evaluation of cancer prevention programmes: the *Swiss Association of Cancer Registries*
- Clinical research in children and adolescents with malignant diseases: the *Swiss Paediatric Oncology Group*
- Clinical research in adults with malignant tumours: the *Swiss Group for Clinical Cancer Research*.

The Swiss Institute for Applied Cancer Research coordinates the research activities at the level of prevention, knowledge, treatments and follow-up of the patients and their physicians in Switzerland.

The epidemiological research is carried out by the Federal Office of Statistics, in collaboration with the Swiss Association of Cancer Registries, and includes participation in scientific studies and the standardisation of the activity at national level. The activity of the Swiss Association of Cancer Registries was recently promoted by the national programme against cancer of Oncosuisse.

There are no programmes of national screening, this faculty is delegated to the organisms of cantonal health. At present screening programmes are being run in five French-speaking Swiss cantons.

⁴⁵ Author: Dr Mario Lazzaro, Cantonal Office of Public Health, Bellinzona.

At regional level (cantonal):

Ticino is one of the 26 Swiss cantons, the only Italian-speaking region in Switzerland with 316,000 inhabitants, on the southern side of the Alps.

The five ministers of the cantonal government are elected directly by the voters; there is no coalition but a government based on consent.

The legislation, health policy and planning are within cantonal competence.

The regional public hospitals, private clinics, the Cantonal Institute of Oncology and the Breast Research Centre are responsible for the clinical part of the fight against cancer; they are grouped together under the Cantonal Hospital Board. The Cantonal Institute of Pathology (CIP) is the institution responsible for the analyses, definition and recording of tumour cases. The institute includes three structures, which collaborate with each other; these are the Pathology Laboratory (PL), the Cantonal Cytological Centre (CCC) and the Cancer Registry of Canton Ticino (TRCT).

The material to be analysed is reported and transmitted by private physicians, by the private and public out-patient structures of the Canton, by public hospitals and private clinics as well as by other residential structures. The results of the analyses carried out by the Institute of Pathology are sent back to the applicant and transmitted to the Cancer Registry.

At regional level there are no screening programmes.

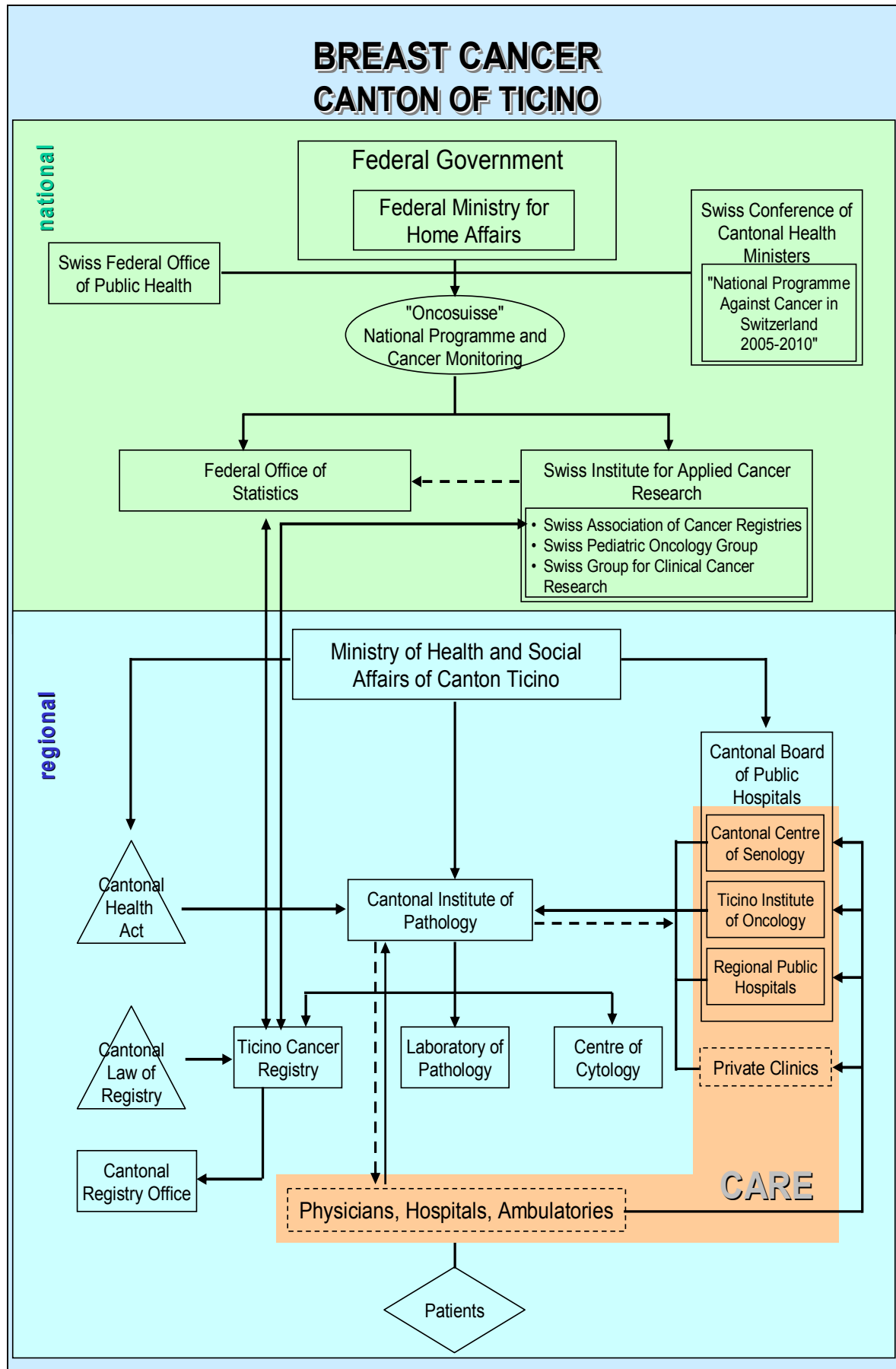
The responsibility for specialist training for physicians lies within the scope of the Cantonal Institute of Pathology.

The activity of the Cancer Registry is regulated by the Cantonal Law on Registries (Law on the Registry of Cancer of 21 June 1994).

Its main aim is the definition of the epidemiological situation in the canton and the comparison with other national and international geographic areas. At national level it collaborates with the Federal Office of Statistics and with the Swiss Association of Cancer Registries.

Moreover, for the data management and the follow-up of the cases the Cancer Registry receives information from the Registry Office of residents at regional level.

The Cancer Registry produces and regularly publishes data on the incidence of tumours and survival and contributes to studies at regional, national and international level.



5.2.14 United Kingdom (England)⁴⁶

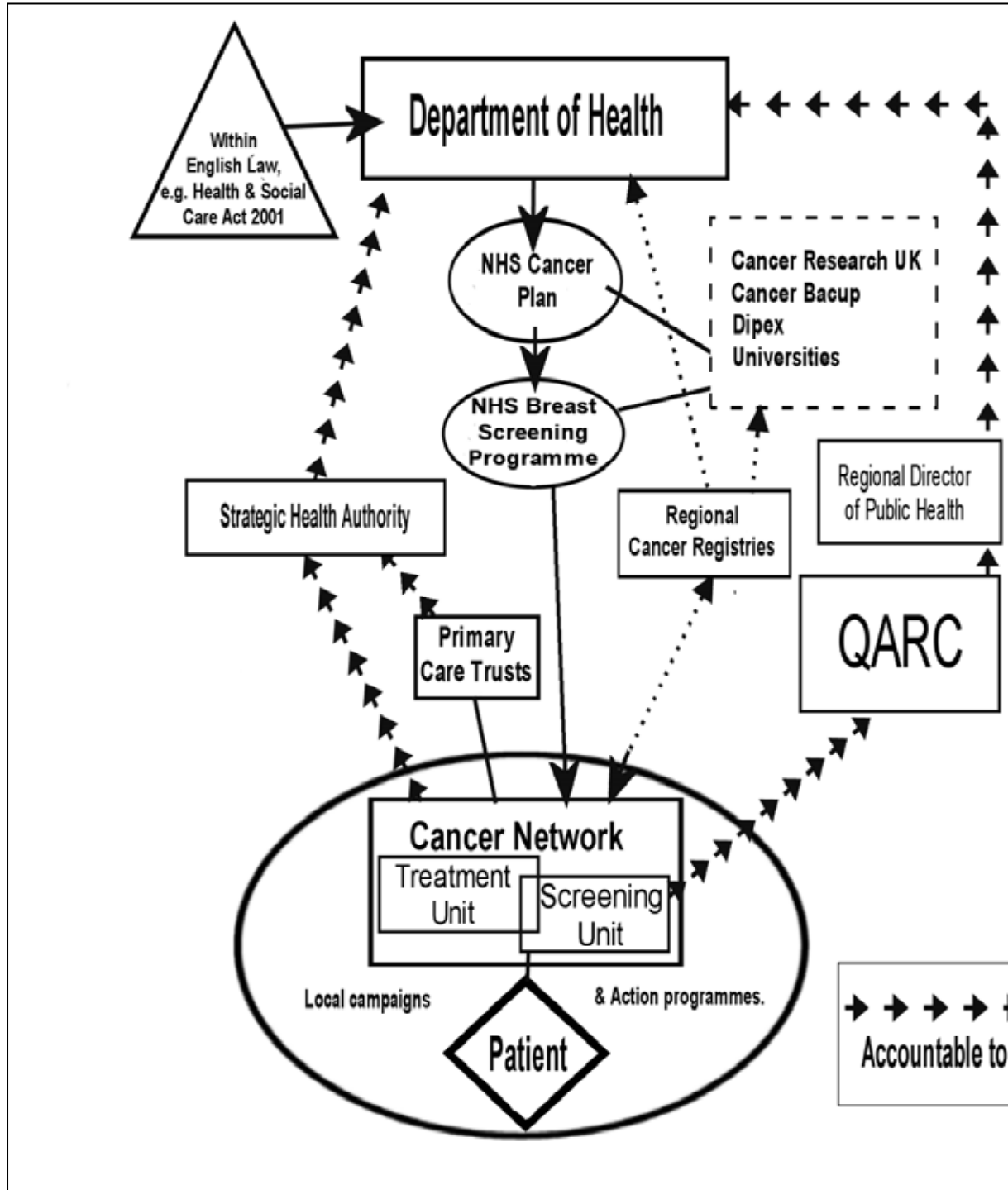
1. **The NHS Cancer Plan** (2000) sets out the first comprehensive national cancer programme for England providing a comprehensive strategy for bringing together prevention, screening, diagnosis, treatment and care for cancer and the investment needed to deliver these services in terms of improved staffing, equipment, drugs, treatments and information systems.
2. **The NHS Breast Screening Programme** provides free breast screening every three years for all women in the UK aged 50 and over. Around one-and-a-half million women are screened in the UK each year. Women aged between 50 and 70 are now routinely invited.
3. **Quality Assurance Reference Centres** Each NHS region has a quality assurance director for breast screening and a quality assurance reference centre. Each regional quality assurance director is supported by a regional quality assurance team which includes a professional coordinator from each of the professions which contribute to the breast screening programme (radiology, radiography, pathology, surgery, breast care nursing, administration and medical physics). Each professional coordinator meets regularly with colleagues in the region to review the performance and outcomes of the breast screening programme, to share good practice and to encourage continued improvements in the programme. There is also a programme of regular quality assurance visits to breast screening units. These provide a further means of assessing the performance of the breast screening programme and of professional competence within the programme. The quality assurance reference centres collect and collate data about the performance and outcomes of the breast screening programme, organise quality assurance visits, and provide support for the regional director of quality assurance and the professional coordinators. The reference centre is the first point of contact for information about the breast screening programme in the region. The QARCs are responsible to regional Directors of Public Health who are responsible to the Department of Health.
4. **The cancer network** is the group of cancer services available in a given area. There are 34 cancer networks in England. The principles behind cancer networks require that their constituent organisations have a duty of partnership to work together effectively to improve cancer services for the benefit of patients. Cancer network services are commissioned by the Primary Care Trusts that govern the areas that

⁴⁶ Author: Author: Paul O'Connell, Research Officer, University of Brighton.

their services deliver to. They are responsible to their host Strategic Health Authority.

5. **Local Breast Screening Units** operate as part of wider Cancer Networks. There are around 90 breast screening units across the UK, each currently inviting an average population of around 45,000 women. They are accountable to Quality Assurance Reference Centres.
6. **Local Breast Treatment Units** operate as part of wider Cancer Networks. They may share some of the same staff as screening units.
7. **Regional cancer registries** are responsible for the collection, analysis and dissemination of cancer data for the whole of an assigned region. There are 9 UK cancer registries.

Breast Cancer: REGIONAL ORGANIGRAPH (ENGLAND)



5.2.15 Discussion⁴⁷

The following discussion draws on the introductory systematic remarks made in the analogous discussion of the measles organigraphs (5.1.16).

Organigraphs and Programme Descriptions for Breast Cancer

Organigraphs for breast cancer were received from 17 of the 19 regions. Programme descriptions were received from 15 regions. No organigraphs or programme descriptions for diabetes were received from Saxony-Anhalt (DE) or Madeira (PT). Gyor-Moson-Sopron County (HU) and Veneto (IT) submitted organigraphs only. Whilst the organigraphs can give an overview of the health management system, the programme descriptions can give a number of more detailed insights into the system.

The programme descriptions received with the organigraphs refer principally to breast screening programmes and to a lesser extent to treatment and care. Two types of screening programme are included – professional breast examination allied to self-examination, and mammography screening.

The first type of screening programme, professional breast examination, is shown or described by 5 regions, Upper Austria (AT), Varna Oblast (BG), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), and Chuvash Republic (RU). Western Greece (EL) has no programme as such but a number of individual initiatives. All of the programmes are national screening programmes implemented nationwide, but with the addition of self-examination campaigns by two regions, North Rhine-Westphalia (DE) and Chuvash Republic (RU). Because they are national programmes they are part of a *chain* from national through regional to local level. Such programmes and self-examination campaigns are in line with the good practice interventions included in the reference framework for breast cancer.

The second type of screening programme, mammography screening, is shown or referred to by 11 of 17 regions, Flemish Community (BE), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Gyor-Moson-Sopron County (HU), Szabolcs-Szatmar (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Vastra-Gotaland (SE), England (UK).

⁴⁷ Kieran Hickey, Health Service Executive, Dublin.

Part of Western Greece (EL) is covered by a mammography screening programme. Varna Oblast (BG) has periodic mammography campaigns and Upper Austria (AT) will participate in a planned national mammography screening programme.

The 11 mammography screening programmes are organised differently in a number of respects, 6 (CZ, DE, HU (2), IE, UK) are organised at national level and 5 (BE, IT (3), SE) at regional level, taking account of the goals of national prevention plans and national guidelines. The *chain of control* can therefore run from national to local level or from regional to local level.

But there are other differences, shown in the business model for the implementation of the programmes. In BE, CZ and HU (2) a number of recognized or accredited screening centres are contracted to provide the mammography screening service. In IT (3) and SE the mammography screening is provided directly by the regional/local health service. In ER (IT) there is a dedicated regional office for screening that co-ordinates the mammography screening programme. In SE there is a separate regional organisation shown screening for breast cancer and co-ordination of management. In IE the mammography screening service is organised and managed by a dedicated, nationally funded, stand-alone statutory board that employs its own staff and resources and contracts with host hospitals for follow-up services. In the UK mammography screening is provided under the NHS breast screening programme. Mammography screening units are part of local cancer networks or *webs* and accountable to a Quality Assurance Reference Centre (QARC) at regional level that has a director and support team including co-ordinators from each of the professions.

Most of the regions with mammography screening programmes indicate or refer to invitation systems and quality assurance arrangements in operation. The programmes operate under national or regional guidelines drawn up with the advice of one or more expert bodies. Some operate under EUREF guidelines or undergo EUREF evaluation, BE, DE and IE.

So, apart from noting that the initiation and promotion of manual breast self-examination, professional non-mammography breast examinations and quality assured mammography screening programmes are integral parts of the reference framework for breast cancer, what other conclusions can be drawn from the above? If one refers to the health performance indicators data available for breast cancer (cf. annex 5) the data for percentage participation rate for eligible women in mammography screening and the breast cancer detection rate, particularly the former, appears to suggest that contracted screening services do not perform as well as directly provided services. The best participation rates for 2005 or nearest year were achieved in directly provided services where there is also a dedicated management or

co-ordination *hub*, i.e. in IE, ER-IT, SE and UK. It may also suggest that the screening services that are contracted out might perform better if a dedicated management hub were in place.

Disease Management Programmes and the provision of integrated care are part of the reference framework for breast cancer; so also is treatment by interdisciplinary teams and the supports of psycho-social care and counselling; also follow-up care and rehabilitation.

In looking at treatment and care services for breast cancer it seems from the organigrams and programme descriptions that for 13 of the 17 regions that responded there is a system or programme of integrated care in operation, Upper Austria (AT), Flemish Community (BE), Varna Oblast (BG), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Szabolcs-Szatmar (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Kaunas (LT), Chuvash Republic (RU), Ticino (CH). England (UK) refers to the principles behind cancer networks, the group of cancer services available in a given area, and indicates that their constituent organisations have a duty of partnership to work together effectively to improve cancer services for the benefit of patients. However no information is given about the operation of the treatment units that are part of the cancer networks.

Integrated care is shown or described by regions as being based on a specialist breast unit or multidisciplinary oncology centre at regional or local level. Some regions indicate that a Disease Management Programme (DMP) is wholly in operation, NRW-DE and Sicily-IT, whilst Upper Austria (AT) indicates that a DMP is partly in operation and Veneto-IT refers to the operation of Disease Management Protocols. The specialist units or centres are shown to be accountable to the regional health service level whereas the DMPs are shown to originate from national level. The guidelines under which they operate are shown to be provided by a national cancer society or institute, a professional association of specialists, a medical association, a scientific society, and in one region, Sicily (IT), patients' associations are also shown to contribute to the DMP. There is reference by some regions, in CZ, NRW-DE and IE, to psycho-social support and also rehabilitation being part of the integrated care. Kaunas-LT refers to rehabilitation as being included in the integrated care.

There is reference in the programme descriptions by a number of regions to surveillance data from breast cancer screening and treatment services being necessary for the evaluation and quality assurance of these services and for linking these two elements of service. The establishment of cancer/breast cancer registers and obligatory reporting are part of the reference framework for breast cancer. Cancer registers are therefore an important *hub* in the overall health management system for breast cancer.

The organigraphs and programme descriptions indicate that surveillance and cancer registers, including breast cancer, are in operation in 16 of the 17 regions that responded. A surveillance *chain* from local to regional to national level is not in place in all of those regions. The most common location for a cancer register is at national level. National cancer registers are shown to be in operation in Upper Austria (AT), Moravia-Silesia (CZ), Western Greece (EL), Győr-Ménfőcsanak (HU), Szabolcs-Szatmár (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Sicily (IT), Kaunas (LT), and Västergötland (SE).

North Rhine-Westphalia (DE) shows a central cancer surveillance programme at national level. Veneto (IT) refers to a national screening monitoring centre. Chuvash Republic (RU) shows a national oncology research institute. Ticino (CH) refers to the Swiss association of cancer registries and to the federal office of statistics.

Regional cancer registers are shown in Flemish Community (BE), Varna Oblast (BG), North Rhine-Westphalia (DE), Western Greece (EL), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Chuvash Republic (RU), Ticino (CH) and England (UK).

Two regions, Emilia-Romagna (IT) and Sicily (IT), show cancer registers at local level.

Information and education for health professionals and training of the breast cancer workforce are part of the reference framework for breast cancer.

The organigraphs and programme descriptions do not touch very much on this area. Varna Oblast (BG), Western Greece (EL), Szabolcs-Szatmár (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Sicily (IT), Kaunas (LT), and Chuvash Republic (RU) refer to provision of information and education for health professionals regarding mammography screening. Kaunas (LT) and Ticino (CH), refer to specialist training for physicians as part of the role specialist particular oncology and pathology institutes.

Information and education of the public and support for mutual self-help groups are included in the breast cancer reference framework.

This area is not touched on very much in the organigraphs and programme descriptions except for references by some regions to public information and education about breast screening programmes, some with the involvement and assistance of NGOs or patients' associations. Wider public information and education campaigns are mentioned by a small number of regions. Also only a small number of regions mention or show wider involvement by citizens associations or initiatives towards patient empowerment.

The organigraphs and programme descriptions demonstrate that a complex system with many actors underlies the management of breast cancer. The challenge of achieving a

concerted approach, maximising the impact of the current ‘state of the art’ is considerable. How to measure success in this regard is also difficult because many factors may underlie the health performance indicators for breast cancer morbidity and mortality. The organigraphs and programme descriptions do however give some useful insights when they are related to the reference frameworks for breast cancer.

5.3 Diabetes (type II)

5.3.1 Austria (Upper-Austria)⁴⁸

The Federal Government is responsible for legislation, formulating health policy and general directives. The State Government, assisted by the Health Authority, is responsible for carrying out directives and implementing laws in policies.

There is no centralised decision making or implementation of health promotion activities, basically due to the federal structure of the country.

Screening

The Ministry of Health and Women, the Austrian National Health Insurance and the National Medical Council create a new basis for Health Screening Examinations (Vorsorgeuntersuchung Neu/VU-NEU 2005). The screening also includes Glucosetests, cardio-vascular prevention checks and anamnesis status (risk factors). I.e. Diabetes Screening is part of the VU-NEU and Diabetes mellitus (Type 2) is one of the prevention targets of the VU-NEU.

Preventive and screening activities are offered by public health offices, social insurance outpatient offices and physicians in ambulatory care (General Practitioner or Specialist).

Care

Diabetes care mainly takes place in ambulatory care and depending upon referral by a GP or a specialist in hospitals. National as well as regional Associations of Diabetes Specialists recommend guidelines and supervise to take part in the Quality Management Programme stated by the WHO-St. Vincent Declaration. Diabetes Management Programmes take place occasionally but not based at national or regional level.

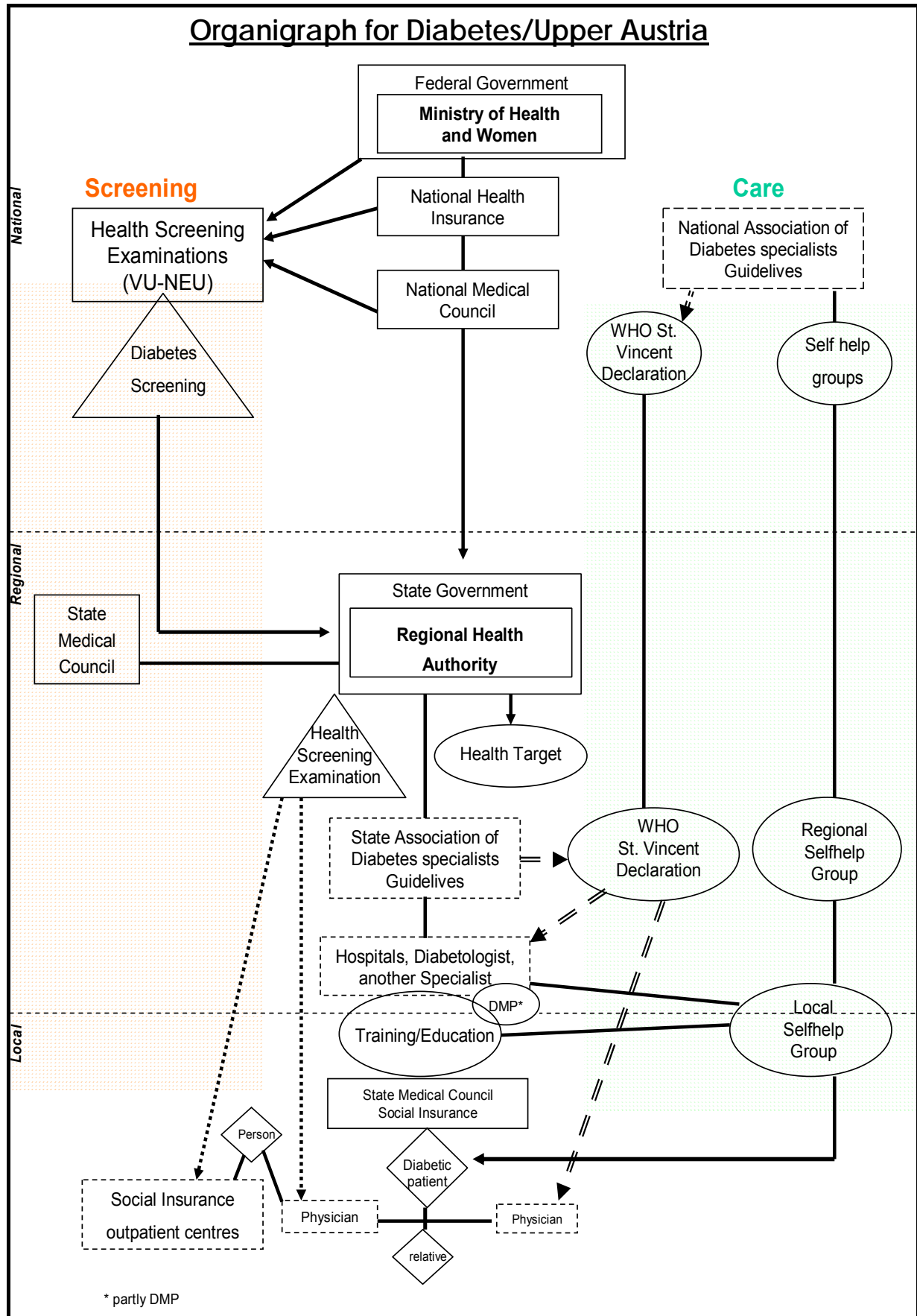
A Diabetes Management Programme (DMP), based on the “Düsseldorfer Modell” took place as a pilot (2002/2003) involving 19 GPs and 470 Diabetes Type-2-patients.

Those programmes include regular screening of the Diabetes patient according to the WHO-St. Vincent Declaration (laboratory checks, foot checks, eye checks etc.). Focus is also training and education as well as to strengthen the empowerment of the Diabetes patient. The region-wide implementation of that DMP is in planning.

In 2000, the regional government of Upper Austria together with the Regional Health Authority and the Insurance Company of Upper Austria came up with 10 targets for the re-

⁴⁸ Author: Dr Reli Mechtler, University of Linz, Departement of Health System Research. Author Organigraph: Dr Heinrich Gemeiner, Health Authority Upper Austria, Linz.

gion. Target 1 is directed at the reduction of Diabetes complications such as amputation, blindness, renal failure or complications in pregnancy.



5.3.2 Belgium (Flemish Community)⁴⁹

Which institutions/organisations have the main responsibility for health management at the local, regional and national level?

- RIZIV: the National Institute for Health Insurance pays for medication and treatment (diabetesconventie and diabetespas)
- FOD Volksgezondheid (national ministry of public health): overall coordination of medical practice for improvement of the medical and social situation of diabetic patients (e.g. consensus conference on social discrimination of diabetic patients in 1998)
- Hospitals (local): specialised diabetes teams (with at least a specialist in internal medicine/endocrinologist/diabetologist, a diabetic nurse and a dietitian, in most cases also with a podologist)

Which further institutions/organisations are involved and how do they relate to each other?

- VDV = Flemish diabetes association (regional). This is a patient organisation in which also care providers are actively involved. This organisation is active in the defence of rights of patients (e.g. against social discrimination), raising awareness (including prevention and early detection), development of optimal treatment (through providing information to patients, distribution of materials, stimulation of self care by patients and organisation of training courses for diabetes educators and other health care providers), and stimulation of scientific research. Website: <http://www.diabetes-vdv.be/>
- BDR = Belgian Diabetes Registry (national) = collaboration of university diabetes research centers, doing clinical research on causes, prevention and treatment of diabetes.
- Scientific Institute of Public Health (national): epidemiological studies, surveillance and registration, initiative for quality improvement (IKED)
- WVVH = Scientific Association of Flemish General Practitioners: collaborates in the development of the diabetic health management project for Flanders, which included development of a consensus document on the interdisciplinary treatment of type 2 diabetes, of expertise packets (on early detection, diet, medication, foot care, motivation

⁴⁹ Author: Dr Pieter Vlandenburg, Ministry of Flanders, Administration of Health Care, Brussels.

and follow up), of expert courses for GPs (CME) and of working with the diabetic passport.

- Ministry of Flanders – administration of health (regional): prevention + surveillance
 - The health promotion unit of the Flemish ministry of health provides funding for partner organisations (VIG + logo's) to promote healthy lifestyles
 - Several projects have been put in place at local level to encourage people at risk to consult their GP and have a test for diabetes mellitus type 2. These are targeted at people from the age of 45 years in the communities involved, who have certain symptoms or risk factors as described in a questionnaire. The goals of the projects are sensibilisation of the inhabitants of these communities for the risk for diabetes and detection of unknown type 2 diabetes in an early stage in patients with risk factors for type 2 diabetes.
- VIG (= Flemish institute for health promotion – regional) + Logo's (local organisations working on health promotion): these organisations are funded by the Flemish ministry of health to implement its policy concerning disease prevention and promotion of healthy lifestyles

Do registries exist? If so, how do they work?

- Morbidat = registration by a Belgian network of primary health care practices, a collaboration between the Scientific Institute of Public Health (department of epidemiology) and the Flemish and Walloon scientific associations of general practitioners. Since 1991, this is financed by the Flemish and French community. Since 1997-1998, a detailed registration of type 2 diabetes is performed by these primary health care practices all over Belgium. The aims of this registration are:
 - to determine the presence of complications and their stage at the moment of diagnosis of new cases of type 2 diabetes;
 - to determine the presence of risk factors at the moment of diagnosis of new cases of type 2 diabetes;
 - study the relationship between the stage of complications and the presence of risk factors;
 - follow up during at least 2 years the treatment of these patients and occurrence of complications;
 - study the relation between follow-up and development of complications at one hand and the stage at diagnosis.

In 2000, the incidence and prevalence of diabetes were studied in the framework of a European project, as well as the circumstances of diagnosis and therapy.

- **IKED-study:** registration and quality improvement project of diabetic care by the convention centres. All Belgian multidisciplinary convention centres for diabetes (N=ca 130) participate in this study, which is coordinated by the Scientific Institute of Public Health and performed in the framework of the agreement for revalidation concerning self regulation of diabetic patients (RIZIV). By repeated (2001, 2002, 2004) collection of data on intensively treated patients (at least 2 insulin injections/day), as admitted to the convention (10% of these patients) followed by feedback, local evaluation in time of the care provided is possible, and this also in comparison with other centres. This is also followed by a qualitative evaluation of measures taken to improve quality in the centres. In this way a continuum of quality evaluation and improvement is realised. A report of each data collection is made, thus providing a general overview of the care provided by the Belgian convention centres.
- A similar registration project aimed at quality improvement was performed in primary practice by the Scientific Institute of Public Health (WIV) in collaboration with the Scientific Association for primary care (WVVH) in 2002.
- **BDR= Belgian Diabetes Registry:** This registry was founded in 1989 to collect scientific data of patients diagnosed under age 40 and of their first degree relatives. Patients who just developed diabetes qualify for registration, free of charge, in the Belgian Diabetes Registry. The only conditions are that the patient in question is younger than 40 years at diagnosis and that registration occurs within 18 months after diagnosis of diabetes was made. The type of diabetes (type 1 or type 2) is not important. Also first degree relatives (parents, brothers or sisters and children) of type 1 diabetic patients may apply on a voluntary basis. After diabetes has been established, the participating physician takes a blood sample and fills in a questionnaire. These data remain absolutely confidential and are only collected with the explicit agreement of the people concerned. They allow distinguishing the different forms of diabetes, to determine the risk to develop diabetes in family members and to select subjects that may participate in prevention studies. Afterwards, there is a yearly follow-up. The registry is directed by a steering committee with specialists in different fields. Meanwhile, more than 100 diabetologists from seven universities and about sixty non-university institutions scattered throughout Belgium are participating. More than 3,000 diabetic patients have al-

ready been registered, and every year about 300 others are added. In many cases data about their relatives were also included. Website (also in english): <http://www.bdronline.be/>.

Are there campaigns/action programmes of major importance?

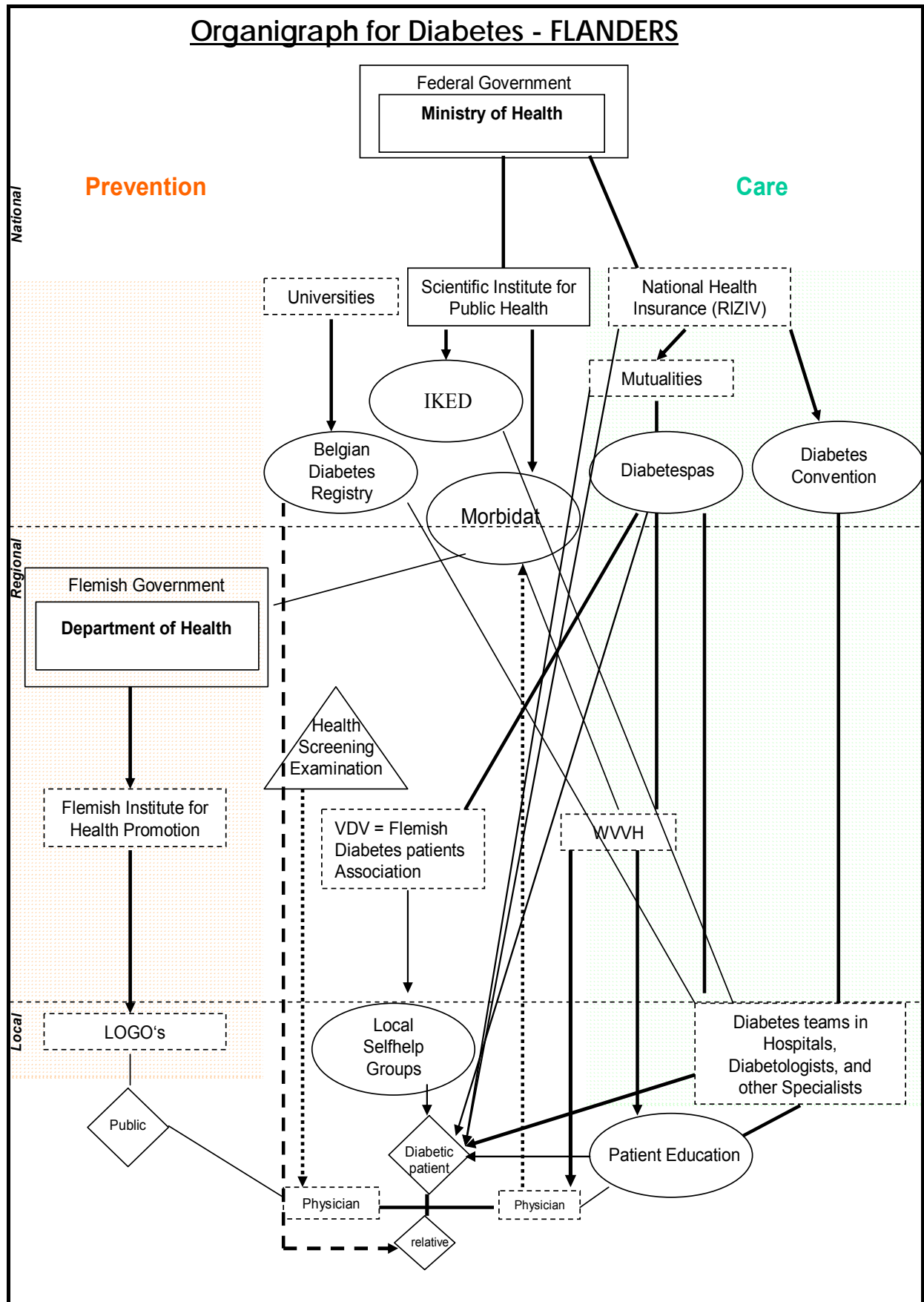
- **Diabetesconventie:** Since 1987 a so-called 'convention for diabetes' exists. This consists of an agreement between the RIZIV and about 130 hospital centres for diabetology, in order to provide testing material for self control free of charge for certain categories of diabetic patients. Only hospitals with a specialised diabetes team (with at least a specialist in internal medicine, a diabetic nurse and a dietitian) can have such a convention. The RIZIV pays for the testing material (a glucose meter, strips, ...) and for the education of the patients, on all aspects of treatment and prevention of complications. Only patients treated with at least 2 insulin injections per day are eligible for the convention. They must be prepared to control their glycaemia at least once daily and have to be followed by the diabetic team, which works in close collaboration with their family physician. There are 3 categories of patients:
 1. diabetic patients who are treated with at least 3 injections daily or with an insulin pump, and who perform intensive self control (4x/d); they can receive a maximum of 140 strips/month.
 2. diabetic patients who are treated with 3 or more injections daily but who do not perform 4 measurements a day; they can receive a maximum of 70 strips if they measure at least 4 day curves a week.
 3. diabetic patients who are treated with 2 or more injections but measure only 2 day curves a week; they receive only 30 strips/month.

Patients who measure less are not taken up in the convention. Patients who use more strips than the maximum have to buy them themselves. To be entitled to receive the strips, patients have to prove that they have measured. This used to be done by holding a diary in which the results were noted, but now meters are used which can be directly printed out, so that there is an immediate control.

Special categories of patients that are admitted to the convention are pregnant women (diabetic patients who want to become pregnant, who are pregnant, and women with pregnancy diabetes), kidney patients (on dialysis or after transplantation), diabetic pa-

tients after pancreatic or b-cell transplantation and children under 18, even if they are not insulin treated.

- Zorgvernieuwingsproject Diabetes, met invoering van **Diabetespas**: In March 2003, a passport for diabetes was introduced as part of a new health care management programme. This 'passport', which is in fact more a small booklet, aims to improve the communication between the health care providers (for patients with type 2 diabetes, which are not in the convention). It contains instructions on the treatment of diabetes, forms to organise follow up and other useful document. Diabetic patients can receive this passport from their mutual insurance fund, with a simple form completed and signed by their treating medicine (general practitioner or specialist). The booklet is held by the patient, who has to take it at each visit to a health care provider (GP, pharmacist, dietician, podiatrist, specialist ...), who can then make notes in it, so that it can be used as a mini-file. In this way, all members of the team are aware of the aims of the treatment, changes in medication, test results, etc. Moreover, a patient with a diabetic passport is entitled to receive extra financial ... (of about 75%) for the following treatments: twice a year a consultation of half an hour with a registered dietician, and two consultations a year with the podiatrist (for patients at risk for foot injuries). The passport is valid for 3 years. It was developed by the Flemish Diabetic Association (VDV) and its Walloon counterpart (ABD), the Flemish and Walloon scientific associations for primary health care and the health insurance companies.
- Nationaal project diabetische voet 2002: as a follow-up of the St-Vincent declaration, a national project focused on the diabetic foot was set up. Concrete initiatives were the use of specific letters for referral and the start of several new diabetic foot clinics, with multidisciplinary teams consisting of a diabetologist, diabetic nurses, a vascular surgeon, an orthopaedic surgeon, a dermatologist, a neurologist, a podiatrist and an orthopaedic shoemaker.
- In 1998, a large campaign called 'Levenslijn' ('lifeline') was set up for sensibilisation and collecting of funds for research and care programmes.



5.3.3 Bulgaria (Varna-Oblast)⁵⁰

The Bulgarian national health care system is built up on three levels – national, regional and municipal. The management and coordination on the three levels is carried out as follows:

- National level – by the Minister of Health, who represents the state institution responsible for health care;
- Regional level – by the Director of the Regional Health Centre, which is the regional representative of the Ministry of healthcare;
- Municipal level – by the Director of the municipal unit responsible for healthcare.
- The total number of diabetics in the country is 300.000, 70.000 of whom use insulin. The National Health Insurance Fund refunds the medications of 180.000 diabetics and is going to refund a third insulin analogue.

The average annual costs of the National Health Insurance Fund for the medications of one diabetic are from 700 to 800 BGL.

The above stated proves that diabetes is a socially significant disease and a national priority.

A consultative council on diabetes was established according to a decree issued by the Minister of Health. The council members are leading specialists in endocrinology, representatives of the National Health Insurance Fund and representatives of non-governmental organisations. The council is responsible for initiating activities and making proposals concerning diabetes policy (including medication policy) to the Minister of Health.

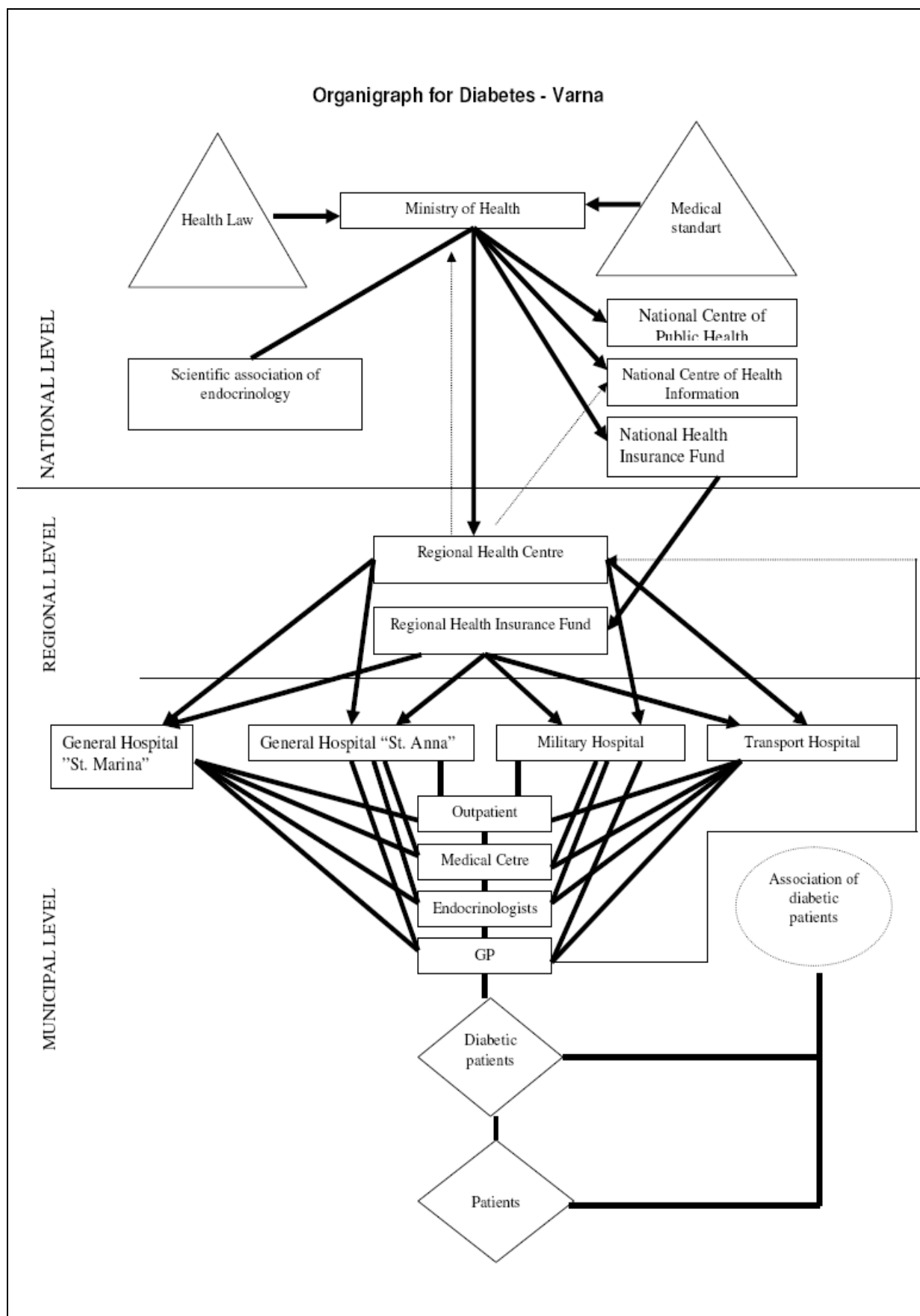
There are four diagnoses relating to diabetes and its complications according to a decree (Decree for determining the diseases fully or partially refunded by the National Health Insurance Fund home treatment) issued by the Minister of Health on the basis of the health insurance law in force. And these four diagnoses are: diabetes mellitus-I, diabetes mellitus-II, diabetic polyneuritis and diabetic gangrene.

The medication list of the National Health Insurance Fund is extremely rich and diverse, exceeding in number of included medications the essential list of the WHO.

Regional Health Centres support a Register of diabetics, the information in which is permanently renewed according to the data coming from the GPs. The register information includes the patient's name and main data regarding diabetic patients.

The collected and generalised information from the register is sent to the National Centre for Health Information.

⁵⁰ Author: Prof Kiril Christozov, MD, PhD, Endocrinology Clinic, General Hospital "St. Marina", Varna.



5.3.4 Czech Republic (Moravia-Silesia)⁵¹

Diabetes screening is performed in the Czech Republic according to the “Health Order“. (Health regulation, which implements the guidelines of the Czech Diabetes Society for the screening of diabetes mellitus). General practitioners have the major role in diabetes screening. They are responsible for inviting people aged more than 45 years old for fasting glycaemia sampling every two years. For the same sampling people at risk (with obesity, occurrence of diabetes in family history, occurrence of gestational DM, hypertensive persons, persons suffering from dyslipoproteinemia etc.) are also invited but in higher frequency (once a year) and independent of their age. The coverage of this screening is from public health insurance.

General practitioners are instructed how to proceed in diagnostic algorithm to confirm or exclude diabetes and how to cope with borderline disorders of glucose homeostasis. These instructions are provided in regular educational activities provided in co-operation between the “Union of General Practitioners“ and the Regional Diabetes Centre.

Unfortunately in the Moravia-Silesia region as in the Czech Republic, there are in general no regular inspection activities of the Regional Health Authority to survey this aspect of diabetes care. Neither the Czech Diabetes Society nor other professional bodies are involved in surveillance activities.

Among the GPs there is an interindividual variability in call and recall systems but there is also an effort from the joint initiative between Health Insurance Companies and Regional Health Authority to fund only properly made screening examinations. The Health Insurance Companies record levels of attendance and non-attendance. Special interest in this field demands screening activities for socially deprived people, disabled people or ethnic minority groups.

Dissemination of results and further treatment

Diabetes screening is carried out by blood sampling in the fasting state. The examined person is informed about the result within a few days afterwards. In the case of elevation of blood sugar, the examined person is asked to undergo consecutive sampling or performance of oral glucose tolerance test, when needed.

Persons diagnosed with diabetes first of all need education and nutritional advice. GPs can usually provide this information in very limited range in our region and that is why they often use the service of special diabetes outpatient offices. In these offices, diabetes nurses

⁵¹ Author: Dr Arnost Martinek, CSc, University Hospital, Ostrava.

provide information so that people with diabetes develop the knowledge to self-manage their diabetes. GP's or diabetes specialists take care of people with type 2 diabetes treated with diet or oral hypoglycaemic agents. In the Moravia-Silesia region as in the Czech Republic in general, diabetes specialists look after people with type 1 diabetes or type 2 diabetes treated with insulin.

Information and education

Citizens of our region were informed about diabetes mainly via booklets and posters produced by the National Institute of Public Health in the past. These information resources were distributed to health care facilities all over the region. Mass media play a great role in information campaigns nowadays, especially the Czech television which devotes several hours of broadcasting weekly to public health service and rises the interest of citizens in diabetes and related disorders. Patient organisations are active in this area too. Above all the „Union of people with diabetes in the Czech Republic“ and the “Association of parents and friends of diabetic children“ organise educational courses, programmes of meetings of young people with diabetes and another activities aiming at motivation of people with diabetes. These organisations also issue specialised periodicals and arrange public collection for diabetes care and other activities for example: public measurement of glycaemia free of charge.

There is a tight co-operation between the Czech Diabetes Society and patient organisations. They together propose to the Ministry of Health changes in health care policy aiming at the improvement of diabetes care. Patient organisations also try to influence policy making processes in the Parliament of the Czech Republic. The Ministry of Health grants the activity of patient organisations as part of the health promotion process.

National Diabetes Programme

Diabetes mellitus in the Czech Republic is a disease with a prevalence of more than 6%. Diabetes has a great impact not only on the level of health, but is also a huge socio-economic burden. The aim of NDP is the creation of conditions in the area of prevention and therapy, which will lead to the gradual decrease of chronic complications of diabetes. Implementation of the NDP supposes interest and co-operation of all governmental and non-governmental bodies, economic support and realization of guidelines developed by the Czech Diabetes Society in practice.

According to this programme, basic diabetes care is organised as mentioned above. Highly specialised care is provided for patients with diabetes in Regional Diabetes Centres.

There are 14 Diabetes Centres in the Czech Republic which are responsible for the treatment of difficult patients and also provide treatment in the case of diabetic complications. Social and juridical areas intent on rights and duties of diabetic patients are solved by patients organisations and Coordination Centre for realization of SVD. NDP was initiated in September 2000 and results should be achieved in 10 years period.. In recent years, the NDP has unfortunately been weakened by the attitude of the Health Insurance Companies. Their policy of setting underestimated budget limits for every person with diabetes cause the situation, when physician cannot treat according to the guidelines, because of shortage of financial funds.

Programme monitoring and evaluation

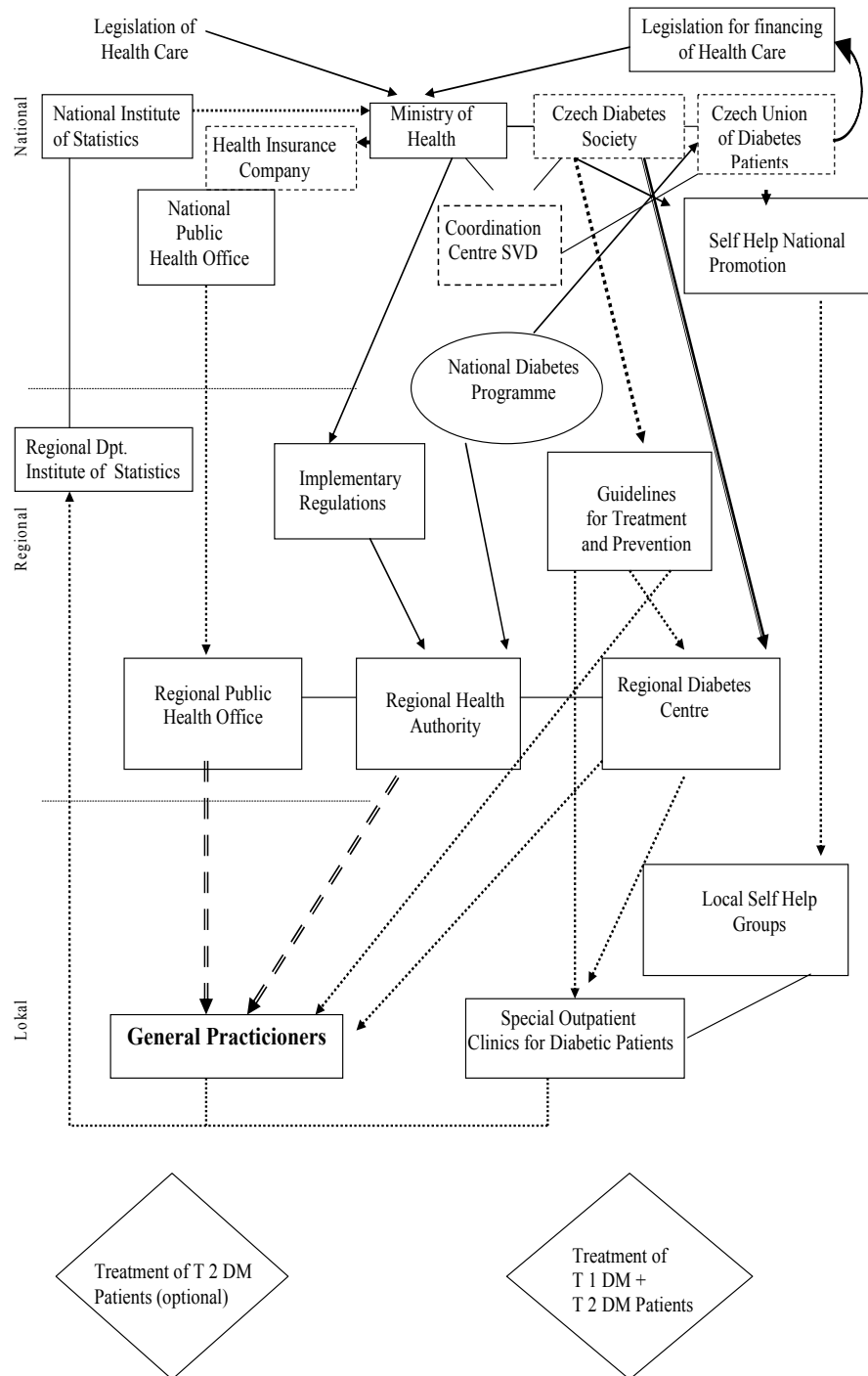
Efforts are made to evaluate partial activities of the National Diabetes Programme in two-year periods at the national level. The NDP has not yet been evaluated at the Moravia-Silesia regional level. The effectiveness of the NDP will be evaluated via data obtained from the regional department of the Institute of Informatics and Statistics. A quality assurance committee appointed by the Czech Diabetes Society and the Ministry of Health will carry out the evaluation of the Regional Diabetes Centres and is responsible for the accreditation of them.

Disease Surveillance

Registries of the rate of diabetic complications are maintained at the national level. Diabetes specialists are bound by law to report the number of their diabetes patients and number of diabetic complications every year. These data are collected by the regional department of the Institute of Informatics and Statistics and then submitted to the central registry of the same institution.

Organigraph for Diabetes

Moravia-Silesian



5.3.5 Germany (North Rhine-Westphalia) ⁵²

In Germany, diabetes mellitus constitutes a significant public health problem with high mortality and serious levels of illness and disability. The number of patients suffering from obesity and diabetes has doubled over the last ten years and over 50% of the people living with diabetes are unaware of their condition.

Research institutions like the German Research Institute of Diabetes and the national health authorities, the Federal Ministry of Health and Social Security and the Federal Bureau of Security have recognised the problem formulating general directives and promoting prevention and early screening and diagnosis.

Among these measures, the preventive check-ups offered since 1989 by the Statutory Health Insurances can be mentioned. According to the Social Security Code (§ 25 SGB V) insured persons who are 36 years old or older have the right to be checked-up for the early detection of diabetes, heart and kidney illnesses. These “health check-ups” which can be carried out every two years have a good public response. In the case of North Rhine-Westphalia for example, the number of these check-ups has increased by around 30 percent, from 1.432.945 in 1995 to 1.865.170 in 2003.

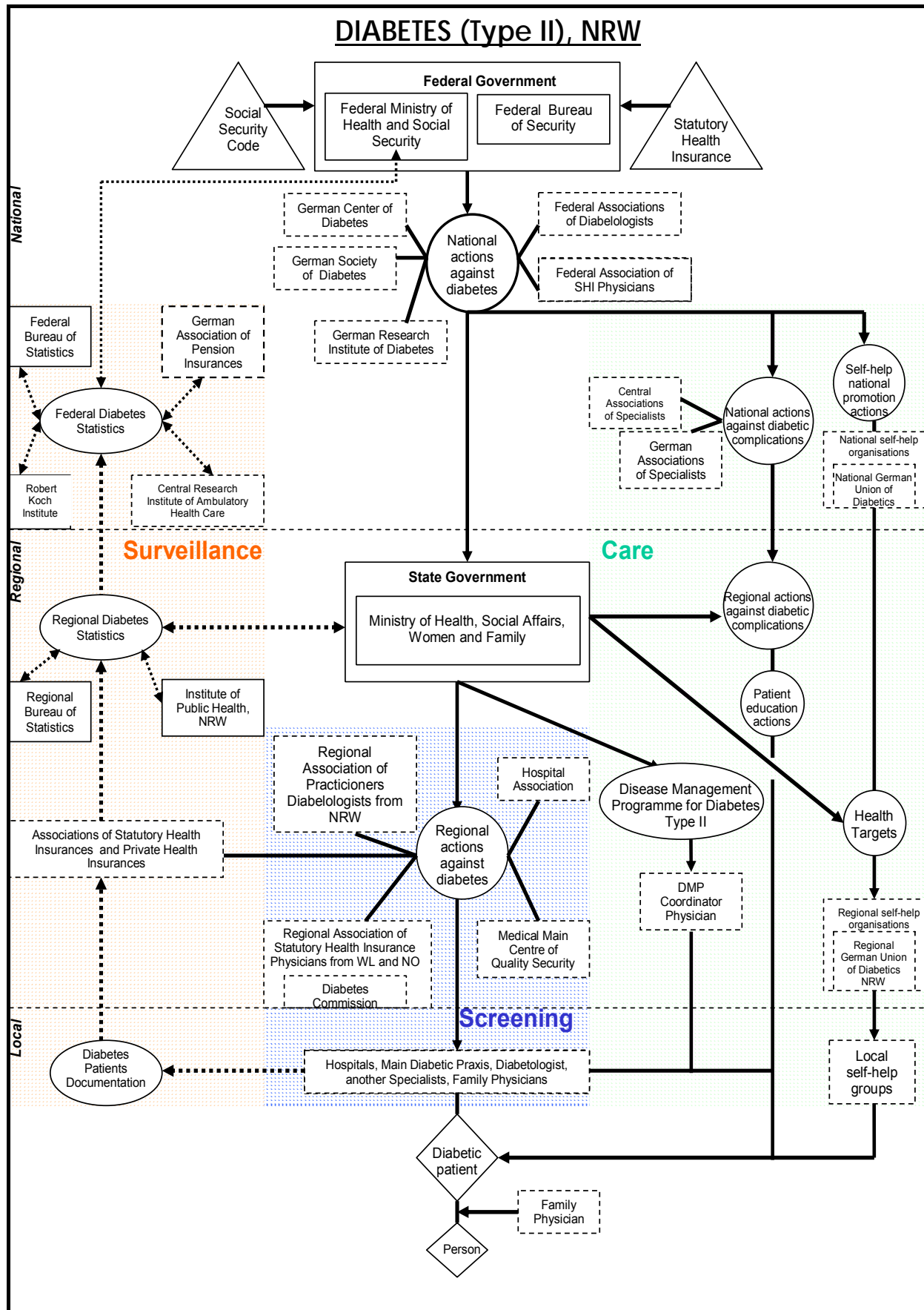
Another national initiative is the project „gesundheitsziele.de” initiated by the Ministry of Health and Social Security in December of 2000. This project, which is carried out by a committee formed by more than 70 organisations, has the purpose to develop national goals in diverse health areas. In this context, partial goals, strategies and measures related to Diabetes mellitus type II, selected as one of the target areas of the project, are developed by the committee.

At the regional level, the Ministry for Health, Social Affairs, Women and Family have played an active and intensive role in the fight against diabetes mellitus. Prevention and care strategies and measures were considered in the regional health targets of North Rhine-Westphalia. With regard to the first target “preventing heart illnesses”, mention could be made for example of the promotion of preventive check-ups and healthier life habits through diverse regional projects and campaigns.

As part of the 6th regional goal “health care”, one could mention the “Health and More” physicians’ organisation, whose objective is to promote integrated care through respective training and quality of care strategies. Nevertheless regarding care, the most important initiative is the Disease Management Programme (DMP) started in summer 2003. The pro-

⁵² Author: Ixhel Escamilla MPH, Institute of Public Health North Rhine-Westphalia, Bielefeld.

gramme aims to achieve better and co-ordinated care supply to improve life quality and to reduce illness complications and mortality of diabetics. Participation in the Disease Management Programme is voluntary and a contract between the Statutory Health Insurances and the patient is needed because it requires the responsible participation of the patient. In North Rhine-Westphalia over 200,000 diabetics, 3,700 diabetologists, 117 main practices and 46 hospitals participate in the program.



5.3.6 Greece (Western-Greece) ⁵³

Structure, Organisation and Management of Diabetes in Western Greece

The Ministry of Health and Social Solidarity (YPYKA) is responsible for legislation, formulating health policy, planning health promotion and prevention programmes and issuing general directives.

One of the main professional associations dynamically involved in the organisation and management of diabetes prevention and care is the **Hellenic Diabetologic Association (EDE)**. The Hellenic Diabetologic Association (EDE) was established in 1975 with the general aim to promote the discipline of diabetology, and especially to encourage research and forward knowledge between specialists, to recommend, implement and improve preventive and screening activities, to inform about therapy and rehabilitation of the diabetic patients and to organise various other activities. The association distributes general and specific information, organises congresses and many other information events with discussions and video clips, edits the journal “Diabetologic News” and cooperates with other scientific associations, self-help groups and clubs. Furthermore, the association has a consulting function concerning health policy in all affected issues.

An important role on behalf of the patients is played by the **Hellenic Federation of Diabetic Patients (ELODI)**, which was established in the year 1997. Members of this Federation are regional and local self-help groups, one of them the **Association of Diabetic-Patients of Western Greece**. The aims of this Federation are multifarious, among other things to achieve an equal handling of the patients from the insurance funds in respect of health care and drug provision, to organise and manage as best as possible the diabetologic centres and outpatient diabetes clinic, to implement training and education programmes for the members, to inform and recommend the diabetic patient in all important topics. Since the year 2000, ELODI is a full member of the International Diabetes Federation (IDF).

Another important organisation constitutes the **National Centre of Research, Prevention and Treatment of Diabetes (EKEDI)**. This pioneering Centre aspires in collaboration with the World Health Organisation (WHO) and the International Diabetes Federation (IDF) to contribute decisively to the prevention and care of diabetes regarding all aspects and to give parallel new impulses towards scientific knowledge. The EKEDI was founded in 1993 and is supervised and subsidised from the Ministry of Health and Social Solidarity. The main aim of the institution is the co-ordination and the assistance in research activities concerning the pre-

⁵³ Author: Dr Eleni Jelastopulu, Laboratory of Public Health, School of Medicine, University of Patras, Rio Patras.

vention and the treatment of diabetes and its complications. Furthermore, it is involved in the planning, co-ordination and monitoring of primary, secondary and tertiary care services, the monitoring and supervision of complications according to the WHO Saint Vincent Declaration, as well as in the description and evaluation of epidemiological characteristics. The EKEDI implements and co-ordinates research programmes and makes proposals to the Ministry of Health for the implementation of relative programmes in order to realise its goals and to support the development of appropriate national policies.

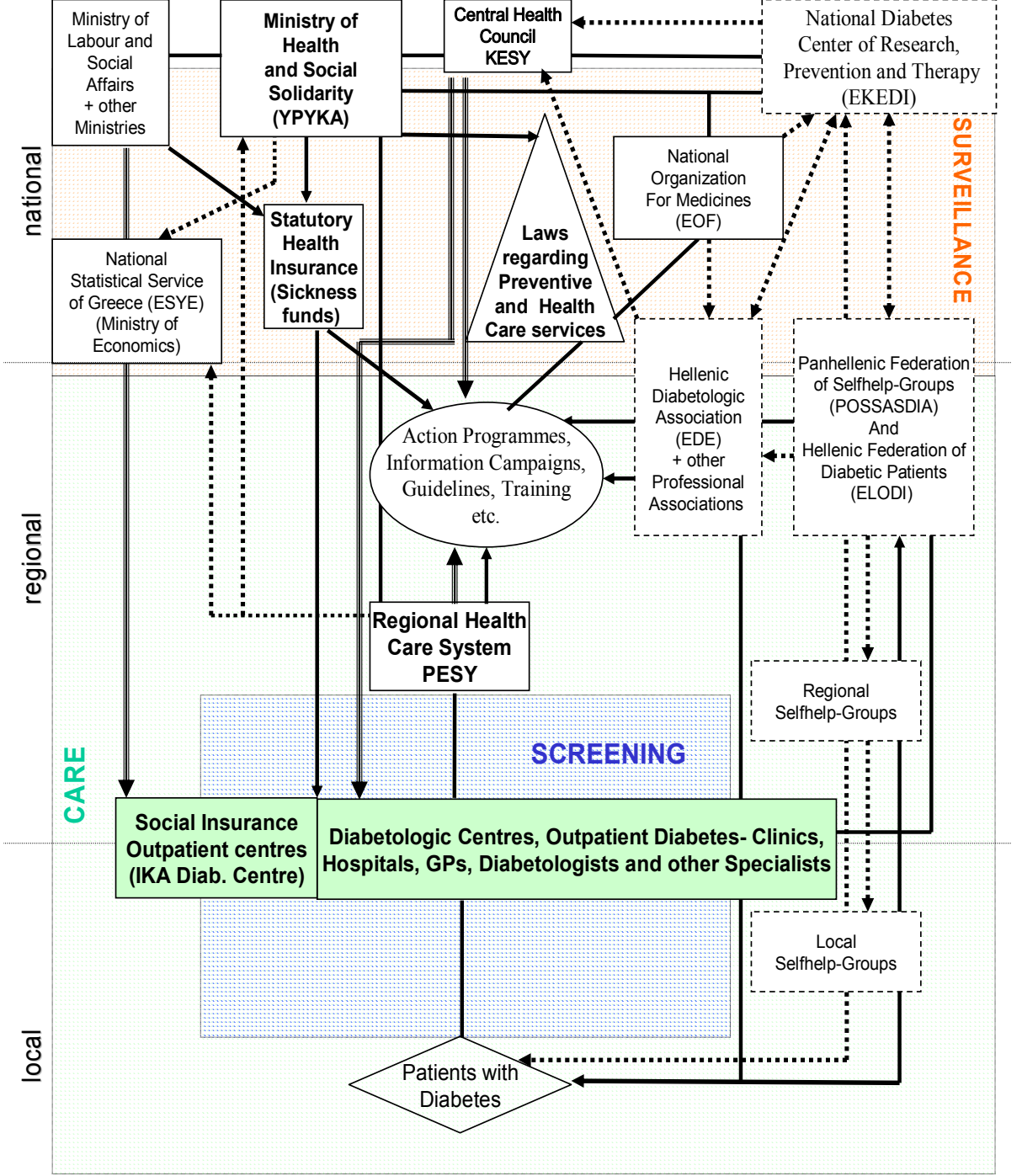
Organisation of screening and care

Screening and other preventive activities are offered by all health insurance funds and are carried out by primary care physicians in public health centres, in private ambulatory offices, in social insurance outpatient polyclinics (IKA) as well as in outpatient hospital clinics.

Diabetes care mainly takes place in the special **outpatient diabetes clinics** and the **diabetologic centres**, which are spread over the whole country. The centres have special outpatient and inpatient care services, beginning from simple screening to the management of serious complications. In Western Greece, one diabetologic centre operates at the University Hospital Rio and an outpatient diabetes clinic at the St. Andreas Hospital in Patras. Other smaller diabetological offices are found in rural health centres in the Region. Generally, there is a very good accessibility for special care of the diabetes patients.

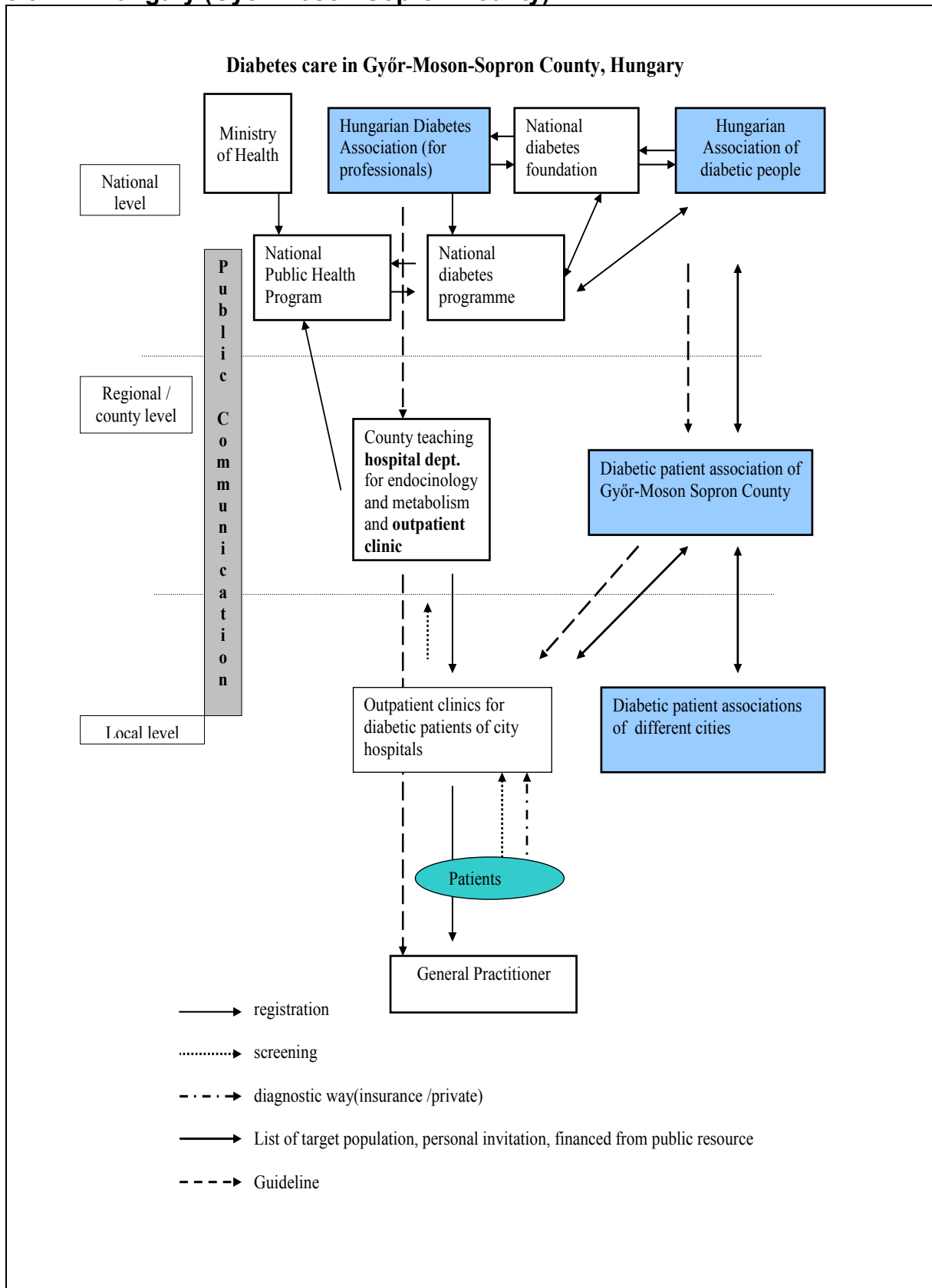
Disease surveillance

No diabetes registry exists in Greece. Efforts to implement a surveillance system and to establish a registry are made by the National Diabetes Centre of Research, Prevention and Therapy (EKEDI) supported by the Hellenic Diabetologic Association (EDE).



5.3.7 Hungary

5.3.7.1 Hungary (Győr-Moson-Sopron County)⁵⁴



⁵⁴ Author: Tibor Hidvégi, MD, PhD, County Teaching Hospital, Department of Metabolism and Diabetes, Győr.

5.3.7.2 Hungary (Szabolcs-Szatmár-Bereg) ⁵⁵

National Level

Hungarian Society of Diabetes

The main professional leading society is the Hungarian Society of Diabetes. This Society is working within the framework of the Federal Physician Council. The responsibility of the Society is to improve and implement different guidelines concerning the screening and care of diabetes. Furthermore they help the self-help diabetic patient board's work and the Ministry of Health to realise their goals in the "Johan Béla National Programme for the Decade of Health". Additionally, they give recommendations for other specialists concerning the diabetic patient's care. Finally, they identify the requirements of the diabetic specialist education program.

The Society has regional reporters in each region who maintain connections with the regional diabetic centres and diabetic outpatients' health care. These representatives of the Society make reports of the regional diabetic care's elements. They work only occasionally if the Society puts the focus on a special topic.

The members of the Society have a consulting function concerning the national health policy in affected items.

National Health Insurance Company

The Health Insurance Company finances all types of health care, except the private suppliers. Hungarian health insurance gives a great subsidy for medical aids, drugs and insulin for diabetic patients. Therefore they regularly and strictly control the health suppliers about observing of prescription convention. They can't control the health service's quality.

Federal Ministry of Health

Taking the morbidity and mortality situation of the Hungarian population into consideration, the Government decided to aim at decreasing the significant difference between the life expectancy at birth between the EU average and Hungary. To fulfil this aim, a strategic programme was elaborated under the name "**Johan Béla National Programme for the Decade**

⁵⁵ Author: Dr Zsuzsanna Tokár, National Public Health and Medical Officer's Service Szabolcs-Szatmár-Bereg County, Budapest.

of Health". This multidisciplinary and intersectorial programme was accepted by Parliament in 2003 and the results are monitored by Parliament as well.

Against the background of preventing diseases and diminishing their burden, those diseases and health states have priority, which are the most frequent in Hungary. For that reason organised screening and care programmes for hypertension and diabetes will be introduced in primary health care settings.

Federal Associations of Diabetic Patients

The group of diabetic patients works to improve information about diabetes. The Hungarian Society of Diabetes gives several recommendations about diet, healthy life style and other important topics. These Associations edit brochures for diabetic patients. The drug companies make a subsidy for edition and distribution.

Regional Level

Local Governments-Municipalities

The Government of Szabolcs-Szatmár-Bereg County operates the County Hospital, which contains the centre of diabetes care. Local governments (in towns, where local hospital also situated) operate special outpatient care for diabetic patients.

Centre of diabetes care, Special outpatient clinic for diabetic patient

This centre and the special outpatient clinics, where specialists work, provide the management of patients with diabetes type 1 and type 2, who suffer from any complication. The Diabetes Centre provides special inpatient and intensive services for serious diabetic patients. They could offer complex supplies, which contain dietetic, educator and other specialist services. All care providers use their own patient register and documentation system. In Hungary, there is no common register and documentation system for diabetic patients.

Regional Public Health Office – Regional professional supervisory system

The Public Health Offices licence certain health suppliers. They have to explain, whether care-givers dispose necessary objective and human condition, which is identified in the “act for special condition of certain health care givers /60/2003/”.

The Public Health Office controls the quality of health care with the help of a regional professional supervisory system. The head of the County Public Health Office commissions

the supervisor who is an expert in the profession concerned. This means, that the professional supervisor draws up an annual report of the care providers (outpatient clinic and family doctors too), who work in his district. Unfortunately they do not work with a common method, they do not evaluate the care providers based on a national common performance indicator system.

Local Level

Family physicians (GPs)

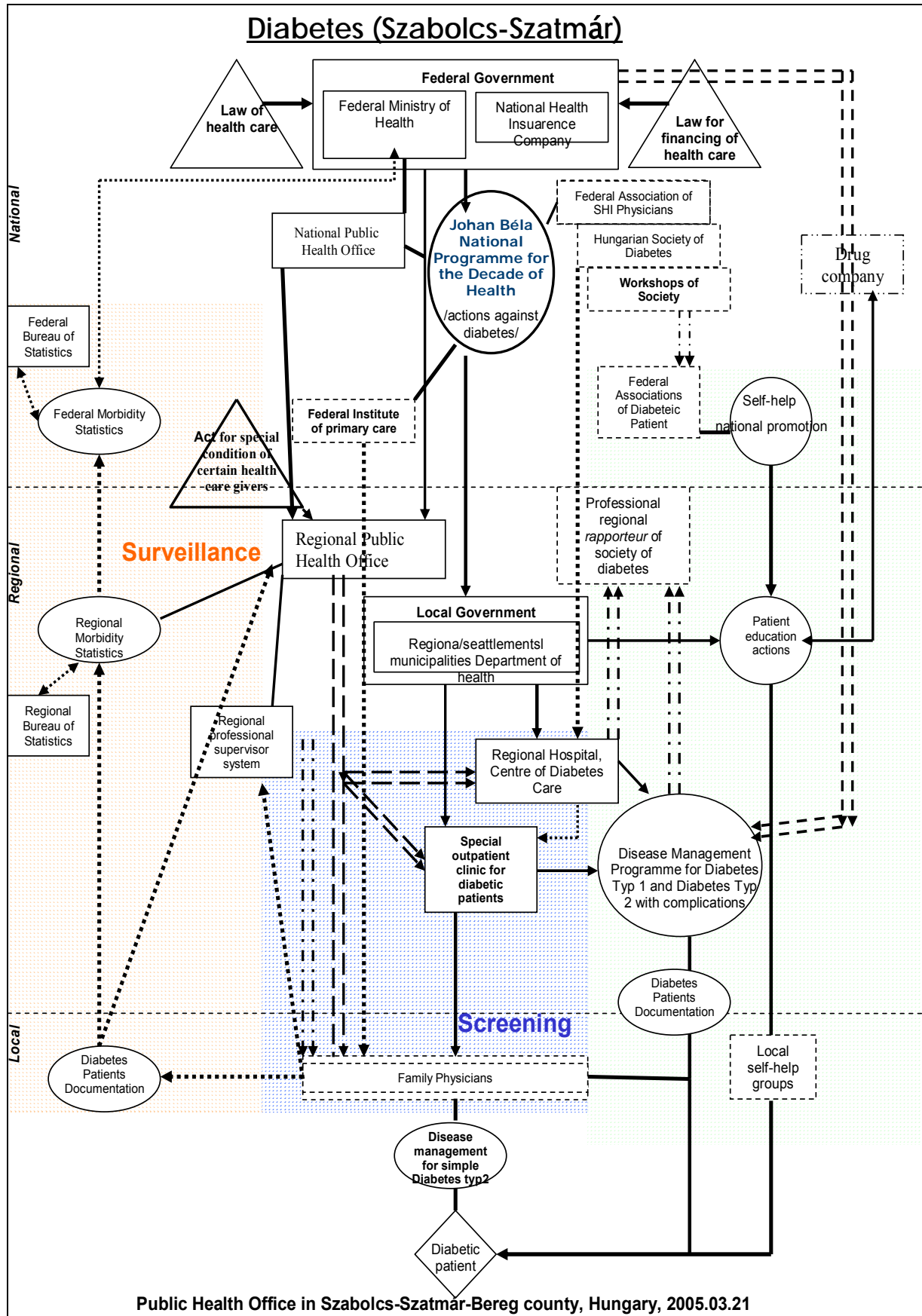
Primary health care is responsible for the management of diabetes type 2, and for the screening of the target population /above 40 years old/. Their work is controlled formally by the regional professional supervisory system, but it does not mean that the experts appraise the management of care or the volume and method of the screening process in primary care. The documentation of diabetic patients is recorded in health care software. The family physicians have to report their patient's morbidity data to the Regional Bureau of Statistics, which is the basis of the federal morbidity statistics.

Disadvantages of the diabetes management in Hungary:

- No patient register
- No quality control in the system
- No real surveillance system

Advantages of the diabetes management in Hungary:

- Strict, well identified licence process for care providers
- Design of Ministry of Health to improve the screening and management process within national public health program
- Diabetic patients have good accessibility to specialised care



5.3.8 Ireland (Dublin/Mid-Leinster and Dublin/North-East Regions)

Health Management Programme: Diabetes⁵⁶

1. Policy is decided at national government level through the **Department (Ministry) of Health & Children**. A health management programme for Diabetes is, relatively speaking, currently underdeveloped in Ireland including in the Dublin/North-East and Dublin/Mid-Leinster regions.

A **National Diabetes Working Group**, chaired by the Department's Chief Medical Officer, was set up by the Minister for Health & Children in 2004 to examine:

- The epidemiology of diabetes in Ireland
- Health promotion and preventative initiatives including screening
- Current service provision including the need to achieve better integration of care using current resources and facilities and the expansion of shared care programmes
- Recommendations for diabetes service provision.

The report of the Working Group, "diabetes: Prevention & Model for Patient Care", published in 2006 (see <http://www.dohc.ie> Publications) sets out the way forward for the future through a number of policy guidance recommendations. These include a model for Diabetes (Type 1 & Type 2) care for children and adults with integrated care pathways covering Primary and Secondary short term and long term care and retinopathy screening. The work of the group was informed by a wide range of available evidence nationally and internationally including a major document produced by the Diabetes Federation of Ireland "Diabetes: Securing the Future" It was recognised that the development of a sound, effective diabetes strategy would have to capture all the elements of modern approaches to chronic disease management such as:

- Effective prevention
- Early diagnosis
- Multidisciplinary, integrated care
- Management protocols based on sound evidence
- Achievable and meaningful performance indicators based on accurate information
- Effective information management at individual and population level

⁵⁶ Author: Kieran Hickey, Health Service Executive, Dublin.

- Participation by patients, their families and support groups.

The **Diabetes Federation of Ireland** (see <http://www.diabetesireland.ie>) is the major patient support group for diabetes in Ireland.

The aims of the Federation are:

- to represent people with diabetes
- to help and provide information for people with diabetes, their families and the community
- to create awareness and to foster programmes for the early detection and prevention of diabetes
- to support and encourage advances in diabetes care and research
- to raise funds which will make the achievement of these aims possible

In 2006 the Federation published its strategy report “The Way Forward 2006-2010” – see website.

Earlier, in 2001, an independent multidisciplinary group, including representatives of the Federation, chaired by a medical specialist member of the Irish Endocrine Society and comprising a range of specialist doctors, nurses and others providing diabetes care, representatives of relevant professional bodies and other interest groups and of the pharmaceutical industry, was established under the title of the **Diabetes Service Development Group**. This Group published at the end of 2002 a report “Diabetes Care: Securing the Future” as referred to in No 1 above. This report contains a framework plan for diabetes service development at national and regional levels aimed at meeting the requirements of desirable standards of care. This was based on the report of the St. Vincent Task Group, reports of then current diabetes service provision in Ireland, current research and standards relating to modern diabetic care and an extensive consultation process aimed at obtaining the views of patients, healthcare professionals, patient support groups, professional bodies and others. The report pointed to significant service and manpower deficits at national and regional levels, and it informed the work of the subsequent Working Group established by the Minister for Health & Children in 2004.

3. In 2004 also, the Minister for Health & Children established a cross-sectoral **National Taskforce on Obesity** that reported in 2005 (see <http://www.dohc.ie/news/2005/obesity/html>). The recommendations in the report addressed the policy challenges for the public and private sectors i.e. for high level government, the education sector, the social & community sector, the health sector, the food sector and the physical environment. The implementation of these recommendations would greatly contribute to the prevention of diabetes.

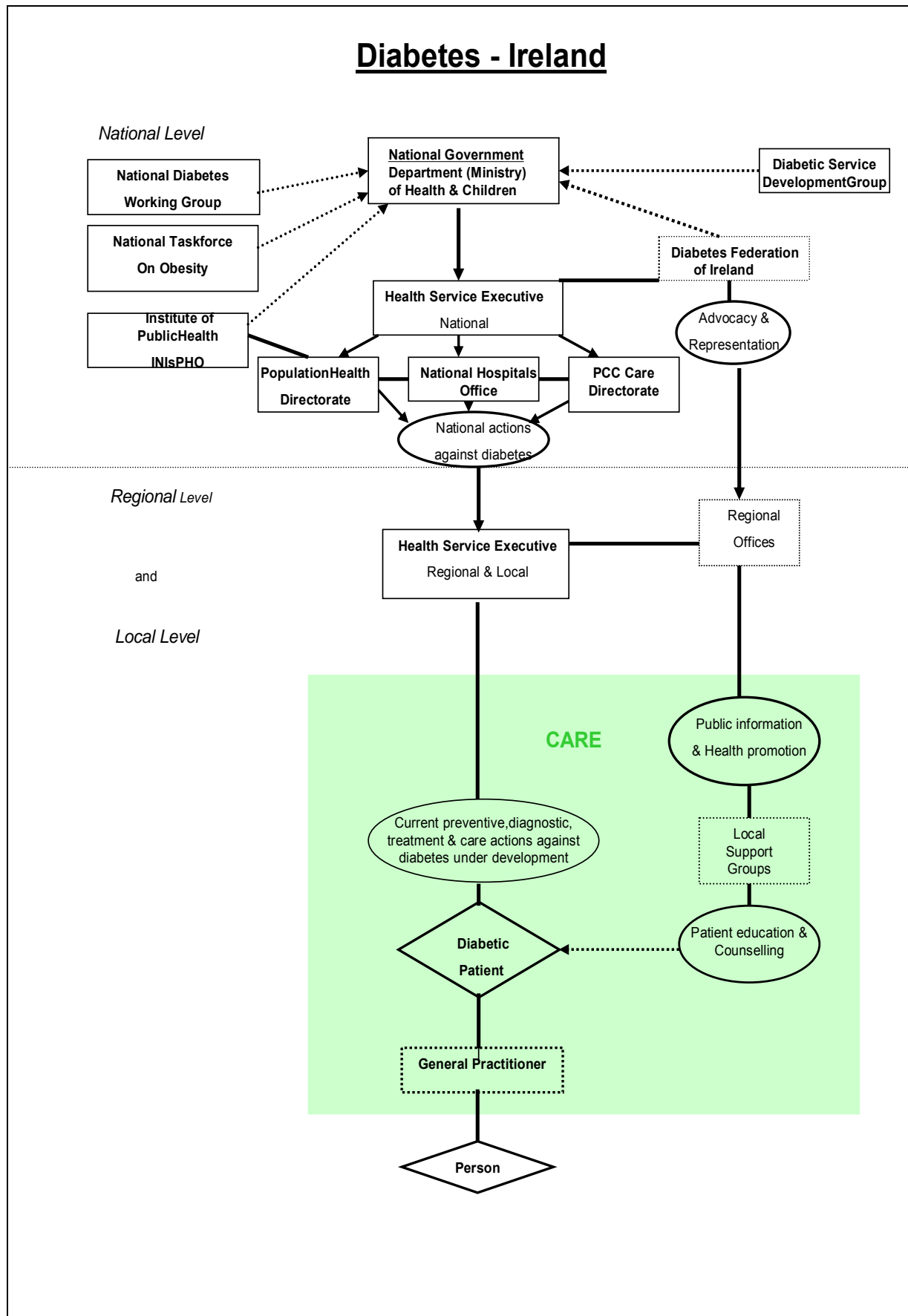
4. The **Institute of Public Health in Ireland**, a cross-border organisation, established an Ireland and Northern Ireland Population Health Observatory, **INIsPHO** covering both parts of the island of Ireland. INIsPHO published in 2006 a report “Making Diabetes Count”, on a study of a systematic approach to estimating population prevalence of diabetes in both parts of the island in 2005 using the PBS model developed in the UK. In addition to producing best available estimates of the population prevalence of diabetes, the report also contained recommendations for a more systematic approach to the development of such estimates and for tackling existing inadequacies in existing data through the establishment of diabetic registers for the island, North and South.

5. The **Health Service Executive (HSE)** was legally established with effect from 1st January 2005 as a result of a major structural reform of the Irish health service. It has replaced the Eastern Regional Health Authority and all eleven of the former Health Boards and has also absorbed or taken responsibility for a number of former semi-state health agencies. It has also taken over responsibility for the executive type functions of the Department (Ministry) of Health & Children, which will now concentrate on policy matters. A number of national directorates have been established by the HSE including a **National Hospitals Office**, a **directorates of Primary, Community and Continuing Care (PCC Care)**, and a **directorates of Population Health**.
 The detailed sub-structures under the HSE are still evolving. On its establishment the Chairman of the HSE indicated that “Ireland will have a single, unified health service with devolved and empowered decision making at local level. The regional offices will be responsible for performance management, translating national policies through the local areas and gathering and relaying information on a regional basis. Interaction with local communities and their public representatives will also be a key function. Hospitals and local structures for primary, community and continuing care will report

to national directorates. This model of service delivery will bring decision making closer to the patient/client through the Local Health Offices.” Regarding Diabetes, the HSE has commenced to take some initial steps towards the implementation of the policy guidelines recommended in the DOH&C Working Group’s report referred to in No 1 above:

- A multidisciplinary Expert Advisory Group on Diabetes was established in October 2006 to give effect to the policy guidelines in the Working Group’s report – see No 1 above. A National Framework for Diabetes is being prepared with the following priorities:
 - National needs assessment including paediatric diabetic needs
 - National agreed shared care protocol between hospital and community sectors
 - Scoping and preparation of a diabetic registry
 - Care guidelines
 - Specific Health Promotion interventions
 - Action plan for structured patient education programme
 - Needs assessment for Retinopathy screening
- In its Service Plan for 2007, the HSE has made financial provision to implement measures to begin the development of an effective systematic approach to the care and management of diabetic patients in local and social care communities starting with the roll out of Self-Care Management education programmes in each local HSE area in liaison with the Diabetes Federation of Ireland. Local plans are being developed for implementation of the wider policy guidelines and priorities referred to in the previous paragraph.
- The HSE was also allocated Eur3M to commence implementation in 2007 of certain recommendations of the National Taskforce on Obesity.
Prior to the setting up of the Expert Advisory Group, the HSE had already taken a number of initiatives at local level to pilot structured integrated diabetes care involving hospital and community services; also to pilot a number of structured education and support programmes for people with type 2 diabetes, both hospital and community based.

6. In the main, the picture regarding disease management of diabetes in Ireland has been that of a patchy and uncoordinated approach with some dedicated focus in a small number of community areas but principally in the hospital setting from specialist medical, nursing and other staff such as dieticians. Prevention, diagnosis, treatment and ongoing care has to date come mainly from mainstream generic health promotion, community or hospital services, with very limited access to dedicated services. Detection examination and screening programmes for diabetes have not been developed and this also applies to screening for complications of the disease such as retinopathy screening. Neither has systematic surveillance of the incidence or prevalence of diabetes been developed to date. Information and education of the public regarding diabetes and education of patients and their families for self-care has not been systematically developed and has been largely provided through the Diabetes Federation of Ireland. The implementation of the policy guidelines from the various reports in recent years now under way as outlined above is now expected to transform the current situation regarding all these aspects of the management of diabetes in Ireland and in the Dublin/North-East and Dublin/Mid-Leinster regions.



5.3.9 Italy

5.3.9.1 Italy (Emilia-Romagna) ⁵⁷

Since 1978 health care in Italy is guaranteed through the National Health Service (SSN) that provides prevention, treatment and rehabilitation services for all citizens and which is financed through tax revenues. The 21 Italian Regions are autonomous in terms of health services organisations and management, even though they follow common rules and guarantee every citizen equal services in the whole country (basic benefit package). The co-ordination among the Regions is guaranteed by the State/Regions Conference, in a framework of shared decisions.

Primary and hospital care is provided by the National Health Service with a network of Local Health Units that can also refer to private structures for some services. Moreover, every citizen is granted a general practitioner paid per capita; children up to 14 years of age refer to a paediatrician.

The 2003-2005 National Health Plan includes diabetes and metabolic diseases among its priority goals and it indicates the opportunity to activate:

- primary and secondary prevention programs, in particular for diabetes mellitus during the years of growth, to reduce hospitalisation and permanent disability;
- strategies to improve the patients' life quality through health education and information programs, in particular meant to face overweight and obesity problems.

Prevention of diabetes is also included among the five priorities of a new national so called Active Prevention Plan. This is led by the National Centre for Diseases Control (CCM) and accomplished through projects developed at the regional level, promoting integrated actions aimed to develop the patient's active participation in the disease management through education and support programmes in particular at primary care level.

The CCM is a national technical structure of the Health Ministry created to:

- coordinate surveillance and active prevention plans;
- define phases and testing modalities for the implementation of the programs;
- support Regions to define executive programs;
- spread initiatives and projects.

Following an agreement between the Ministry for innovation and technologies and the Health Ministry, a new national health information system is going to be implemented and it will

⁵⁷ Author: Dr Angela Paganelli, Community Health Care Planning and Development Department, Bologna.

include also specific projects for monitoring and evaluating management of diabetes prevention programs.

A study on care quality of diabetics from the patients' point of view was realised in collaboration with the National Institute of Health, the scientific societies of diabetologists and patients' associations in some Italian Regions.

In Emilia-Romagna, a regional expert panel defined guidelines for the treatment of Type 2 diabetes mellitus.

Clinical recommendations and monitoring indicators have been defined on the basis of a comparative analysis of technology assessment reports. The guidelines published in 2003 included the criteria for integrated disease management, defining the role of the diabetologists' team, general practitioner/paediatrician, primary care and diabetic services at local level.

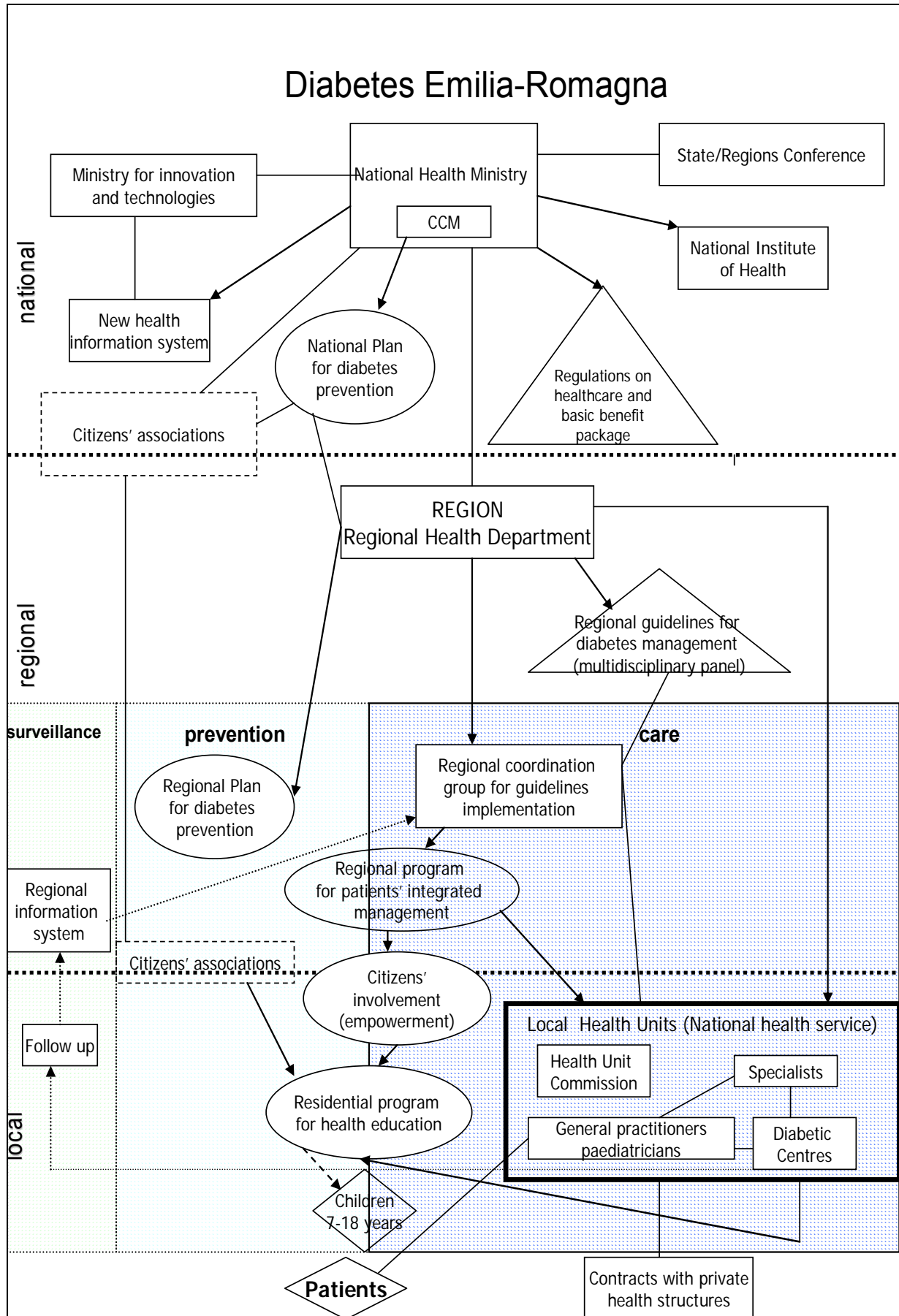
Guidelines also offer indications for diabetic children care, and quote national standards for an education programme on diabetes mellitus.

These guidelines permitted new agreements with general practitioners and promoted active involvement of citizens' and diabetics' associations.

Local commissions with the participation of the main actors of integrated management (general practitioners, diabetologists, – at District and hospital levels – and patients' representatives) were created in every Local Health Unit, in order to monitor the correct and equal implementation of guidelines. Contact people at District and hospital levels have also been selected and they collaborate with the regional coordination group for defining annual goals and verifying results.

An individual recording report with minimal essential data and monitoring indicators has been agreed between general practitioners and Diabetic Centres, which are also present in every Local Health Unit. Twice a year aggregated data are sent to the Region.

A special residential programme for health education addressed to children/adolescents aged 7-18 years with Type 1 diabetes and specifically funded by the Region involves about 100 youths every year. Educational-therapeutic stays are organised by diabetic services and patients' associations to promote specific education for diabetes self-treatment, to stimulate independence in diabetes management while parents are away, to favour confrontation and problems sharing with people of the same age, to develop self-esteem and overcome the feeling of isolation and diversity, to promote education and professional enrichment of the diabetologists' team, to reinforce the relationship between the team and the young patients.



5.3.9.2 Italy (Sicily)⁵⁸

- 1) Prevention and strategy programmes are defined and issued at national level by the Health Ministry through agreements with the scientific associations and the *Centro Nazionale per la Prevenzione e il Controllo delle Malattie* (CCM – Italy's National Centre for Disease Prevention and Control).

The Prevention Department is in charge of health co-ordination, supervision and intervention and also of the information for citizens and health personnel.

With the passing of Law 138, 2004 ("Urgent interventions for confronting public-health hazards"), CCM was established at the Ministry of Health. The main objective of CCM is that of active prevention through both the promotion of healthy life styles and screening and of confronting a variety of health emergencies. CCM has been created as a network of existing institutions and experts: the activities of CCM are coordinated with those of the Regional Health Authorities and with national institutions and organisations (ISS – Italy's National Health Institute; University research centres; Associations involved in healthcare and in public and private research). Following the Agreement of March 23rd, 2005 (State-Regions Conference) Regional Authorities have to bring into action National Prevention Plan objectives, intended to improve the effectiveness and the efficacy of prevention programmes at regional level and to lower National Health Service costs. CCM will coordinate with Regional Health Authorities for surveillance and active prevention programmes. The main areas of concern of the National Prevention Plan, which will last three years, also include: vaccination plan, prevention of complications in diabetes and cancer screening.

The National Health Plan has issued the directives for the prevention and care of diabetes.

The National Diabetes Project was created in accordance with the lines of the NHP on the basis of information given by the Scientific and the ill Patients Associations and it is addressed to promote a correct lifestyle and to give adequate information on the pathology and on reference centres for screening and care.

In 2004, an epidemiological study was carried out in all Italian Regions in order to evaluate the level of services quality addressed to the patients affected with diabetes. The QUADRI project, realised with the coordination of the National Health Institute, had as objective to evaluate the quality of perceived assistance, the regularity of the clinical and biological follow-up and the adequacy of the proposed information to im-

⁵⁸ Author: CEFPAS – Centre for Training and Research in Public Health, Caltanissetta.

prove the quality of life and to avoid the most frequent complications. The study gives useful information for the elaboration of more efficient and effective strategies of the disease management.

- 2) The Sicilian Region has a “Special Statute”. The Sicilian Regional Assembly issues and adopts national laws. The Ministry of Health is a government authority. It is the institutional body that addresses, coordinates and gives the programmatic lines in the field of population health through decrees and regional laws. The Regional Health Plan adopts the national directives, and explains the organisational strategies and the objectives to be achieved.

For diabetes, specific Regional directives have been issued “Guidelines for the prevention of acute and chronic complications linked to the diabetic illness and for the organisation of the structures of diabetology in Sicily” (Law 30 April 2002).

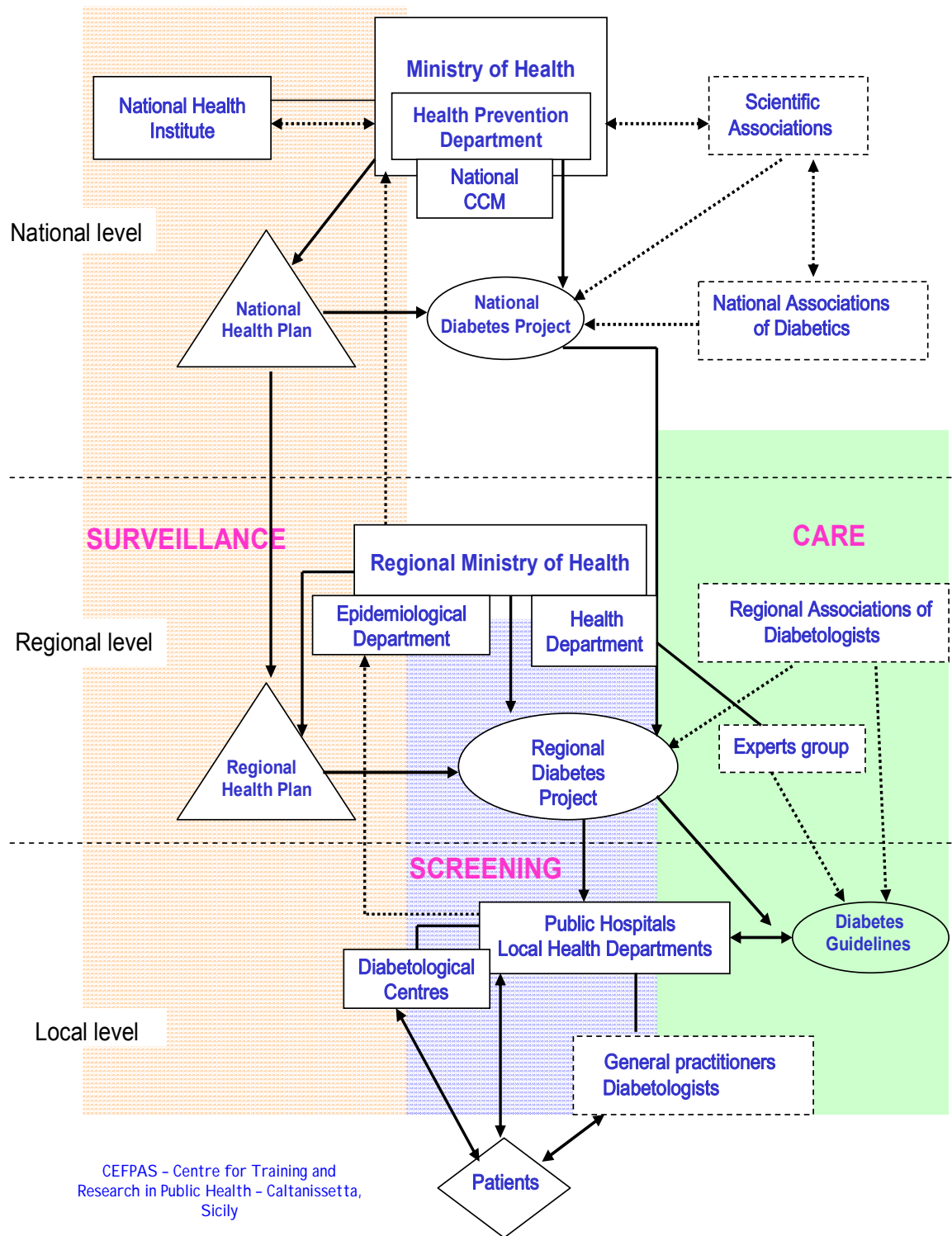
- 3) Primary Care for the diabetic patient is provided by GPs; specialised assistance is offered by the Diabetic Centres created in the Health Districts (Local Health Departments) and in the Public Hospitals. The screening programmes, care and surveillance are then carried out in an integrated way by GPs, Public Hospitals and Diabetic. This kind of organisational structure is recommended in the recent National Prevention Plan 2005/2007 of CCM that stresses the effectiveness of the integration programmes of active prevention and disease management.

A regional Health System Disease Management Project is going to start next year.

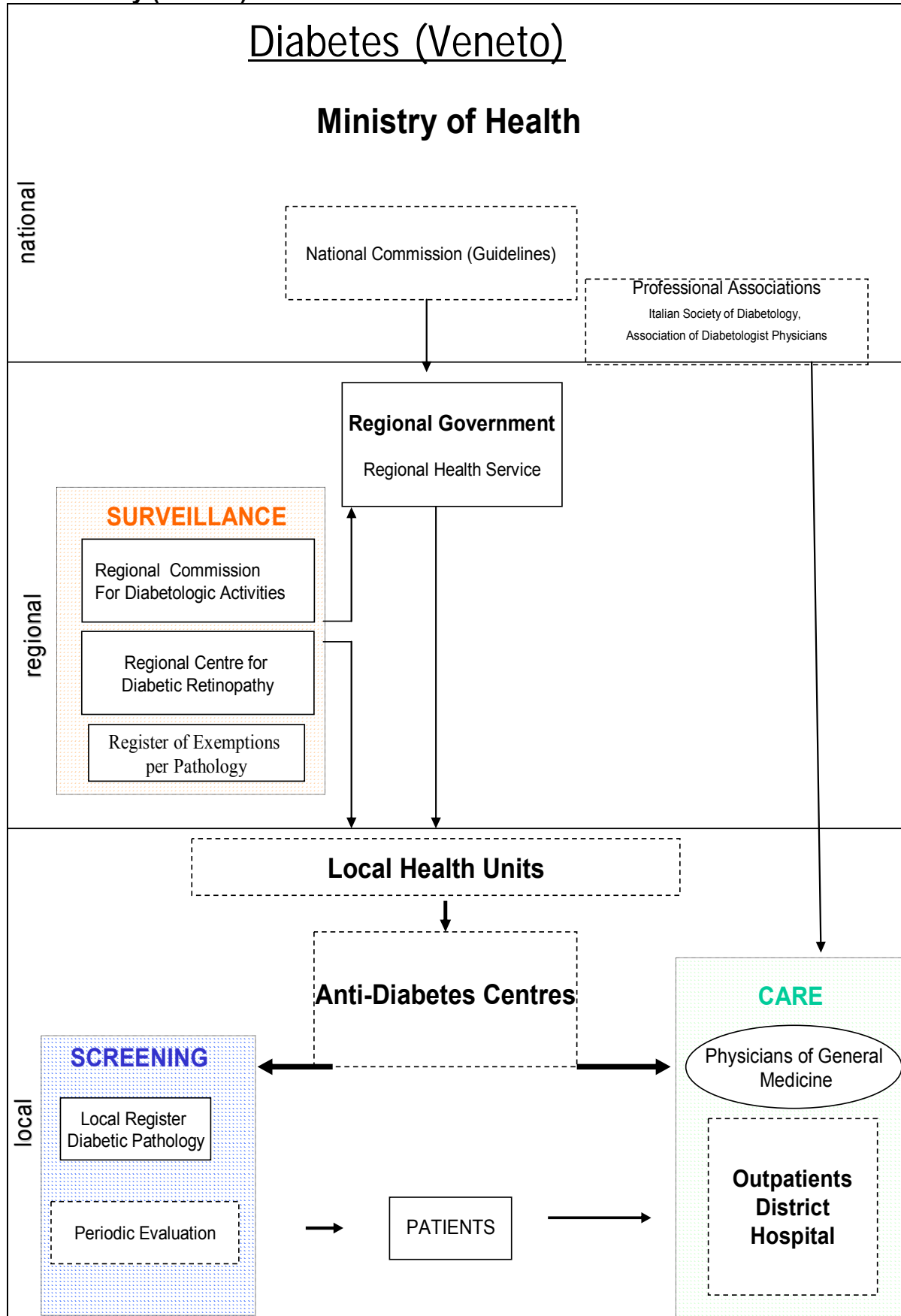
The objectives of the programme are the following:

- To implement a governance system for diabetes allowing the promotion and the monitoring of the quality of the assistance, the monitoring of the effectiveness, efficacy and clinical/organisational appropriateness.
- To promote the integration and the continuity of the assistance.
- To improve the equity and the accessibility of health services.
- To implement a benchmarking process among the Health Organisations on the clinical/organisational indicators related to the treatment of chronic diseases.

Organigraph for Diabetes - Sicily



5.3.9.3 Italy (Veneto)⁵⁹



⁵⁹ Author: Marina Canapero, International Health & Social Services, Veneto Region.

5.3.10 Lithuania (Kaunas) ⁶⁰

The Ministry of Health of the Republic of Lithuania is the executive power institution of Lithuania. In its activity, the Ministry of Health is conform to the law, to the Lithuanian Republic constitution and is following all law statements, documents adopted by the Lithuanian Parliament, it is following international treaties and presidential decrees, Lithuanian Government's decisions and Prime Minister's orders. The main task of the Health Ministry is to take care of the population's health, to strengthen and promote health.

Diabetes diagnostics, treatment and care in Lithuania are organised according to "Diabetes diagnostics and out-patient treatment compensated from obligatory insurance fund budget methodics" approved by the Health Minister of Lithuania, August 14, 2002, Order No 422.

Diabetes control of type 2 is performed by family physicians. Diabetes control of type 1 is performed by endocrinologists. When a patient is treated with insulin, physicians of both types provide treatment.

The Endocrinology Clinic is one of the clinics of Kaunas University of Medicine Clinics. A lot of people from all regions of Lithuania are treated in a Department of Diabetes. There we can find "Diabetes feet" and "Diabetes school" rooms. Conferences and seminars on actual endocrinology and diabetes aspects are organised there. The Endocrinology Clinic takes part in the activity of the European Diabetes Association, the International Diabetes Federation and in activities of many other organisations in Lithuania. The Endocrinology Clinic has founded the Diabetes Union of Lithuanian Physicians and the Lithuanian Diabetes Association. The journals "Panorama of Diabetes", "Lithuanian Endocrinology" and the newspaper "Diabetes" are published by the Endocrinology Clinic. The Endocrinology Clinic performs educational, scientific and clinical work.

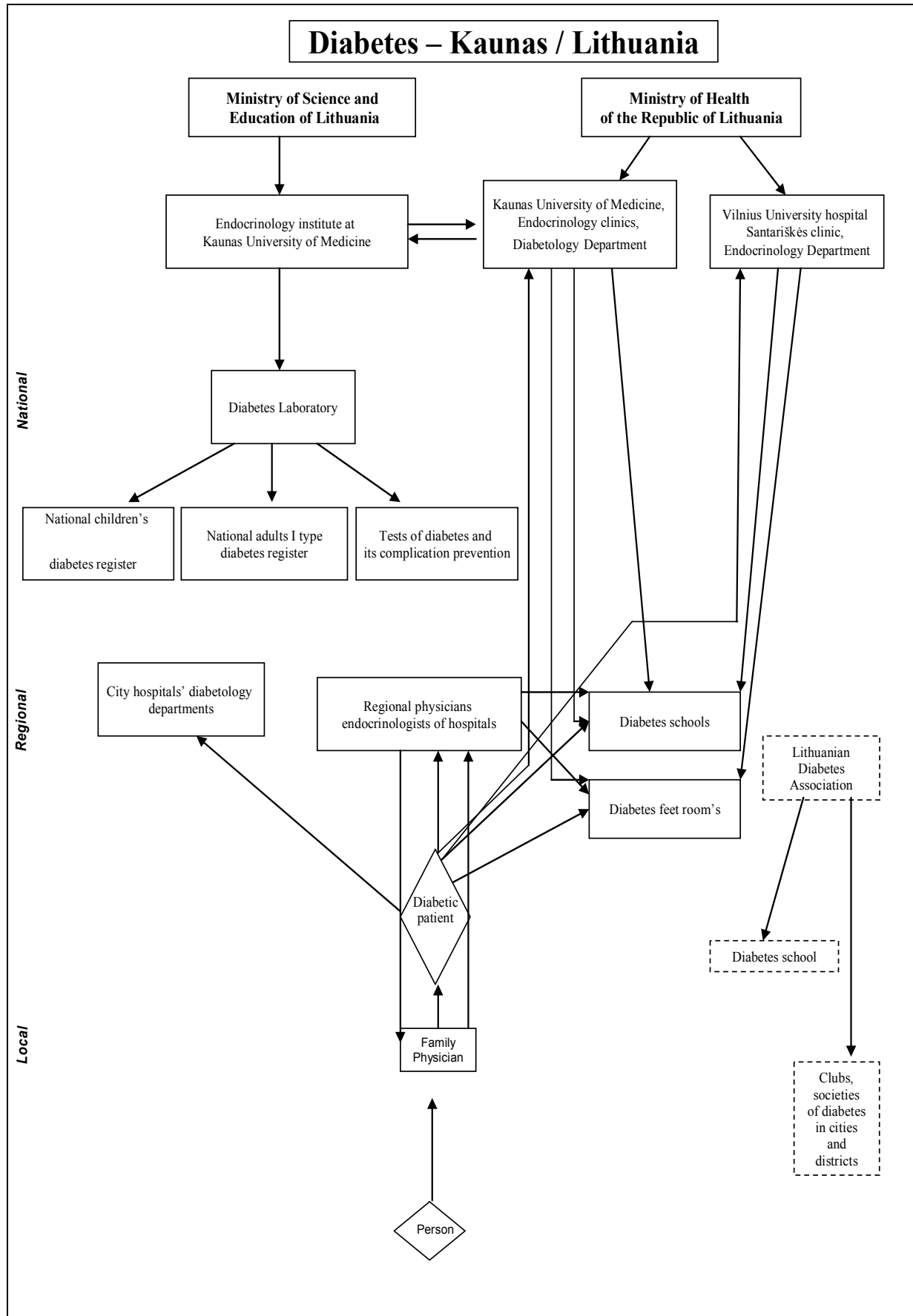
The Endocrinology Institute at Kaunas University of Medicine is a diabetes laboratory. It is subordinated to the Ministry of Science and Education of Lithuania. The diabetes laboratory was established in 1978. There were no data about diabetes spread in Lithuania, there were no unanimous diabetes classification and diagnostics criteria, early diagnostics, early diabetes complication diagnostics and their prophylaxis. These were the first and the most important tasks to be performed. Diabetes epidemiology researches were started in 1979. In 1981, on WHO initiative, an integrated non-communicable diseases prophylaxis programme was started, then the laboratory took active part in these investigations. In 1982, the diabetes

⁶⁰ Author: Zaneta Paviloyte, Kaunas Public Health Center, Kaunas.

laboratory started an adults' diabetes register in Kaunas and in 1983 children's diabetes register in Lithuania. In 1991, the adults addicted to insulin register was established. This register was included into the European register system. Diabetes diseases, diagnostics, spread and mortality rates are being studied. Information about diabetes prevalence in Lithuania, cases of diabetes complications, information about the effectiveness of its treatment are collected.

The Vilnius University Hospital Santariškės Clinic is equipped with an Endocrinology Department. Educational and research work alongside treatment are being performed there.

The Lithuanian Diabetes Association is a member of the International Diabetes Federation. It aims to unite medical workers, patients and other people to distribute information about diabetes in society and to governmental institutions, to provide patients with social and psychological aid to prevent offences for patients with diabetes. The Lithuanian Diabetes Association organises seminars, conferences, propagates and collects methodical literature about new ways of diabetes treatment, medicine, healthy lifestyle. It publishes a newspaper called "Diabetes".



5.3.11 Russian Federation (Chuvash Republic)⁶¹

The Ministry of Health and Social Development of the Russian Federation is the state executive Body at the national level, the Ministry of Health of the Chuvash Republic at the regional level, and the Municipal Health Authority at the municipal level, involved in developing the state policy on prevention of diabetes and regulation of related laws.

The Federal service of surveillance in health care and social development is responsible for quality control of medical care provided with regard to diabetes (including prevention), state registration and control of quality of the medical equipment and drugs used in the prevention and treatment of diabetes, licensing as well as funding of the federal targeted programs.

Scientific and methodological support of the activities on the prevention of diabetes is provided by *the Federal Center of Diabetes at the Ministry of Health and Social development of the Russian Federation* in cooperation with *the Scientific Research Institute of Diabetes at the National endocrinology center of the Russian Academy of medical sciences* and *other related federal scientific research institutes* (in vascular surgery, ophthalmology, nephrology, neurology, perinatal care). The Center is responsible for the elaboration of a unified national methodology and informational materials, protocols of treatment of diabetics, collection, review and assessment of the federal and regional statistics on risk factors of diabetes and its complications, morbidity and mortality from diabetes and complications, comprehensive assessment of epidemiology and prevalence of diabetes, elaboration of targeted programmes on the prevention and treatment of diabetes and its complications and delivery of highly specialised endocrine care at the Federal level. At the Federal Center of diabetes, there is a *State Registrar of the diabetics*.

The Association of endocrinologists and diabetes specialists of the Russian Federation together with the Association of general practitioners and other professional medical associations organises seminars, scientific conferences, takes part in the development of the methodology on the prevention of diabetes and help disseminate practical national and international experience on the treatment and prevention of diabetes. The Association of endocrinologists and diabetes specialists of the Russian Federation works in partnership with the *Regional Association of endocrinologists and diabetes specialists of the Chuvash Republic*.

There is a *Federal targeted programme “Diabetes mellitus”* at the Federal level.

⁶¹ Author: Nadezda Kudriashova, Republican Dispensary of endocrine diseases, Cheboksary.

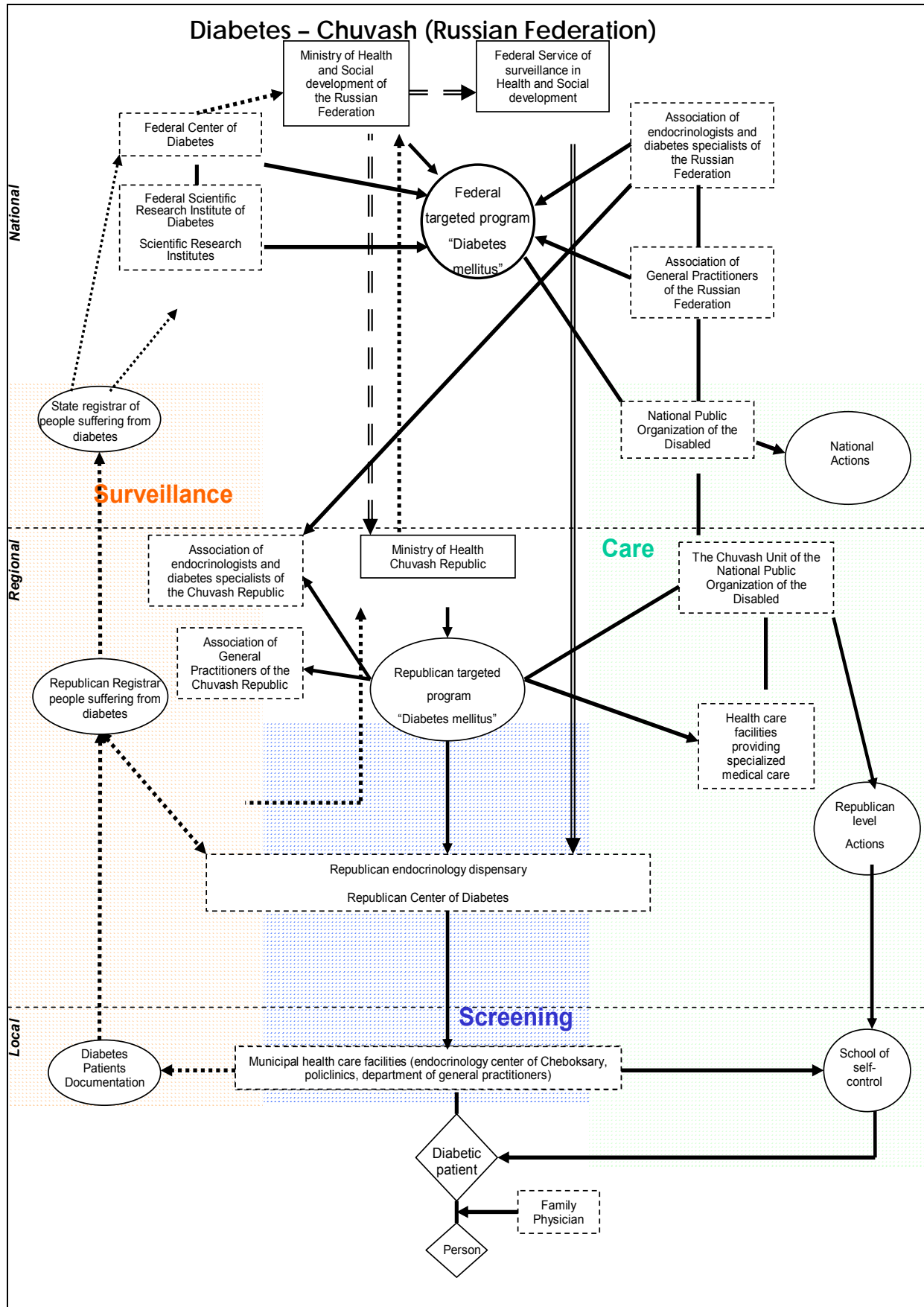
The Republican endocrinology dispensary is a leading endocrinology facility in the Republic. Within its structure the *Republican Center of diabetes* is responsible for the prevention and treatment of diabetes.

Key roles of the Republican Center of diabetes are the following:

- Organisation of the epidemiological trial on the prevalence of diabetes at the regional and municipal level, reporting on the statistics of the epidemiology of diabetes.
- Introduction and maintenance of the republican registrar of the patients with diabetes using the automatic programme called “Registrar” which includes passport data, the data on diagnosis and progress of the disease and information about treatment.
- Development and implementation of the *republican programmes of prevention of diabetes and its complications*.
- Rehabilitation and treatment of patients with diabetes based on diabetes treatment protocols approved by the Ministry of Health and social development of Russia.
- Interaction with health care facilities delivering specialised care in the treatment of diabetes and its complications: ophthalmologic, surgical, cardiologic, haemodialysis, observation of pregnancies and delivery in diabetics.
- Control of activities of the municipal health facilities on the prevention and treatment of diabetes, gathering and processing of the screening results at the municipal (local) level.
- At the republican level there is the republican targeted programme “Diabetes mellitus”.

The main guidelines of activities of *the regional unit of the Diabetic Public Organisation for the Disabled and Disabled from childhood* titled “*The Chance*” is to systematise information and attract attention of the state, business and public organisations to the problems of people suffering from diabetes by doing public actions.

At the local level (regions and cities of the republic), in the polyclinics and departments of general / family practice the risk groups among the population served are revealed and primary prevention of diabetes in such groups is organised. As well, the control of implementation of the programme needed for the prevention of complications of diabetes, rehabilitation of the diabetics, organisation of the schools of self control of diabetes for patients and their family members, diabetic drug supply such as insulin and the syringes and gathering of information for the diabetes registrar is provided.



5.3.12 Sweden (Västra Götaland) ⁶²

Local level

Primary responsibility for care and diagnosis of diabetes lies with the Primary Health care Centres together with endocrinologists at hospitals. PHC operate at local level and manage the major part of diabetes patients, diagnosis and care. Most of PHCs have an assigned, specially trained nurse to deal with everyday care. GPs act as consultants to the nurse and have responsibility for the treatment/management of the more complicated cases.

Regional level

Diabetologists/endocrinologists at hospitals act as consultants for GPs but also have the responsibility for the most complicated cases. Especially the younger patients, mainly type I diabetes, are primarily taken care of within the children and adolescents wards at hospitals to start up treatment.

The main aim with the management of diabetes is to bring the patient in the situation where he/she manages the disease by her/himself with the health care organisation acting as a backup when necessary.

National level

The national Board of Health and Social Welfare is an institution with a supervisory function. It has the responsibility to supervise, to coordinate guidelines, and to promote the regions/county councils to provide care in accordance with the Act of Health Care.

The national diabetes register shows both results from the diabetes care and quality measures of the organisations managing diabetes. The register allows comparisons between care units and benchmarking of the quality of care delivered.

Variables included are among others year of debut, treatment, BMI, HbA1c, Lipid status, blood pressure, s-creatinine, self reported smoking, BP-treatment, microalbuminuria, kidney disease, eye bottom photos, retinopathy, ischemic heart disease, investigation of the foot and amputation over ankle.

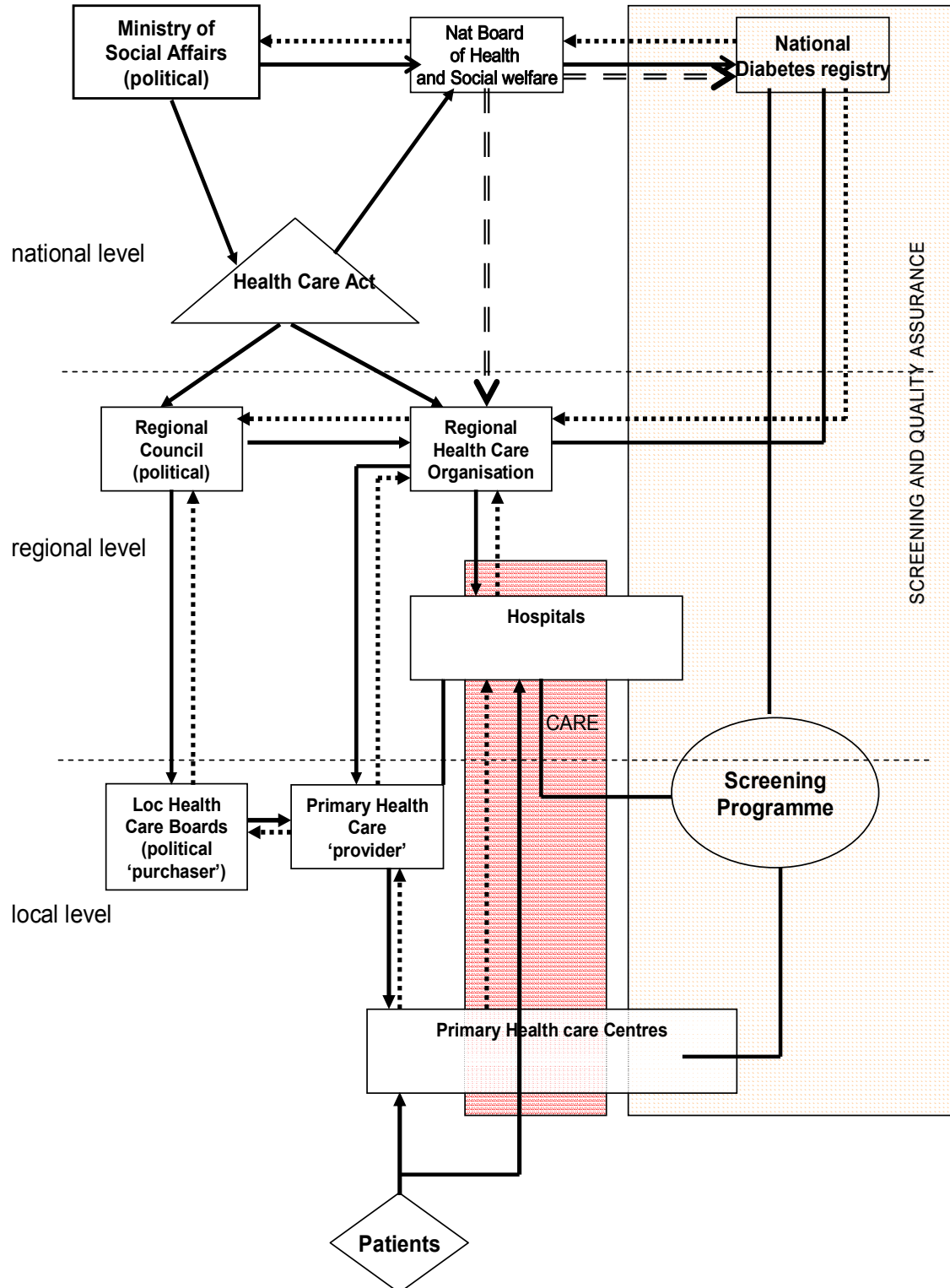
2003 it was estimated that 25% of Swedish diabetics were registered, reports from 90% of care units at hospitals and 45% of PHC.

Participation is not mandatory but it offers a valid and high quality feedback of the care delivered, feedback is maintained via Internet.

⁶² Author: Dr Göran Henriksson, Folkhälsokommitténs kansli Västra Götalandsregionen, Mariestad.

The resource allocation for diabetes care is part of the allocation to the entire health care organisation. This is a matter of ‘negotiation’ between ‘purchaser’ and ‘provider’ at the local level. The resources are allocated from the regional council via budget systems to the 12 local HC boards, which decide after a negotiating process how to allocate the resources, transferred from the Regional Council. From 2004 the local health care boards are ‘purchasing’ health care from both local Health Care Centres and subregional hospitals. It is only the highly specialised health care which is still ‘purchased’ from the Regional Council via the regional health board. The resource for health care is derived from taxes and, to a small extent, from patients’ fees. The regional council has the right to decide on the taxation from regional inhabitants.

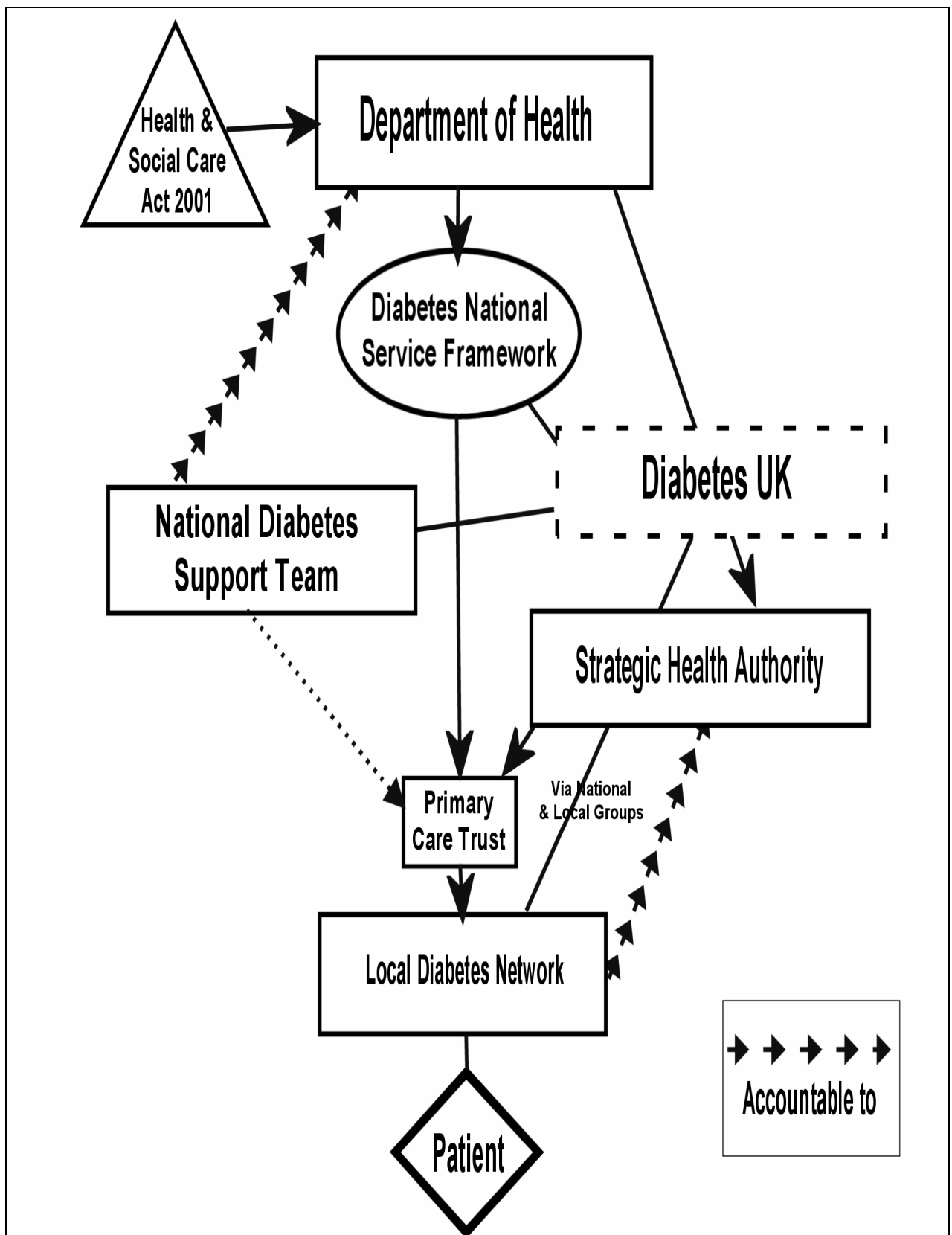
Organigraph for Diabetes Management in Västra Götalandsregionen



5.3.13 United Kingdom (England) ⁶³

1. Every part of the UK has its own history of diabetes planning. There is no uniform national approach to the management of diabetes. Policy is nationally set, but decisions are made locally.
2. **Diabetes UK** are a voluntary sector organisation and one of the UK's largest funders dedicated to diabetes research, with an annual research budget of around £5 million. In the early 1990's Diabetes UK championed the idea of multi-disciplinary integrated planning for the management of healthcare for people with diabetes. This led to creation of 'Local Diabetes Service Advisory Groups' in some areas of the UK.
3. The Department of Health's **Diabetes National Service Framework (DNSF) (2002)** proposed a ten year plan to build on and further develop this model of locally developed diabetes health management in all areas of the UK.
4. In terms of the health management of Diabetes Type 2, the **Department of Health's** role is to set overall policy direction (DNSF) and hold service providers to account.
5. The role of the **National Diabetes Support Team** is to help support the implementation of the Diabetes National Service Framework by working with local services to improve diabetes care. The key areas that the team work in are Information Initiatives, Structured Education and Care Planning, User Involvement, Paediatric Services, Knowledge Management, Retinopathy and Workforce.
6. The role of **Strategic Health Authorities** is to facilitate service development and improvement, agree and performance manage whole system strategy and 3 year local delivery plans and assure networks are in place and comparative data is available.
7. It is the role of **Primary Care Trusts** is to commission delivery of the DNSF and produce a whole system delivery and implementation strategy. PCT's are responsible to their host Strategic Health Authority and the Department of Health.
8. **Local Diabetes Networks** are the multi-disciplinary teams with local frontline responsibility for diabetes health management.
9. **Diabetes UK** continues to inform locally and nationally the health management of diabetes through local groups informing local practice and national involvement in policy development.

⁶³ Author: Paul O'Connell, Research Officer, University of Brighton.



5.3.14 Discussion⁶⁴

The following discussion draws on the introductory systematic remarks made in the analogous discussion of the measles organigraphs (5.1.16).

Organigraphs and Programme Descriptions for Diabetes

Organigraphs for diabetes were received from 17 of the 19 regions. Programme descriptions were received from 15 regions. No organigraphs or programme descriptions for diabetes were received from Saxony-Anhalt (DE) or Madeira (PT). Gyor-Moson-Sopron County (HU) and Veneto (IT) submitted organigraphs only. Whilst the organigraphs can give an overview of the health management system, the programme descriptions can give a number of more detailed insights into the system.

It is clear from the organigraphs and programme descriptions for diabetes that for 8 of the 17 regions that replied, overall policy objectives, rather than detailed programmes, are decided at national government level and transmitted, as directives and guidelines for the development of more detailed plans and decisions for management of the disease at regional and local levels. Thus *chains* of transmission from national ministry level of planning objectives, general policy directives or guidelines to regional level for diabetes prevention, screening, early diagnosis, treatment and care, can be seen in the organigraphs or programme descriptions for Upper Austria (AT) (policy directives for screening), North Rhine-Westphalia (DE) (general directives), Western Greece (EL) (policy and general directives), Emilia-Romagna (IT) (objectives of national plan), Sicily (IT), (objectives of national plan/project), Veneto (IT) (guidelines), Vastra-Gotaland (SE) (guidelines), England (UK) (policy direction through a service framework). Regions have the responsibility of drawing up implementation programmes also involving the local level and in that regard, disease management programmes have been introduced in some regions and are planned in some of the other regions. These and evaluation and quality assurance actions will be referred to again later in this discussion. In 4 of the 17 regions the *chain* of transmission from national level is for an actual diabetes programme to be implemented at regional level and local levels, as shown by Moravia-Silesia (CZ) (national diabetes programme), Szabolcs-Szatmar (HU) (national action programme), Kaunas (LT) (national diabetes programme). There is a *chain* shown by Gyor-Moson-Sopron County (HU) for Public Communication (unspecified), linking all three levels.

Decisions taken nationally on objectives and guidelines or on a diabetes programme are shown to be informed by specialist expertise and knowledge of diabetes, and requirements

⁶⁴ Kieran Hickey, Health Service Executive, Dublin.

for its management, from one or more bodies of experts such as scientific associations of endocrinologists, diabetes specialists or physicians/GPs, a scientific diabetes society, federation or association, research institutes or university institutions such as specialist tertiary hospital treatment departments and clinics. These centres of expertise can be regarded as *hubs*. Some of these expert bodies, in addition to advising ministries at national level, are also shown to be linked directly to regional level and indeed in some instances to local level *hubs*. The resultant *chains* show a relationship or a flow of information to branches of the relevant body of experts at those levels, through direct consultation links with diabetes centres or through collaboration with patients' organisations. Such *chains* are shown by 9 regions, Upper Austria (AT), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Western Greece (EL), Győr-Ménfőcsanak (HU), Szabolcs-Szatmár (HU), Veneto (IT), Kaunas (LT), Chuvash Republic (RU). In 2 regions, Emilia-Romagna (IT) and Sicily (IT) regional guidelines for diabetes management are drawn up by an expert panel or group and transmitted for implementation at local level

Another *chain* from national to regional and local levels can be seen when looking at patients' organisations and their activities. These activities may include collaboration with public authorities, and expert bodies in providing information and education for patients at regional and local levels, also supporting patient participation and empowerment and promoting and supporting local self-help groups. Chains of this type, covering all three levels, are apparent in 12 of 17 regions, Upper Austria (AT), Moravia-Silesian (CZ), North Rhine-Westphalia (DE), Western Greece (EL), Győr-Ménfőcsanak (HU), Szabolcs-Szatmár (HU) (regional to local), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Sicily (IT), Kaunas (LT), Chuvash Republic (RU), England (UK). Flemish Community (BE) shows a regional to local level link between a diabetic patients' association and local self-help groups.

A *chain* for surveillance of diabetes or in some instances the existence of registers at either regional or national levels is shown by 9 regions, Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Szabolcs-Szatmár (HU), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Kaunas (LT), Chuvash Republic (RU). In addition, Varna Oblast (BG) describes a register of diabetics at regional level and Flemish Community (BE) and Västra-Götaland (SE) show a diabetes registry at national level.

The groups of experts and the patients' organizations already discussed can also appear as *hubs* of expertise or knowledge, or as part of networks i.e. *webs*, advising or collaborating with ministries either at national or regional levels. No further reference will be made

to them in that role as the outcome of such activity is best demonstrated in the *chains* discussed above showing the resulting flow of actions.

When identifying *hubs* or *webs* it is more informative from a benchmarking viewpoint to identify those that are significant in demonstrating good practice as defined in the diabetes reference framework.

Organigraphs or programme descriptions from 12 of 17 regions indicate or describe diabetes screening, preventive activities or structured testing for at risk groups, in different *hubs*, e.g. by GPs. Some refer to screening/testing for complications. These regions are, Upper Austria (AT), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Western Greece (EL), Győr-Ménfőcsanak (HU), Szabolcs-Szatmár (HU), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Kaunas (LT), Chuvash Republic (RU), Västmanland (SE). The most usual approach is that family physicians/GPs deal with primary prevention and care of diabetes type 2 and specialists at hospitals deal with the more difficult cases including screening for complications and with diabetes type 1 cases.

The diabetes reference framework for good practice includes the development of Disease Management Programmes (DMPs), or at least an integrated care approach to the management of diabetes. Such an approach involves different levels of collaboration between different actors, health authorities and expert institutes, and family physicians/GPs, diabetes specialists, patients and their respective associations, in a network or *web* and is indicated by 12 of 17 regions, Upper Austria (AT), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Western Greece (EL), Szabolcs-Szatmár (HU), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Kaunas (LT), Chuvash Republic (RU), Västmanland (SE), England (UK). Formal DMPs are shown to already exist in, North Rhine-Westphalia (DE) where there is a regional DMP co-ordinator and Szabolcs-Szatmár (HU) where there is a regional professional supervisor to control quality of care. Upper Austria (AT) is planning a diabetes DMP following a successful pilot programme and Sicily (IT), is planning a regional health system DMP. In some of the other regions there are arrangements to support integrated disease management or monitoring of quality or effectiveness of diabetes services, notably in Emilia-Romagna (IT) where there is a regional co-ordination group for implementation of guidelines for diabetes management and a local health unit commission involving the main actors in integrated management, general practitioners, diabetes specialists and patients' representatives. The organigraph from Flemish Community (BE) shows a diabetes passport which is held by the patient and which can serve as an interesting means of communication between different health professionals.

The reference framework for the health management of diabetes contains a number of policies and interventions relating to patient education, training and participation in preventive check-ups, in care planning and in self-care, also extending to include patients' families and support for mutual or self-help groups. Such actions involve collaboration between health professionals and patients/families and can also include bodies of experts, patients' associations and self-help groups networking together as *webs*. What is involved is a good diabetes education aimed at increasing "patient empowerment". The organigraphs and programme descriptions indicate that in 13 of 17 regions some or all of these policies or interventions are in place, Upper Austria (AT), Flemish Community (BE), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Western Greece (EL), Szabolcs-Szatmar (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Kaunas (LT), Madeira (PT), Chuvash Republic (RU), Vastra-Gotaland (SE), and England (UK). Some interesting interventions are the special residential education programme annually for 7-18 year olds with Type 1 diabetes in which diabetes services and patients' associations collaborate; the diabetes schools at regional and local levels in Kaunas (LT), and schools of self-control of diabetes for patients and their family members at local level in Chuvash Republic (RU); and the policy in Vastra-Gotaland (SE) where the main aim of the management of diabetes is to bring the patient to the situation where he/she manages the disease by him/herself with the health care organisation acting as a backup when necessary. Reference should perhaps again be made under this heading to the diabetes passport shown in the organigraph from the Flemish Community (BE), which can help the patient to manage his or her health and understand the goals towards which he/she is being guided by various caregivers.

The reference framework for diabetes includes investment in the professional development of the diabetes workforce and the provision of education programmes for health professionals and improving their competence to communicate with and educate patients. Such education activity usually involves expert bodies or centres collaborating in a network or *web* with health professionals and their representative organisations. Only 5 of the 17 regions make reference to education of health professionals, Moravia-Silesian (CZ), North Rhine-Westphalia (DE), Szabolcs-Szatmar (HU), Kaunas (LT), and Chuvash Republic (RU).

The reference framework also includes policies and interventions aimed at reducing prevalence of diabetes through health promotion and lifestyle oriented prevention campaigns thus improving the education of the population about lifestyle related health risks. This usually requires collaboration between ministries at national and regional level with expert groups and patients' associations networking together as a *web*. The organigraphs or pro-

gramme descriptions of 9 of the 17 regions only make any reference to health promotion or public education/communication, Flemish Community (BE), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Győr-Ménfőcsanak District (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Sicily (IT), Kaunas (LT), and Chuvash Republic (RU).

6. Analysis of the response to the in-depth-interviews

6.1 Measles

6.1.1 Prevention

In some European regions, measles immunisation is stipulated by law. This leads to the fact that some of the measures are quite naturally implemented in the regions involved in the study, whereas other measures such as for example informing the population about the benefits of measles immunisation have no relevance at all.

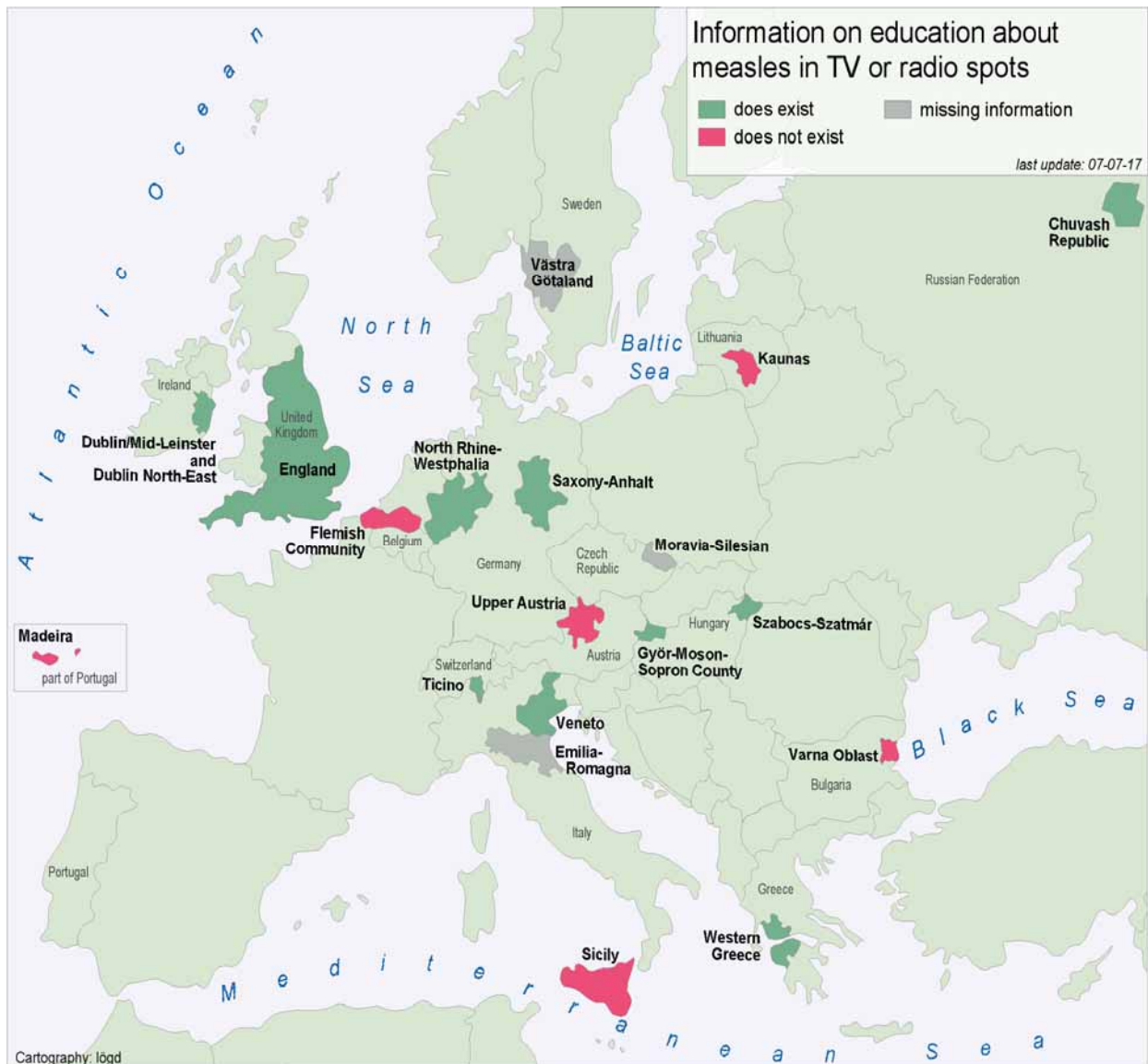
6.1.1.1 Type of public information and education about measles vaccination

Today, a huge part of the population in all parts of Europe can be reached through mass media such as television and radio. These media can therefore help to inform many people about the benefits of measles immunisation or the possible consequences of measles infection.

The project has revealed that ten European regions use this way of informing and educating the population.⁶⁵ These regions are Ticino (CH), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Western Greece (EL), Győr-Moson-Sopron County (HU), Szabolcs-Szatmár-Bereg (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Veneto (IT), Chuvash Republic (RU) and England (UK).

⁶⁵ Missing information: Västra Götaland (SE).

Illus. 6: Information and education about measles on TV or radio



Although radio and television do not always report about measles diseases in all regions, these information channels are preferably used for specific immunisation campaigns.

A comparison of the Italian regions of Sicily and Veneto shows differences in their public relations approach. In contrast to Veneto, television and radio are not being used in Sicily to broadcast information on measles immunisation at the regional level.

6.1.1.2 Responsible organisation regarding vaccination

When dealing with the question as to which organisations might be responsible for measles immunisation, we have discovered a variety of different institutions.⁶⁶ This has already been established in chapter 5 with the help of the strongly differing organigraphs. From the information given, no uniform tendency could be established. The following is an enumeration of the responsible organisations at the national level: Ministry of Health (AT), Institute of Health Insurance (BE), Ministry of Health and National Centre for Infectious and Parasitic Disease (BG), National Committee of Immunisation of Health Ministry and benefit from other organisations: Department of Public Hygiene (Division Disease Epidemiology) National Committee of Immunisation (EL), Ministry of Health, National Epidemiological Centre, Methodological Centre (HU), Health Service Executive HSE through HSE Population Health Directorate (Health Protection Department), National Immunisation Office (HSE NIO), HSE Primary Community & Continuing Care Directorate (HSE PCC & C) (IE); Hygiene Department of the Ministry of Health and National Health Institute (IT), Centre for Communicable Diseases Prevention and Control at the state service of public health care under the Ministry of Health (LT), Health Directorate-General (PT), Ministry of Health and Social Development of the Russian Federation and the Federal Service of Surveillance for Consumers' Rights (RU), Federal Office of Public Health (CH) and DoH (UK).

The great number of different institutions which are responsible for immunisation events at the national level shows that responsibilities have not been organised in a uniform way. Although in many cases responsibility lies with the ministries of health, these are supported by many different organisations and/or institutions. This phenomenon is also found at the regional level.

6.1.1.3 Strategies to reach social subgroups

A conspicuous fact revealed by the project is that in a huge number of European regions there is no ideal way of reaching social subgroups. Nevertheless, in particular the point in time when children enter the kindergarten or school is regarded as an opportunity for catching up on measles immunisation as part of the corresponding entrance examinations. In addition, parents are invited in writing to have their childrens' immunisation protection completed. As

⁶⁶ Missing information: Västra Götaland (SE).

an example it should be mentioned that after intensive communication with the subgroups in Győr-Moson-Sopron County (HU), health visitors are employed as advisors and, in a second step, local workers of the Public Health Institutes – (at first advisory) and only according to need – as officers of the law. In Szabolcs-Szatmár-Bereg, home visitor nurses, GPs or public health experts are employed, who directly visit members of civic organisations and persons opposed to immunisation, people living in disadvantageous situations, gypsies and people with a low education level.⁶⁷

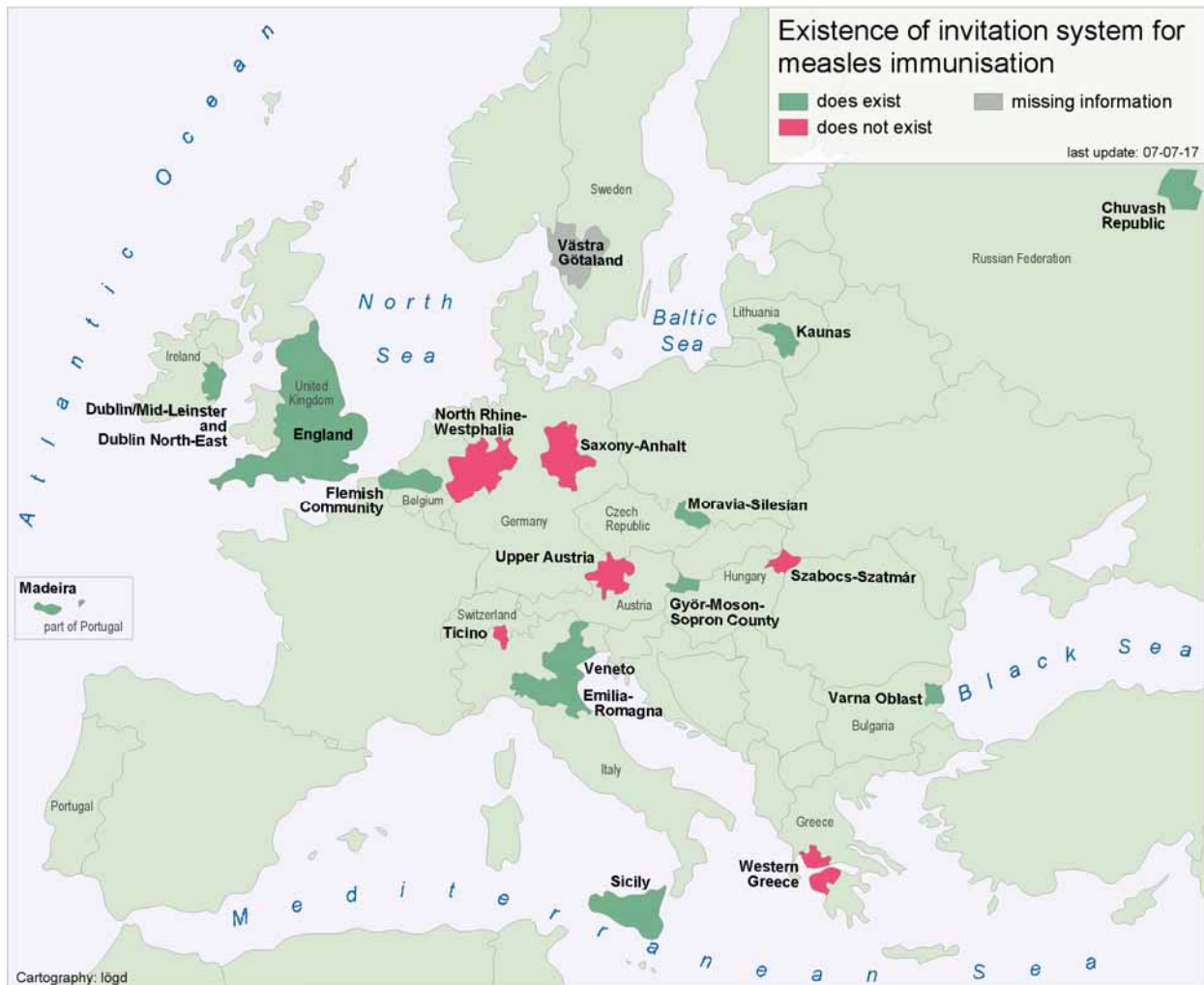
6.1.1.4 Invitation system for measles immunisation

A quite interesting question is whether invitation systems have been established for measles immunisation. We found out that the term “invitation system” is defined in very different ways by the regions concerned. Sometimes invitation systems consist of written and oral invitations for participation in immunisation events issued by paediatricians or general practitioners as well as of oral ways of approaching parents by nurses. In 12 of the 19 regions interviewed, invitation systems for measles immunisation have been established.⁶⁸

⁶⁷ Missing information: Västra Götaland (SE).

⁶⁸ Missing information: Västra Götaland (SE).

Illus. 7: Establishment of invitation systems for measles immunisation



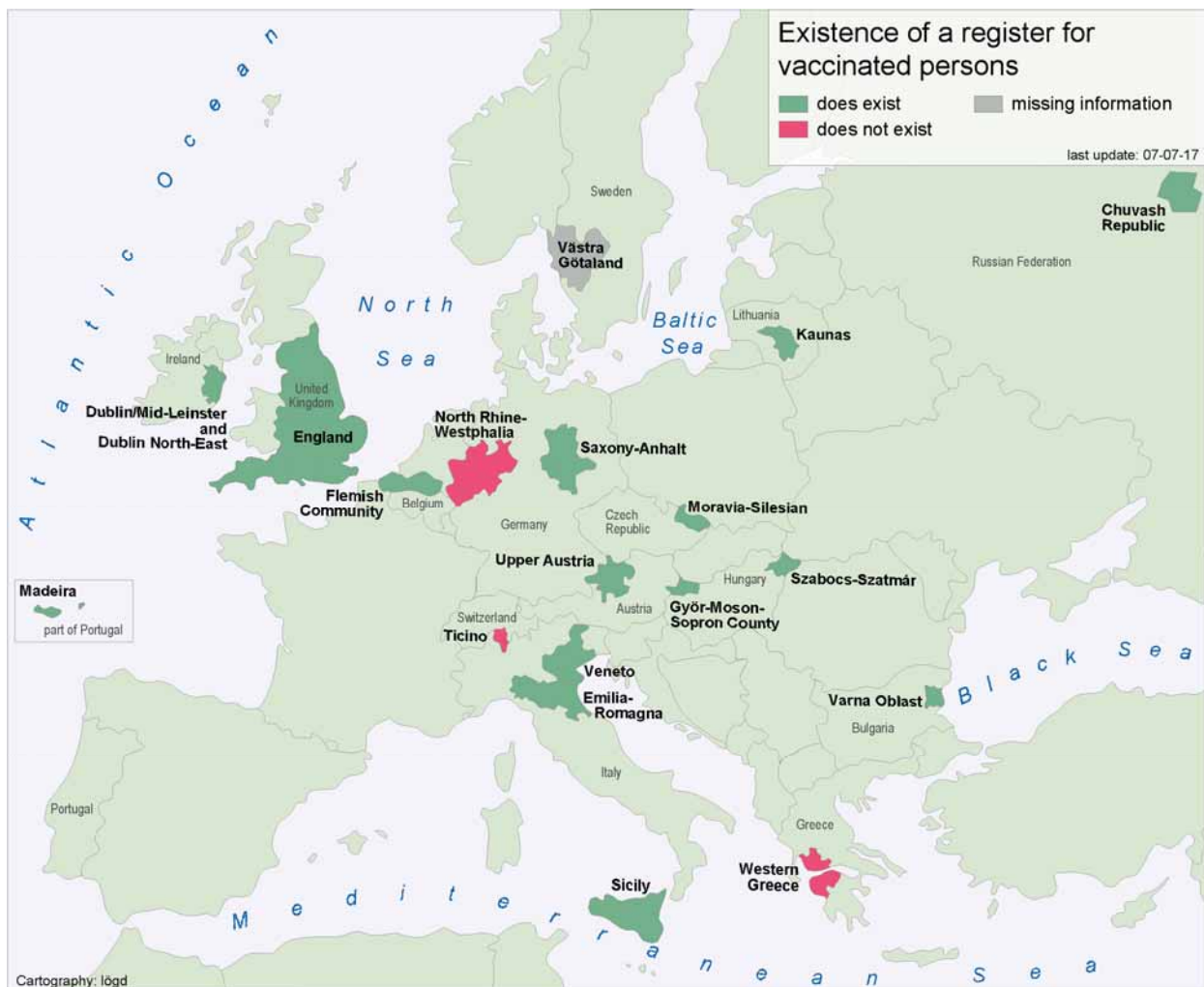
Only six regions, i.e. Upper-Austria (AT), Ticino (CH), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Western-Greece (EL) and Szabolcs-Szatmár-Bereg (HU) have no such system. It should in this context, however, be noted that Upper-Austria (AT) is planning the introduction of an invitation system. In Szabolcs-Szatmár-Bereg (HU), on the other hand, such an invitation system is not regarded as necessary since visitor nurses and family doctors are responsible for inviting people to participate in measles immunisation.

When comparing the regions at the national level, it becomes obvious that Hungary has no uniform regulation for an invitation system at the national level because, whereas in Győr-Moson-Sopron County an invitation system for measles immunisation has been established, no such system has been implemented in Szabolcs-Szatmár-Bereg.

6.1.1.5 Register of vaccinated persons and adverse reactions

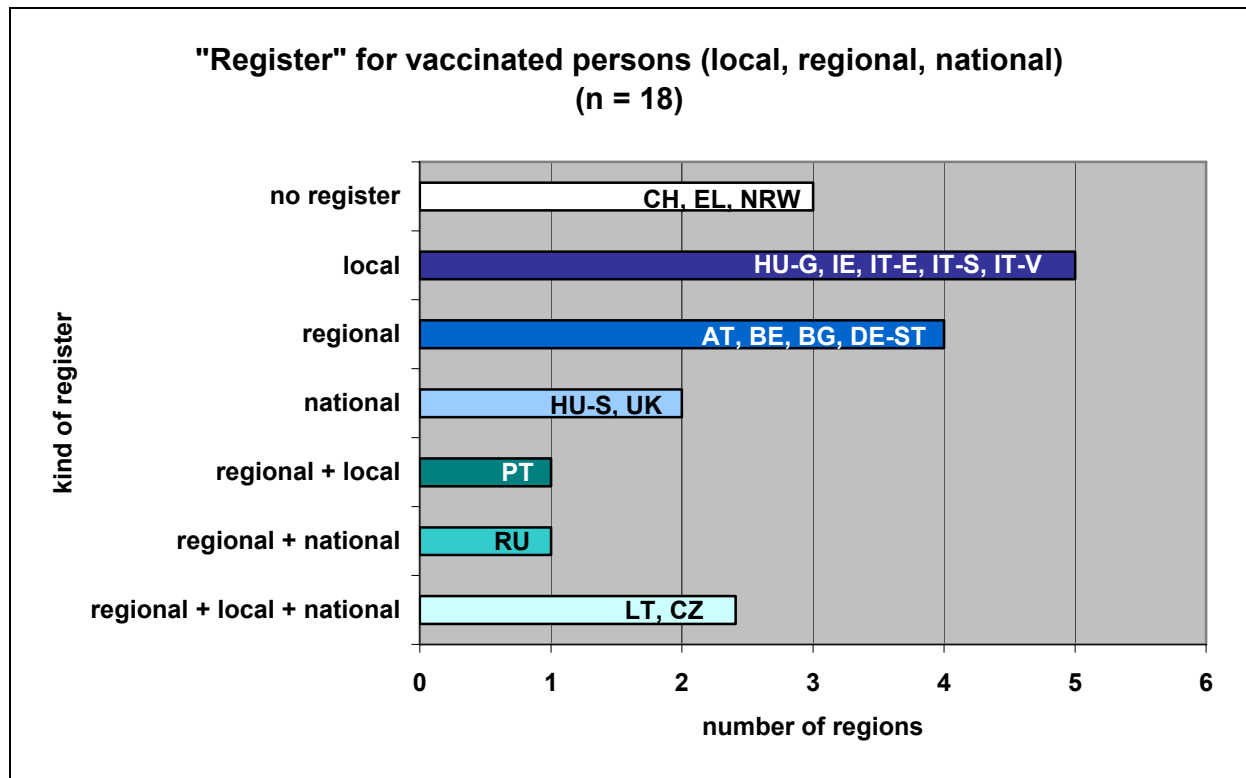
The term “register” not only refers to registers at the local, regional and national level but also includes documentations held by paediatricians or general practitioners. According to our survey results, vaccination registers exist in 15 regions.⁶⁹ Only North Rhine-Westphalia (DE), Western-Greece (EL) and Ticino (CH) have no such registers.

Illus. 8: Existence of a register for vaccinated persons



Moreover, the collection of data on vaccinated persons has to be regarded as very heterogeneous. The following illustration shows the type of the various registers.

⁶⁹ Missing information: Västra Götaland (SE).

Illus. 9: Type of register for vaccinated persons⁷⁰


The project thus shows that most regions keep vaccination registers at the local level. It is quite interesting that in each Italian region these registers have been implemented at the local level. The project moreover reveals that the most extensive documentation is being held by Moravia-Silesia (CZ) and Kaunas (LT) since these regions capture vaccinated persons at the local, regional and national level.

Apart from Upper-Austria (AT), all regions interviewed keep a register on severe adverse reactions.⁷¹ In Upper-Austria, this type of information is collected by the health authorities.

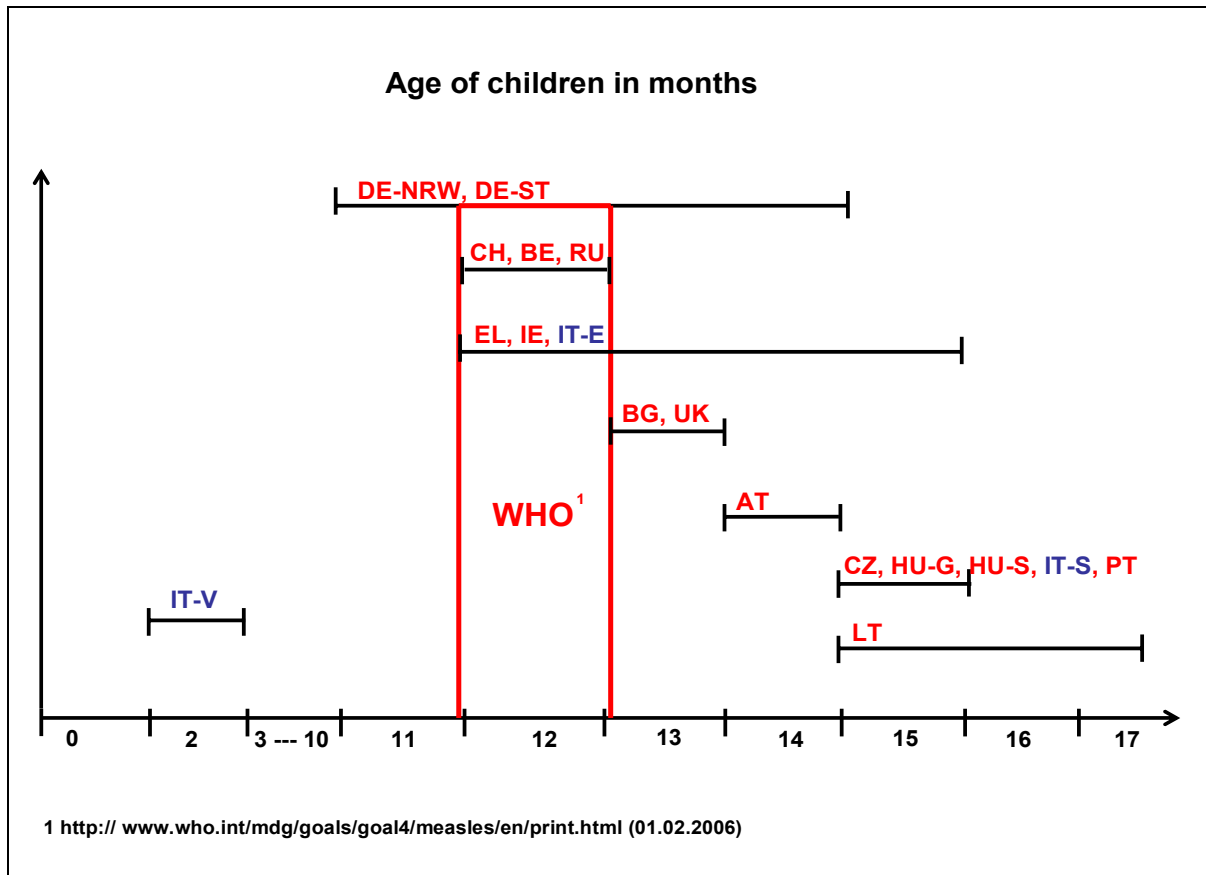
6.1.1.6 Target groups for the first and second measles vaccination

The World Health Organisation recommends the first measles vaccination be given to children at the age of 12 months. In the regions interviewed, we discovered that the age at which children are vaccinated against measles for the first time varies considerably.

⁷⁰ Missing information: Västra Götaland (SE).

⁷¹ Missing information: Västra Götaland (SE).

Illus. 10: Immunisation schedule: first measles vaccination

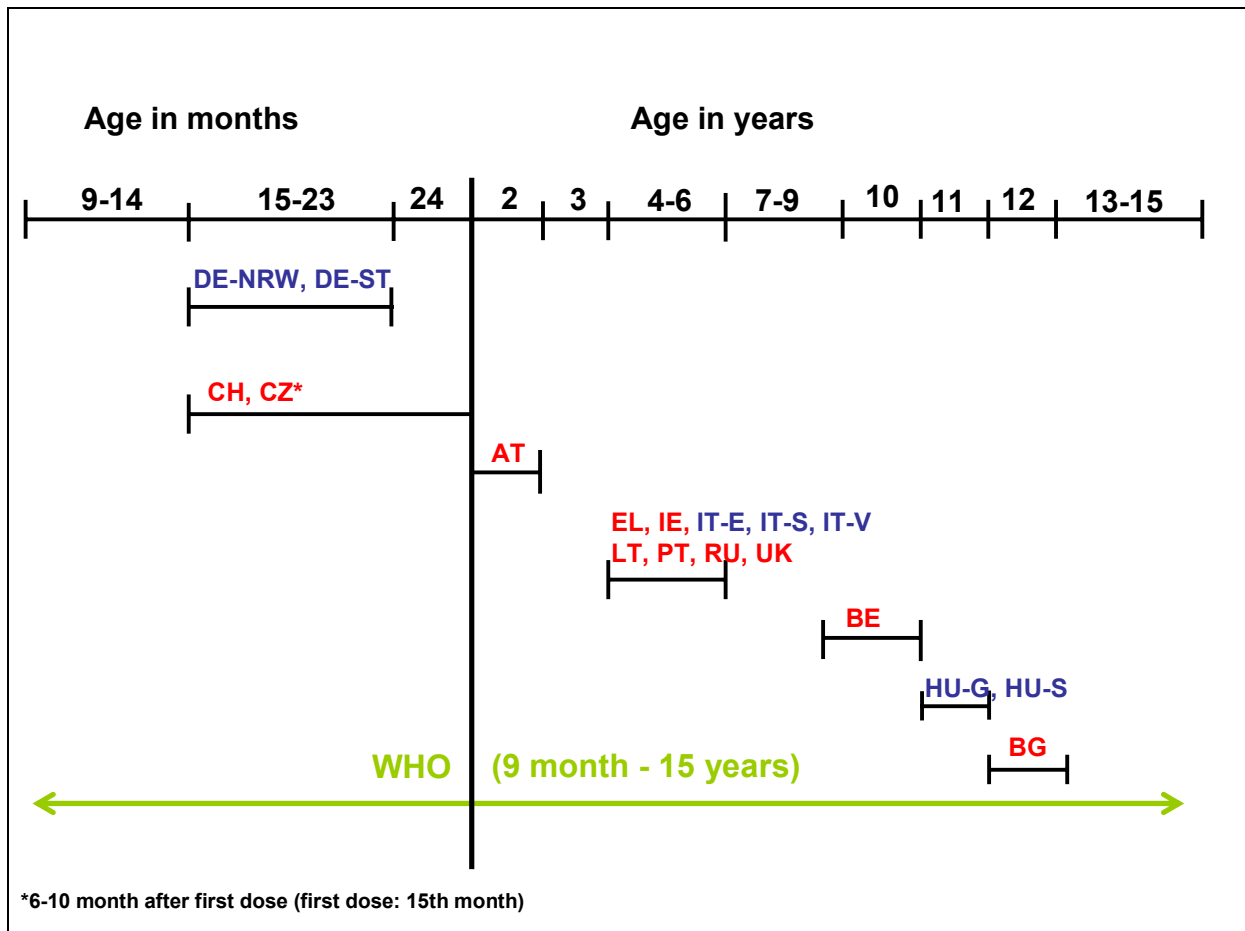


Three regions, i.e. Ticino (CH), Flemish Community (BE) and Chuvash Republic (RU) precisely stick to the WHO recommendation⁷². In Veneto (IT), “newborns up to two months of age” are already immunised against measles. With 11 up to 14 months respectively, the time-frame in North Rhine-Westphalia (DE) and Saxony-Anhalt (DE) is wider. A similar time-frame for the first measles immunisation exists in Western-Greece (EL), Dublin/Mid-Leinster and Dublin/North-East (IE) and Emilia-Romagna (IT). They recommend the first measles immunisation between the 12th and 15th month of life.

⁷² Missing information: Västra Götaland (SE).

Children in Varna-Oblast (BG) and England (UK) are immunised during their 13th month of life. In Upper-Austria (AT) children are immunised against measles in their 14th month of life. In Moravia-Silesia (CZ), Sicily (IT), Madeira (PT) and in the two participating Hungarian regions, children receive their first immunisation dose at the age of 15 months. In Kaunas (LT), children are immunised against measles between their 15th and 16.5th month of life.

Interesting insights were revealed by the project when taking a look at different regions of the same country. Whereas no *differences can be discovered for the participating regions in Germany and Hungary, dissimilarities are very pronounced in Italy because each of the three regions has fixed its own timeframe*. They require measles vaccination to be administered at the age of two months, between the 12th and 15 month of life or in the 15th month of life respectively. It is also interesting to look at the point in time at which children receive their second measles vaccine dose. Only in the participating regions of Germany, Switzerland and Czech Republic children are immunised between their 15th and 23rd or 24th month of life. In Upper-Austria (AT) children are immunised against measles for the second time in their second year of life. It can be stated that the second vaccine dose is mainly given to children between four and six years old. In Flemish-Community (BE), 10-year-old children are immunised for the second time. In the two participating regions of Hungary, the immunisation age is eleven years and twelve years in Varna-Oblast (BG). No difference for the second measles vaccination was discovered for the three Italian regions.

Illus. 11: Immunisation schedule: second measles vaccination⁷³


Another interesting aspect is the timeframe for the second dose fixed by the World Health Organisation. According to WHO recommendations, children should be immunised between the age of nine months up to 15 years of life. In contrast to the first measles immunisation, no differences were discovered in the interviewed Italian regions for the second immunisation.

6.1.1.7 Type of vaccine

In a lot of countries where the public health burden of rubella and/or mumps is felt to be important, measles vaccine is often incorporated with rubella and/or mumps vaccine as a combined, live, attenuated (weakened) Measles-Rubella (MR) or Measles-Mumps-Rubella

⁷³ Missing information: Västra Götaland (SE).

(MMR) vaccine.⁷⁴ “Measles vaccine is equally effective whether in the monovalent or in the combined form.”⁷⁵

*The project shows that all participating regions exclusively use MMR vaccine for measles immunisation.*⁷⁶ This vaccine is a combi-product which is being administered for immunisation against measles, mumps and rubella.

6.1.1.8 Financing of measles vaccination

Particularly in times of scarce financial resources above all in the health sector, the question of how to finance measles immunisation is quite important. The following illustration shows the wide variety of regulations and arrangements pertaining to the financing of measles immunisation in the interviewed regions.⁷⁷

Table 9: Financing of measles immunisation in the participating regions

National Budget	National Health Insurance Fund / Service	Health Insurance	Ministry of Public Health, Social Assurance, European Union, Unicef, Red Cross, Médecins du Monde, Physicians without Frontiers	2/3 Government, 1/3 Regional Government	2/3 Government, 1/6 Regional Government, 1/6 Health Insurance Company	National Budget, Budget of the Subject, Compulsory Health Insurance Foundation	National and Regional Health System	Regional Health Government
6	2	3	1	1	1	1	1	2
CZ, HU-Q, HU-S, IE, IT-V, LT	BG, UK	CH, DE-NRW, DE-ST ¹	EL	SE	AT	RU	IT-E	IT-S, PT
¹ National is also financed by Health Service Executive who receive funding from Department of Health and Children. ² And partly by the regional government.								

In most cases, i.e. in six regions, measles immunisation is financed through the national budget. Whereas at the national level, no differences in financing are noticed for the regions in Germany and Hungary, differences in Italy are very pronounced because every region mentions a different way of financing. In Emilia-Romagna (IT), costs are borne by the national and regional health system, whereas in Sicily (IT) exclusive responsibility lies with the re-

⁷⁴ <http://www.who.int/mediacentre/factsheets/fs286/en/> (3th July 2007).

⁷⁵ <http://www.who.int/mediacentre/factsheets/fs286/en/> (3th July 2007).

⁷⁶ Missing information: Västra Götaland (SE).

⁷⁷ Missing information: Västra Götaland (SE).

gional health government. In Veneto (IT) in contrast, immunisation costs are covered by the national budget.

In Western-Greece (EL), costs for measles immunisation are covered by various financial sources such as the Ministry of Public Health, Social Assurance, the European Union, UNICEF, Red Cross, Médecins du Monde and Physicians Without Frontiers. It has moreover to be stated that Chuvash Republic (RU) is the only region where patients or the patients' parents have to pay a contribution to financing the costs for measles immunisation.

6.1.2 Screening

6.1.2.1 Focal-, catch-up or follow-up campaigns

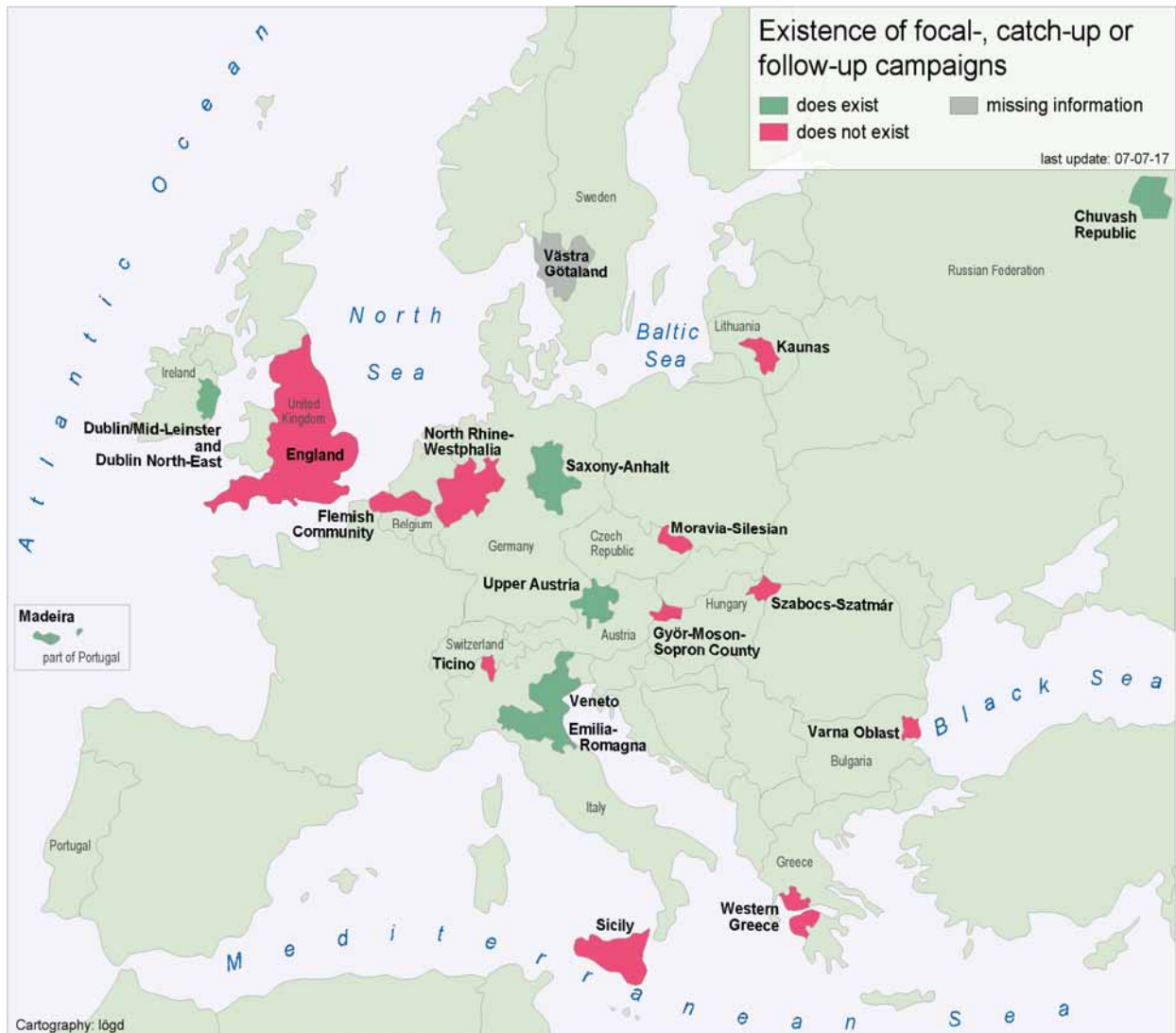
Focal-, catch-up or follow-up campaigns for measles immunisation can be an essential part of the health management. "Catch-up is a one-time only vaccination activity targeting all children from 9 months to 15 years of age. Catch-up activities not only provide direct protection to children who are immunised against measles but also provide direct protection to unvaccinated infants and young children by decreasing their risk of being exposed to circulating measles virus. Follow-up vaccination activities are conducted every 3 to 4 years and target children from 9 months to 5 years of age."⁷⁸

Currently, these campaigns are being carried out in seven regions, i.e. in Upper-Austria (AT), Saxony-Anhalt (DE), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Veneto (IT), Madeira (PT) and Chuvash Republic (RU) (see illus.12).⁷⁹

⁷⁸ WHO/UNICEF; Joint Statement, Global plan for reducing measles mortality 2006 - 2010.

⁷⁹ Missing information: Győr-Moson-Sopron County (HU), England (UK) and Västra Götaland (SE).

Illus. 12: Existence of focal-, catch-up or follow campaigns



Placing the focus more on the participating regions of the same country, it turns out that there are differences between the participating regions in Germany because the campaigns are organised at the regional level.

6.1.3 Health service

6.1.3.1 Specific law for immunisation

Of 19 interviewed European regions, 15 regions have updated specific laws on measles immunisation. Only Dublin/Mid-Leinster and Dublin/North-East (IE), England (UK) and Ma-

deira (PT) have no legislation to this effect and Västra Götaland (SE) has not provided corresponding information.

6.1.3.2 Measles elimination on the political agenda

Of considerable interest is the question in how far the elimination of measles forms part of the current political agenda in the European regions since measles elimination is also a target of WHO Europe. Of 19 regions interviewed, 17 regions have put the elimination of measles on their current political agenda. This result underlines the importance of prevention and treatment of this disease. Only in Madeira (PT) was measles elimination not incorporated in the current political agenda and Västra Götaland (SE) not provided corresponding information.

6.1.4 Discussion of the analysis of the responses from the participating regions⁸⁰

The aim of the in-depth interviews was to get responses to a questionnaire that would give us detailed information for analysing the health management systems of the participating regions (at the beginning of 2006). However, as some of the activities or regulations are governed or conducted at the national level and are, as such, also relevant to the regional level, regions were asked to also consider these for inclusion in their responses.

As previously indicated, we wanted, using the open question method, to give all interview partners a chance to mention all important aspects from their point of view since closed/standardised questions would have deprived us of much of the information given.

It is apparent from the analysis in the preceding paragraphs that *the responses showed immense differences in the policy, organisation and management of measles immunisation programmes in the participating regions*. These differences may be explained to some degree by differences in health systems in operation within the regions e.g. publicly funded versus health insurance systems, or by the socio-political or socio-economic background and culture of the different regions. However, it is very informative to note the significant differences in either policy, organisation or management approach to measles immunisation programmes by regions within the same country operating within the same national environment, e.g. in Italy. Why should this be so? *It may signal the degree of autonomy exerted by a given region*. Just

⁸⁰ Author: Kieran Hickey, Health Service Executive, Dublin.

as there may be differences of approach between regions of different countries so also there may be differences between autonomous regions within the same country.

It is clear from the analysis of the responses of the regions that although there are differences, a majority may have given a similar response to a particular question thus constituting what might be regarded as a “norm”. The important question from the Ben RHM II perspective is: Can this “norm” be regarded as representing *good practice* that might be emulated by other regions and, if so, how does it equate/relate to one of the evidence-based interventions and policies selected for the reference frameworks?

Another question that occurs from the results of the analysis is: Did the open question method used in the interviews always obtain the right information?

Applying these two questions to the results of the analysis of the responses, a number of observations can be made.

The use by 10 of the 16 regions that responded, of mass media, radio and television, for public information and education about measles vaccination, constitutes a “norm” of sorts. However the incidence of measles in 3 of the 6 regions that do not conform to this “norm” is zero and the uptake of measles vaccination is high in 2 of them. They may be satisfied with the results of other methods and might not see any need to use mass media at present, as it can be relatively expensive.

However, regions were not asked why they do not use or why they use, mass media. Also, circumstances may determine its use. For example, it may be necessary for some regions to use mass media to counteract other information carried by the mass media itself, such as claims about risks from the use of MMR vaccine.

The establishment of an invitation/reminder/recall system for measles immunisation is an evidence-based intervention included in the reference framework for measles. *The analysis of responses shows that this good practice norm has been implemented by 12 of the 18 regions that responded and it is reasonable to assume that other regions should follow suit.* However, it is clearly demonstrated by 1 of the 6 regions that has not implemented a formal written invitation system, *that a personal approach by the visiting nurse or family doctor is an effective alternative for that region since uptake of measles vaccination is exceedingly high, 99.8%, and the incidence of measles is zero.* This demonstrates that it is for the policy makers and managements of the regions to choose which interventions are the most appropriate for adoption by their region.

Vaccination registers are held at different levels in 15 of the 18 regions that responded. The establishment of a vaccination register, and surveillance of uptake rates, is another evi-

dence-based *good practice* norm in the reference framework. The analysis examined the level at which such registers are held by the regions and showed that whilst the majority (5) are held at local level only, a lesser number (4) hold them at regional level only, and a lesser number again (2) hold them at national level only. However they are held at all three levels in 2 regions and at two of the three levels in the remaining 2 regions. This shows the difficulty of adopting a good practice norm and demonstrates the need for more explicit definition of the relevant policy or intervention. As a general comment it can be said that the performance indicators in terms of vaccine uptake and incidence of measles, are comparatively less favourable in the regions that hold the register at the local level only and that the holding of information at different levels may contribute to more effective management of measles immunisation programmes. The target age groups chosen by the regions for the first and second measles vaccination show a wide range of variation but, for the first dose, 17 regions (of 18) start within 3 months of the WHO recommended age of 12 months. Although there is a wide variation also for the second dose, all regions are within the WHO recommendation that it be given between 9 months and the 15th year of life. The age at which vaccination is given is not included as an evidence-based intervention in the reference framework.

It should be noted that all of the regions that responded to the in-depth interview exclusively use MMR vaccine and that there is an obligation in all regions to register adverse reactions from the vaccine. The latter requirement is included as an evidence-based intervention in the reference framework.

The financing of measles vaccination also produced a wide variety of approaches by the 18 regions that responded. As one would expect, given the different health systems, in most cases funding comes exclusively from the national government budget in 6 regions and from health insurance or the national health insurance fund in 5 regions. Financing in the other regions comes from different combinations of national government, regional or health insurance budgets and, in the case of 2 regions, exclusively from the regional budget. It should be noted that the latter 2 regions are islands, Sicily (IT) and Madeira (PT). Differences in financing arrangements between regions or between regions within the same country may be related to socio-political or socio-economic circumstances and are not all that significant from a Ben RHM II perspective as financing arrangements are not included in the reference framework.

What would be interesting in the context of financing is whether the budget for measles immunisation has to compete with other services as part of a general budget for mainstream services or whether any part of it is a dedicated ring-fenced budget for measles immu-

nisation, e. g. a dedicated budget for special campaigns or for public or professional information and education campaigns or activities. We had not asked for information on this or on the views of regions regarding the benefits or otherwise of ring-fenced budgets.

Focal, catch-up or follow-up campaigns for measles immunisation are included as an evidence-based intervention in the reference framework. The analysis of responses shows that such campaigns are being carried out in 7 of the 18 regions, but not in the other 11 regions. The latter group includes a number of regions where uptake of measles vaccination is high and where incidence of measles is zero; but this group also includes a number of regions whose performance indicators are comparatively less favourable. This once again demonstrates that it is a matter for policy makers and management in each region to choose which *good practice* interventions are appropriate for their region.

Responses from 15 out of 18 regions show that they have a specific law for measles immunisation. A law on infectious diseases in general is included in the reference framework and this may exist in the other 3 regions.

The responses show that the elimination of measles is part of the current political agenda in 17 of the 18 regions interviewed. In the case of the 1 region where measles is not currently part of the political agenda, this may be related to the fact that it has reported a zero incidence for measles in the four years up to and including 2005.

6.2 Breast Cancer

6.2.1 Prevention and Screening

6.2.1.1 Education campaigns about the benefits of breast cancer screening

A breast cancer screening programme is a complex multidisciplinary undertaking. The objective of screening for breast cancer is to reduce morbidity and mortality from the disease without adversely affecting the health status of those women who participate in the screening.⁸¹

Education programmes about the benefits of breast cancer screening have been established in 13 regions, i.e. in the Flemish Community (BE), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Western-Greece (EL), Győr-Moson-Sopron County (HU), Szabolcs-Szatmár-Bereg (HU), Dublin/Mid-Leinster and Dublin/North-East (IE),

⁸¹ European guidelines for quality assurance in breast cancer screening and diagnoses (2006: 17, Fourth Edition).

Emilia-Romagna (IT), Veneto (IT), Kaunas (LT), Chuvash Republic (RU) and England (UK).⁸²

Only four regions, i.e. Upper-Austria (AT), Varna-Oblast (BG), Sicily (IT) and Ticino (CH), do not carry out any of these campaigns.

With regard to education campaigns about the benefits of breast cancer screening, different approaches can be observed in the participating regions. These among other things include campaigns in the mass media, in the hospitals of the respective region, services provided by women's organisations, invitations to information days and presentations by the Red Cross, the church and the dissemination of information materials.

6.2.1.2 Invitation strategies for mammography screening

The invitation strategies for mammography screening vary considerably in the European regions. While Upper-Austria (AT) and Moravia-Silesia (CZ) have no specific strategy for inviting women to mammography screening, women in the Flemish Community (BE) and in Chuvash Republic (RU) are not only invited just by mail, but in addition by their general practitioner and/or gynaecologist. In all other participating regions, with the exception of Varna-Oblast (BG) and Ticino (CH), which have no mammography screening programme, women are exclusively invited by mail to participate in the mammography screening.

No specific information on this point has been provided by Győr-Moson-Sopron-County (HU).⁸³

6.2.1.3 Invitation registers for mammography screening

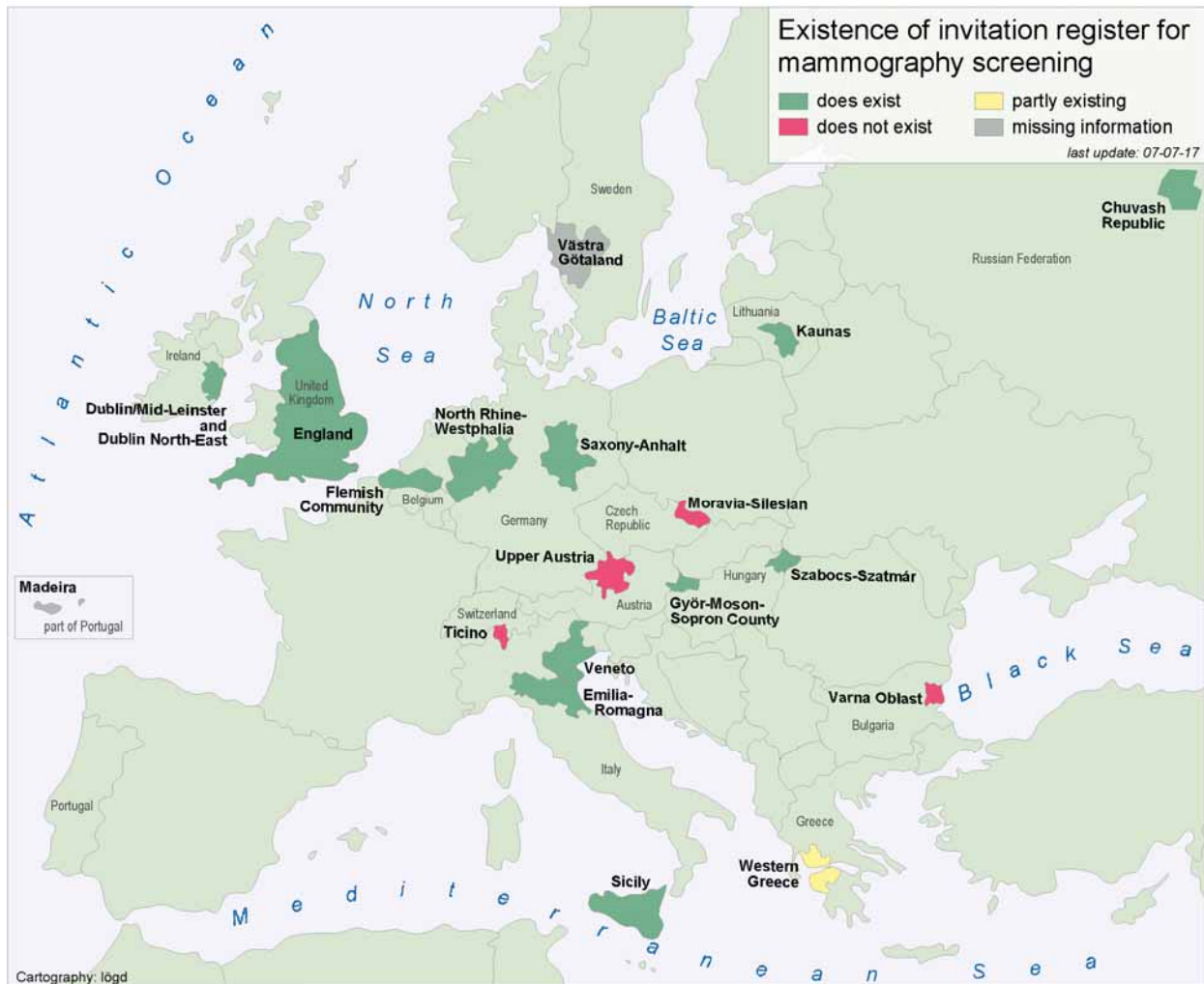
An interesting aspect is the question concerning the existence of invitation registers for mammography screening because sometimes more women can be motivated to participate in the screening programme if they are invited directly or personally. It is shown that in twelve participating regions invitation registers exist. In Western Greece (EL) this type of register only exists in some parts of the region. In Moravia-Silesia (CZ) and in Upper-Austria (AT) no invitation registers have currently been established. But in Upper-Austria (AT) an invitation

⁸² Missing information: Madeira (PT) and Västra Götaland (SE).

⁸³ Missing information: Västra Götaland (SE) and Madeira (PT).

register is planned and will be implemented in the near future. In Ticino (CH) and Varna-Oblast (BG) no mammography screening programmes are being implemented.⁸⁴

Illus. 13: Existence of invitation registers for mammography screening



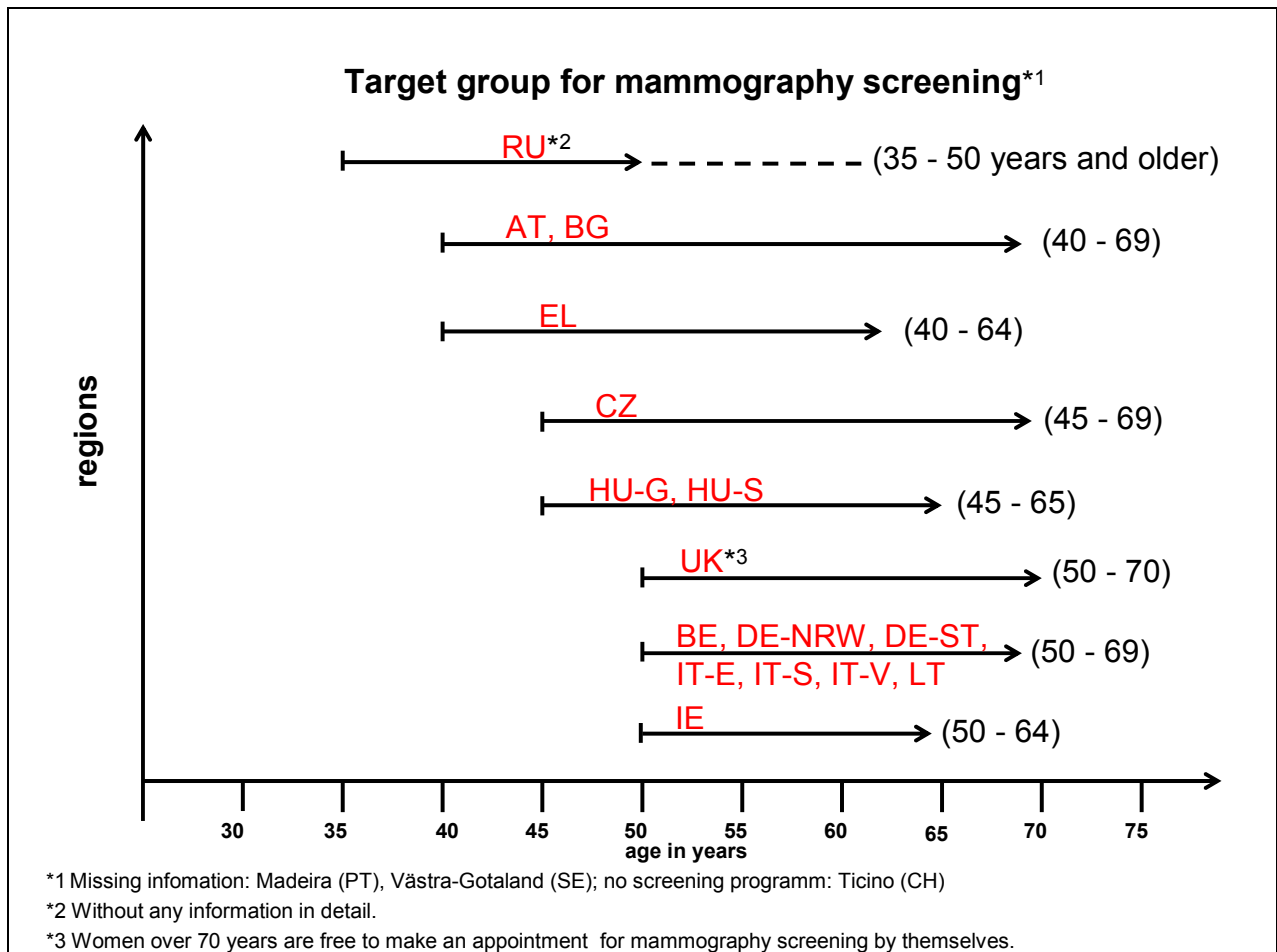
6.2.1.4 Target group of women for mammography screening

A further interesting aspect refers to the age of the women who are invited to breast cancer screening programmes because the participating European regions vary considerably on this point (see illus. 14).⁸⁵

⁸⁴ Missing information: VästraGötaland (SE) and Madeira (PT).

⁸⁵ Missing information: Madeira (PT) and Västra Götaland (SE).

Illus. 14: Target group of women for mammography screening



In Chuvash Republic (RU), the target group for mammography screening comprises all women between 35 - 50 years of age and older.⁸⁶ In Upper-Austria (AT), Varna-Oblast (BG) und Western-Greece (EL), women of the age groups of 40 years and older are invited to mammography screening. In Western-Greece (EL), women aged 40 years and older are invited.

Moravia-Silesia (CZ), Győr-Moson-Sopron County (HU) and Szabolcs-Szatmár-Bereg (HU) start their breast cancer screening programmes for women at 45 years of age and older with both Hungarian regions ending these programmes for women aged 65 years and older and the Czech Republic for women who have reached their 70th year of life.

Most regions start their breast cancer screening programmes for women at age 50 years and older. These regions include the Flemish Community (BE), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Kaunas (LT), Dublin/Mid-Leinster and Dublin/North-East (IE) and England (UK). The maximal screening age in these regions is 69 years with the exception of England (UK) and Dub-

⁸⁶ We do not have further information in detail.

lin/Mid-Leinster and Dublin/North-East (IE). Whereas in England the maximal age for mammography screening is 70 years, it is limited to 64 years in Dublin/Mid-Leinster and Dublin/North-East (IE). It should in addition be mentioned that in England (UK) women of the age groups of 70 years and older are free to make an appointment for mammography screening by themselves.

The longest timeframe for mammography screening can be observed for Upper-Austria because here it spans a period of altogether 29 years. With a time span of 14 years, the shortest time-frame for inviting women to breast cancer screening programmes is offered to women in Dublin/Mid-Leinster and Dublin/North-East (IE). It should moreover be stated that there are no differences between regions of the same country. It has, however, already been said that Ticino (CH) and Varna-Oblast (BG) have implemented no breast cancer screening programmes at all.

6.2.1.5 Intervals for mammography screening

For the great majority of 12 of the 19 participating regions, it can be stated that mammography screenings are held at two-year intervals. It should in addition be said that Ticino (CH) and Varna-Oblast (BG) have not implemented any breast cancer screening programmes. These include the regions of Upper-Austria (AT), Flemish Community (BE), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Győr-Moson-Sopron County (HU), Szabolcs-Szatmár-Bereg (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Sicily (IT), Veneto (IT) and Kaunas (LT).

Table 10: Intervals for mammography screening

three years	UK
two years	AT, BE, CZ, DE-NRW, DE-ST, EL*1, HU-G, HU-S, IE, IT-E, IT-S, IT-V, LT, RU*1
every year <i>(at the age of 50 years and older)</i>	EL, RU
every year <i>(at the age of 35 years and older with higher risk)</i>	EL
one time <i>(at the age of 35 - 40 years)</i>	RU
*1 at the age of 40 – 50 years No screening programm: Varna-Oblast (BG) and Ticino (CH) Missing information: Madeira (PT) and Västra-Gotaland (SE)	

Both in Western-Greece (EL) as well as in Chuvash Republic (RU), the intervals for mammography screening depend on the age of the women. In Western Greece (EL), women aged 35 years and older with a higher risk of breast cancer can have mammography screening every year. Women between 40 and 50 years of age can have this examination at two-year intervals. Women aged 50 years and older are entitled to this examination every year. It should in addition be said that Ticino (CH) and Varna-Oblast (BG) have not implemented any breast cancer screening programmes.⁸⁷

In Chuvash Republic (RU), women in the age group of 35 to 40 years are entitled to once-a-year mammography screening, regardless of whether they have complaints or not. Likewise, women aged 40 - 50 years may participate in screening programmes every two years. From the age of 50 years onwards, these examinations can be carried out every year in these regions. England (UK) is the only region with three-year intervals for mammography screening. It should in addition be said that Ticino (CH) and Varna-Oblast (BG) have not implemented any breast cancer screening programmes.

6.2.1.6 Responsibility for the planning of mammography screening programmes

Very great differences are apparent with regard to the question as to which organisations or institutions are responsible for the planning of mammography screening programmes. Exam-

⁸⁷ Missing information: Madeira (PT) and Västra Götaland (SE).

ples are: Ministry of Health and Women, National Government, National Public Health Centre, Associations of Statutory Health Insurance, Statutory Sickness Funds, Department of Health, Department of Public Health, National Breast Screening Board, National and Regional Ministries of Health and the Ministry of Health and Social Development. It is thus noticeable that at the superior level there is very little harmonisation as far as responsibility for the planning of screening programmes is concerned.

6.2.1.7 Financing of mammography screening programmes

With regard to the financing of mammography screening programmes, an enormous variety of possibilities is apparent in the interviewed regions. Since a graphic presentation would not give a detailed overview, some of the various funding methods mentioned in the interviews are given in the following: State Patient's Fund, Federal budget funding, Self funding, State funds, National Taxation by Allocation from Department of Health and Children, Foundation of Oncology, Public health Insurance Fund, National Public Health Centre, Sickness funds, Health insurance, Government, Regional Health Care Budget and Federal Social Insurance System.

These results clearly show that both the planning and implementation of mammography screening programmes as well as the financing differ considerably at the regional level in Europe and that in this respect there are no "uniform patterns".

6.2.1.8 Recall-Systems

Recall-Systems refer to women having to consult for the first time or once again their radiologist/clinician or screening units, i.e. women who, as a consequence of their first screening examination, are recalled. Currently much importance is being attached to recall systems in order to remind women of their upcoming medical examinations within the framework of optimal prevention, treatment and follow-up care.

6.2.1.8.1 Recall-Systems for clinical examination

A recall system for patients who are overdue for clinical examination exists in Győr-Ménfőcsanak (HU), in Chuvash Republic (RU) and only in some cases (not regularly) in Moravia-Silesia (CZ). In most participating regions, in Upper-Austria (AT), Flemish Com-

munity (BE), Varna-Oblast (BG), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Western Greece (EL) and Kaunas (LT) there are no recall systems for clinical examination.⁸⁸ Dublin/Mid-Leinster and Dublin/North-East (IE) has no clinical examination screening programme.

6.2.1.8.2 Recall-Systems for mammography screening

Recall systems for women who are overdue for mammography screening have been implemented in Flemish Community (BE), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), partly in Western-Greece (EL), Győr-Moson-Sopron County (HU), Szabolcs-Szatmár-Bereg (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Veneto (IT) und in Chuvash Republic (RU) and in England (UK). Only in four regions, i.e. in Upper-Austria (AT), Moravia-Silesia (CZ), Sicily (IT) and Kaunas (LT) no such systems have been installed. It should be taken into consideration that in Varna-Oblast (BG) and Ticino (CH) no mammography screening programme has been implemented.⁸⁹

When comparing both types of recall systems, it is noticeable that they are increasingly being used for mammography screening. Recall systems for clinical examination are only used in three of the interviewed regions, whereas 11 regions use recall systems for mammography screening. It should moreover be taken into consideration that in Moravia-Silesia (CZ) the recall system only functions to a limited extent.

6.2.1.9 Use of guidelines

In 2006, the European Commission, in cooperation with EUREF, EBCN and EUSOMA, published the 4th edition of the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. These guidelines aim to raise quality standards by bringing together at EU level the best examples from regional and national breast cancer screening programmes over the last 20 years. They are a manual for health professionals and advocates everywhere, describing good practice evolving from regional and national breast cancer screening programmes based on mammography.⁹⁰ The fourth edition has been coordinated by EUREF and

⁸⁸ Missing information: North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Szabolcs-Szatmár (HU), Emilia-Romagna (IT), Sicily (IT), Veneto (IT), Madeira (PT), Västra Götaland (SE), Ticino (CH) and England (UK).

⁸⁹ Missing information: Madeira (PT) and Västra Götaland (SE).

⁹⁰ European guidelines for quality assurance in breast cancer screening and diagnosis (2006).

developed with the input from over 200 professionals from 23 countries. New issues include digital mammography and advice for specialist breast units.

Many different guidelines exist for the prevention and treatment of breast cancer. These have been issued by various institutions at the national and international level.

6.2.1.9.1 Guidelines for clinical examination

Eight regions, i.e. Upper-Austria (AT), Varna-Oblast (BG), Switzerland (CH), Moravia-Silesia (CZ), Győr-Moson-Sopron County (HU), Szabolcs-Szatmár-Bereg (HU), Sicily (IT) and Chuvash Republic (RU) use guidelines by which clinical examinations are being performed. Only four regions, i.e. Flemish Community (BE), Veneto (IT), Kaunas (LT) and England (UK) refrain from using such guidelines.⁹¹

It has finally to be stated that the regions interviewed display a very high degree of heterogeneity in the way the guidelines are being used. In addition to EUREF-guidelines, national guidelines or guidelines developed in universities or ministries are applied (see illus. 15).

Illus. 15: Use of guidelines for clinical examination



⁹¹ Missing information: North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Western Greece (EL), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Madeira (PT) and Västra Götaland (SE).

6.2.1.9.2 Guidelines for mammography screening

It remains to be stated that *all* regions which have implemented breast cancer screening programmes use guidelines for the performing of mammography screening e. g. single view or two views. In Varna-Oblast (BG) and Ticino (CH) no mammography screening programmes have been implemented. The European regions display an enormous degree of heterogeneity concerning the type of guidelines applied. In addition to EUREF guidelines, national guidelines or those developed at universities or by ministries are being used. Moreover, the degree to which the guidelines are applied varies considerably. Upper-Austria (AT) for example, describes the degree to which guidelines are used as “partial application”.

6.2.2 Treatment and Care

6.2.2.1 Duty to notify cases of breast cancer

The project has shown that the interviewed regions have no standardised regulations concerning the obligation to report breast cancer diseases in Europe. In 14 of the 19 participating regions, breast cancer is a notifiable disease.⁹²

⁹² This statement must be qualified by saying that there is an obligation to report breast cancer diseases in Western-Greece (EL) but that in reality it is sometimes ignored.

Illus. 16: Duty to notify cases of breast cancer



In Ireland, in the region of Dublin/Mid-Leinster and Dublin/North-East there is no general duty to notify cases of breast cancer but all cases detected by the mammography screening programme are automatically notified of the national cancer registry. Considerable differences can moreover be noticed for the three interviewed Italian regions. In the region of Emilia-Romagna (IT), breast cancer must for example be notified at the *regional* level, whereas Sicily (IT) has issued no more than a recommendation but no duty to notify cases of breast cancer with the objective to collect data at the *local* level, and in Veneto (IT) there is no duty at all to report breast cancer cases.

6.2.2.2 Integrated treatment and care programmes

Under this project, integrated treatment and managed care concepts are not perceived as a closed theoretical system but as a set of management instruments and organisation forms to enhance efficiency in health care provision.

“The managed care concept refers to a principle of health care provision which is aimed at the efficient allocation of funds and resources so that every patient will receive the “right” type and amount of preventive and curative medical services. Superfluous and questionable services are excluded from this process. Managed care is provided in quite a number of sometimes very different forms of organisation.“ Schwartz/Wismar 2003: 571). In the American literature, this form of treatment and health care provision is defined by Fox in the following way: ”When one thinks about managed care, one should distinguish between the techniques of managed care and the organisations that perform the various functions. Managed care can embody a wide variety of techniques, These include various forms of financial incentives for providers, promotion of wellness, early identification of disease, patient education, self-care, and all aspects of utilization management.” (Fox 2001: 3).

6.2.2.2.1 Integrated care programmes

Many breast cancer patients are currently being treated under integrated care programmes. This is the case in ten regions, i.e. in Upper-Austria (AT), Flemish Community (BE), Varna-Oblast (BG), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Győr-Moson-Sopron County (HU), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT) and Chuvash Republic (RU).⁹³

Dublin/Mid-Leinster and Dublin/North-East (IE) has an integrated care programme for mammography screening and primary treatment (including surgery) of detected cases.

Five European regions, i.e. Ticino (CH), Western Greece (EL), Veneto (IT), Kaunas (LT) and England (UK) do not use integrated care programmes.

⁹³ Missing information: Szabolcs-Szatmár (HU), Sicily (IT), Madeira (PT) and Västra Götaland (SE).

6.2.2.2.2 Disease Management Programmes

Disease Management Programmes (DMP) are systematic treatment programmes for people with chronic diseases. They are based on the findings of evidence-based medicine. The idea of using disease management schemes as an instrument for the centrally organised steering of patients with chronic diseases stems from the USA. There is no standardised definition for the term of “disease management“ but as an example, the definition of the Disease Management Association of America (DMAA) will be given in the following.⁹⁴

“Disease Management is a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant.

Disease management:

- Supports the physician or practitioner/patient relationship and plan of care,
- Emphasises prevention of exacerbations and complications utilizing evidence-based practice guidelines and patient empowerment strategies, and
- Evaluates clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health.

Disease management components include:

- Population identification processes
- Evidence-based practice guidelines
- Collaborative practice models to include physicians and support-service providers
- Patient self-management education (may include primary prevention, behavior modification programs, and compliance/surveillance)
- Process and outcomes measurement, evaluation, and management
- Routine reporting/feedback loop (may include communication with patient, physician, health plan and ancillary providers, and practice profiling).⁹⁵

Disease Management Programmes for breast cancer are implemented in Upper-Austria (AT), Flemish Community (BE), Varna-Oblast (BG), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Győr-Moson-Sopron County (HU), Dublin/Mid-Leinster and Dublin/North-East (IE) (mammography screening and primary treatment, including surgery), Emilia-Romagna (IT) and Sicily (IT). Integrated Care Programmes do not exist

⁹⁴ Disease Management Association of America, http://www.dmaa.org/dm_definion.asp (18th June 2007).

⁹⁵ Disease Management Association of America, http://www.dmaa.org/dm_definion.asp (18th June 2007).

in Veneto (IT), Kaunas (LT), Western-Greece (EL), Ticino (CH), and England (UK).⁹⁶ In this context, regional differences in implementing disease management programmes are revealed within national borders because of the three interviewed regions in Italy, two regions have implemented such a programme. As far as Germany is concerned, there are, however, no differences between the regions interviewed (see illus. 17).

Illus. 17: Existence of Disease Management Programmes



6.2.2.3 Establishment of breast units

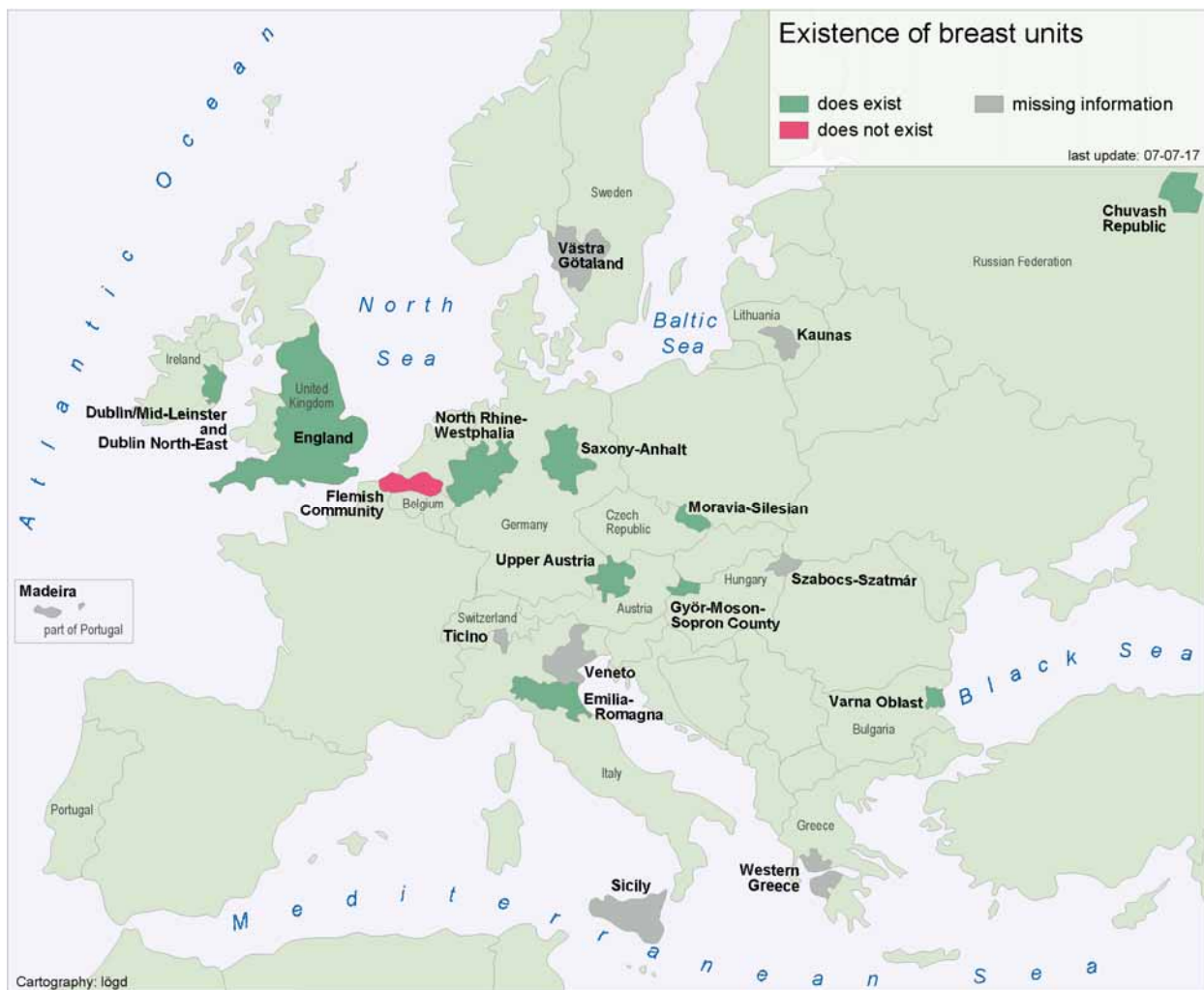
“Across Europe, an increasing number of well-organised multidisciplinary Breast Units have been established but overall the quality of each service is variable.” (EUSOMA 2000: 2288 - 2293; European guidelines for quality assurance in breast cancer screening and diagnosis 2006: 345) At the moment it is necessary that standards are set which any hospital wishing to

⁹⁶ Missing information: Szabolcs-Szatmár (HU), Madeira (PT), Chuvash (RU) and Västra Götaland (SE).

form a recognised Breast Unit must meet. In our analysis, we have also found out that there are great differences between the regions interviewed.

Breast units can be found in 10 of 19 regions interviewed, i.e. in England (UK), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Dublin/Mid-Leinster and Dublin/North-East (IE), Chuvash Republic (RU), Moravia-Silesia (CZ) Upper-Austria (AT), Győr-Moson-Sopron-County (HU), Emilia-Romagna (IT) and Varna-Oblast (BG). In Flemish Community (BE) no such centre has on the other hand been established.⁹⁷

Illus. 18: Existence of breast units



⁹⁷ Missing information: Kaunas (LT), Ticino (CH), Sicily (IT), Veneto (IT), Madeira (PT), Szabolcs-Szatmár (HU), Western Greece (EL) and Västra Götaland (SE).

6.2.2.4 Rehabilitation

Being diagnosed with breast cancer is a most dramatic event for the women concerned with not only serious consequences on their physical health but also mental health because in most cases surgery is required. Although in most cases breast-preserving surgery is performed, the mental and physical stresses and strains caused among other things by accompanying radiation, chemo or hormone therapies have serious consequences for the breast cancer patients. The provision of rehabilitation services may therefore help the women concerned to find their way back to their normal way of lives.

6.2.2.4.1 Type of rehabilitation

It can in general be said that all participating regions carry out rehabilitative measures.⁹⁸ Some rehabilitation services comprise inpatient hospital stays whereas other services consist of outpatient rehabilitation measures.

According to what was said in the interviews, great differences exist in the “type of rehabilitation”. Unfortunately, no valid statements can be made on the type and extent of breast cancer rehabilitation measures in the interviewed regions since the information given differs considerably. In addition to breast reconstruction, the measures mentioned comprise physiotherapy, physical rehabilitation, medicinal-gymnastic, Lymphoedema drain and also treatment with drugs.

6.2.2.4.2 Rehabilitation with socio-psychological aspects

Considerable differences are however revealed in the type and content of socio-psychological rehabilitation measures in place in the regions. Whereas in Ticino (CH), this type of service is only provided to a very limited extent, breast cancer patients in Varna-Oblast (BG) are offered no rehabilitation under the socio-psychological heading. It has on the whole however to be stated that all other regions interviewed provide socio-psychological rehabilitation services for breast cancer patients.⁹⁹

⁹⁸ Missing information: Szabolcs-Szatmár (HU), Veneto (IT), Western Greece (EL), Madeire (PT) and Västra Götaland (SE).

⁹⁹ Missing information: Western Greece (EL), Szabolcs-Szatmár (HU), Veneto (IT), Madeira (PT) and Västra-Gotaland (SE).

6.2.2.4.3 Availability of prosthetic fitting service

Apart from Varna-Oblast (BG), all regions interviewed provide a prosthetic fitting service. The reason given by Varna-Oblast in the interview was that “protheses are very expensive for Bulgariens patients”.¹⁰⁰ This has to be taken as a hint that in Varna-Oblast (BG) costs for protheses are not borne by health insurances or other organisations/institutions but by the patients themselves.

6.2.3 Health Service

6.2.3.1 Monitoring satisfaction regarding treatment and care

Monitoring satisfaction regarding treatment and care is being carried out in ten regions involved in the project, i.e. in Varna-Oblast (BG), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Győr-Moson-Sopron County (HU), Szabolcs-Szatmár-Bereg (HU), Sicily (IT), Kaunas (LT) and in Chuvash Republic (RU) . In Upper-Austria (AT) on the other hand, the monitoring of the patients’ satisfaction with regard to treatment and care is carried out on a partly and/or unsystematic basis. In Dublin/Mid-Leinster and Dublin/North-East (IE) monitoring of patient satisfaction is well established for mammography screening and primary treatment services. Such monitoring is planned for symptomatic breast disease services under new standards published in 2007. Only the Flemish-Community (BE), Moravia-Silesia (CZ) and Veneto (IT) refrain from performing such monitoring programmes.¹⁰¹

6.2.3.2 Part of the political agenda

Questions pertaining to the “current status of the disease on the political agenda” are particularly notable since this can be interpreted as a hint to the present status of this disease in the corresponding regions.

¹⁰⁰ Missing information: Madeira (PT) and Västra-Gotaland (SE).

¹⁰¹ Missing information: Madeira (PT) and Västra-Gotaland (SE).

6.2.3.2.1 Breast cancer prevention (e. g. mammography screening programmes)

It is a remarkable fact that in 13 European regions, breast cancer prevention, e. g. mammography screening programmes, have become part of the political agenda.¹⁰² It should be said that Ticino (CH) and Varna-Oblast (BG) have implemented no breast cancer screening programme. This result has to be regarded as supporting evidence for the high status of these prevention measures in the European regions because no region has said that breast cancer prevention measures are no integral part of their current political agenda.

6.2.3.2.2 Promotion of self-help groups

The promotion of self-help groups as a part of the political agenda differs considerably in the interviewed regions. Whereas in six regions, i.e. in Upper-Austria (AT), Flemish Community (BE), Moravia-Silesia (CZ), Győr-Moson-Sopron County (HU), Kaunas (LT) and Chuvash Republic (RU) the promotion of self-help groups has become an integral part of the political agenda, this is not the case in seven regions (Varna-Oblast (BG), Ticino (CH), Western Greede (EL), Dublin/Mid-Leinster and Dublin/North-East (IE), Emilia-Romagna (IT), Sicily (IT) and England (UK)).¹⁰³ In Upper-Austria (AT) self-help groups are promoted at the regional level, whereas no detailed information has been given by the other regions.

6.2.3.3 Support of self-help groups

In all European regions interviewed, it becomes apparent that apart from Sicily (IT), Kaunas (LT) and England (UK) self-help groups are supported by official institutions.¹⁰⁴ These results show that in all participating European regions official institutions and organisations attach much importance to breast cancer self-help groups.

¹⁰² Missing information: Ticino (CH), Western-Greece (EL), Győr-Moson-Sopron County (HU), Emilia-Romagna (IT), Veneto (IT), Madeira (PT), Västra Götaland (SE) and England (UK).

¹⁰³ Missing information: North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Szabolcs-Szatmár (HU), Veneto (IT), Madeira (PT) and Västra Götaland (SE).

¹⁰⁴ Missing information: Szabolcs-Szatmár (HU), Veneto (IT; because it is unknown), Madeira (PT) and Västra Götaland (SE).

6.2.4 Discussion of the analysis of the responses from the participating regions¹⁰⁵

It is apparent from the analysis in the preceding paragraphs that the responses showed many differences in the policy, organisation and management of breast cancer screening, treatment and care programmes in the participating regions. These differences may be explained to some degree by differences in health systems in operation within the regions e.g. publicly funded versus health insurance systems, or by the socio-political or socio-economic background and culture of the different regions. However, there may also be differences in regions within the same country operating within the same national environment, e.g. in Italy for duty to notify cases of breast cancer. Why should this be so? It may signal the degree of autonomy exerted by a given region. Just as there may be differences of approach between regions of different countries so also there may be differences between autonomous regions within the same country.

It is clear from the analysis of the responses of the regions that although there are differences, a majority may have given a similar response to a particular question thus constituting what might be regarded as a “norm”. The important question from the Ben RHM II perspective is: Can this “norm” be regarded as representing *good practice* that might be emulated by other regions and, if so, how does it equate/relate to one of the evidence-based interventions and policies selected for the reference frameworks?

Another question that occurs from the results of the analysis is: Did the open question method used in the interviews always obtain the right information?

Applying these two questions to the results of the analysis of the responses, a number of observations can be made.

Education programmes about the benefits of breast cancer screening have been established in 13 of the 17 regions that responded. There is no screening programme in 2 of the other 4 regions and of the remaining 2, 1 reported a good mammography screening participation rate of 75% in 2005 despite the absence of an education programme. No information on participation rate was received from the other region. The fact that such a large majority of regions has established an education programme suggests that this can be regarded as a *good practice* norm. However, these programmes can have many different formats depending on the choice of the region and this gives rise to difficulties of comparison as there is no information on the effectiveness of the different formats. The reference framework for breast cancer

¹⁰⁵ Author: Kieran Hickey, Health Service Executive, Dublin.

includes, as an evidence-based intervention, education of physicians and the political community regarding the risks and benefits of mammography screening.

The analysis of responses shows that invitation strategies for mammography screening have been developed in 13 of the 17 regions that responded. Of the remaining 4 regions, 2 have no invitation strategy and 2 have no screening programme. The mammography screening participation rate in 1 of the 2 regions without an invitation strategy is low and no information on participation rate was received from the other region. Identification and invitation of eligible women for mammography screening (every two/three years) is included in the reference framework for breast cancer.

Invitation registers for mammography screening have been established in 12 of the 17 regions whose responses were analysed. Such a register exists in parts of 1 region and not at all in 4 regions, but 2 of the latter do not have a mammography screening programme. The same remarks as in the previous paragraph regarding participation rate, again apply to the 2 regions that do not have an invitation register. In addition to the identification and invitation of eligible women, the reference framework for breast cancer also includes as good practice norm, the existence of an invitation system for mammography screening.

The analysis of responses shows that the age at which women are invited to mammography screening varies considerably. The target age group for 7 out of 16 regions is 50-69 years of age and this coincides with the evidence-based intervention included in the reference framework for breast cancer. The target age group for the other 9 regions varies with 5 of them starting at between 35 and 50 years of age, rising to 69 or 70 years. The remaining 4 regions start at between 40 and 50 years of age rising to 64 or 65 years of age. This means that 12 of the 16 regions meet the *good practice* norm for the age at which women are invited to mammography screening.

As regards the interval between mammography screenings, the analysis shows that for 12 of the 15 regions with screening programmes, the interval is two years. The reference framework indicates a good practice norm of two/three years. In another 2 regions the interval is either one or two years depending on risk or age. The interval is 3 years in 1 region. All 15 regions therefore meet the good practice norm.

The responses show that responsibility for the planning of mammography screening programmes varies very widely with regions citing National Government, Ministries at National or Regional levels, National Public Health Centre or Department, National Associations of Statutory Health Insurance or Statutory Sickness Funds, and one dedicated National Breast Screening Board. This lack of harmonisation is not entirely surprising given the differences in

health systems of the regions and other factors. The organigraphs were drawn up to provide an overview of the organisation of the regional health management systems and the relationships of the different decision-making bodies to each other as well as the flow of actions within the health management process. These may provide further insights into the governance process in regions.

The responses regarding financing of the mammography screening programmes also produced a wide variety of approaches by the regions. This is as one would expect, given the different health systems, socio-political or socio-economic circumstances. These differences are not all that significant from a Ben RHM II perspective as financing arrangements are not included in the reference framework.

One region has a dedicated ring-fenced budget for mammography screening. What would be interesting in the context of financing is whether the budget for mammography screening has to compete with other services as part of a general budget for mainstream services or whether it is a dedicated ring-fenced budget for all services related to a mammography screening programme. We had not asked for information on this or on the views of regions regarding the benefits or otherwise of ring-fenced budgets.

The analysis of responses shows that recall systems for mammography screening have been installed in 11 of the 17 regions that responded. There is no such system in 4 regions and 2 regions do not have screening programmes. This compares to recall systems for clinical examination installed in 3 regions.

It is clear that recall systems are associated with invitation systems and, as such, are equivalent to a *good practice* norm as in the reference framework.

The responses show that guidelines aimed at raising quality levels are used for clinical examination and for mammography screening. They are used by 8 regions for clinical examination and by all regions that have mammography screening programmes. A number of European best practice guidelines have been published and the reference framework makes specific reference to the use of EUREF guidelines for breast cancer screening.

The responses also show that differences exist between the degree to which guidelines are used by some regions; also the EUREF guidelines are supplemented by national or locally developed guidelines in a number of regions. The wide range of such differences makes it difficult to judge the degree to which *good practice* is being implemented through the use of guidelines.

Regarding surveillance of breast cancer, the responses show that there are some differences of approach amongst regions concerning breast cancer being a notifiable disease. In 14

of the 17 regions that responded, there is a duty to notify cases of breast cancer. The difference of approaches is most evident in the 3 Italian regions where notification is not obligatory in 2 of the regions. It should be noted that obligatory reporting is included as an evidence-based policy in the reference framework.

Turning to treatment and care, the analysis of the responses shows that 10 of the 15 regions that responded have Integrated Care programmes and 5 regions do not have such programmes. A similar number, 10, responded to say that they have Managed Care Programmes and 5 said that they have do not have these programmes.

The reference framework for breast cancer includes an evidence-based policy for the development of Disease Management Programmes/Integrated Care and the responses show that this *good practice* norm has been adopted by 10 regions.

Regarding the establishment of multidisciplinary Breast Units, the responses from 11 regions show that 10 of them have developed Breast Units. No information was received from 8 regions. European guidelines for quality assurance, published by EUSOMA, apply to such units but these are not applied in all regions, or partially applied along with other guidelines.

The reference framework includes a number of policies regarding Breast Units. These are the establishment of specialised centres (with defined minimum number of primary therapies); certification of centres according to EUSOMA; establishment of internationally recognised performance indicators (e.g. mastectomy rates). It is not clear from the analysis of responses how many regions have Breast Units that conform to all of these criteria.

The responses show that, in general, all regions that responded carry out some rehabilitation activities in different settings. However, because of difficulties in classifying the range of information given it has not been possible to give any precise summary by region of the types and an extent of rehabilitation being carried out. It is possible to say that in addition to breast reconstruction, physical therapies, lymphoedema and drug therapies are included. Socio-psychological rehabilitation is provided by 12 regions, partly by 1 region and not at all by 1 region. There was no response from 5 regions.

A prosthetic fitting service is provided in 16 regions out of 17 that responded. It is not provided in 1 region and the reason given for this is the expense involved.

The reference framework includes a number of interventions and policies regarding rehabilitation: psycho-social counselling; establishment of psycho-social centres; consideration of psychological factors in guidelines; improvement of psychosocial competence of health professionals; implementation of guidelines for rehabilitation; improvement of ambulant rehabilitation.

It would seem from the fragmented nature of the responses to some of the questions about rehabilitation that regions in general fall short of some of the *good practice* requirements in this area.

Monitoring of patient satisfaction regarding treatment and care is included in the analysis of responses. This shows that 10 regions out of 13 that responded do, and 3 do not, carry out such monitoring. There was no response from 6 regions. This activity is not included as such in the reference framework but patient empowerment to encourage rights of participation and also access to information assessing the quality of the care provider, are two activities that are included.

The analysis shows that in response to a question about breast cancer being part of the political agenda, 13 regions said that prevention through mammography screening programmes has currently become part of the political agenda. When this question is expanded to ask about the promotion of self-help groups as part of the political agenda, 6 regions said it is and 7 said it is not. However, in response to a further question all the regions that responded, with the exception of 3, said that self-help groups are supported (may include financial support) by official institutions in their regions.

6.3 Diabetes (type II)

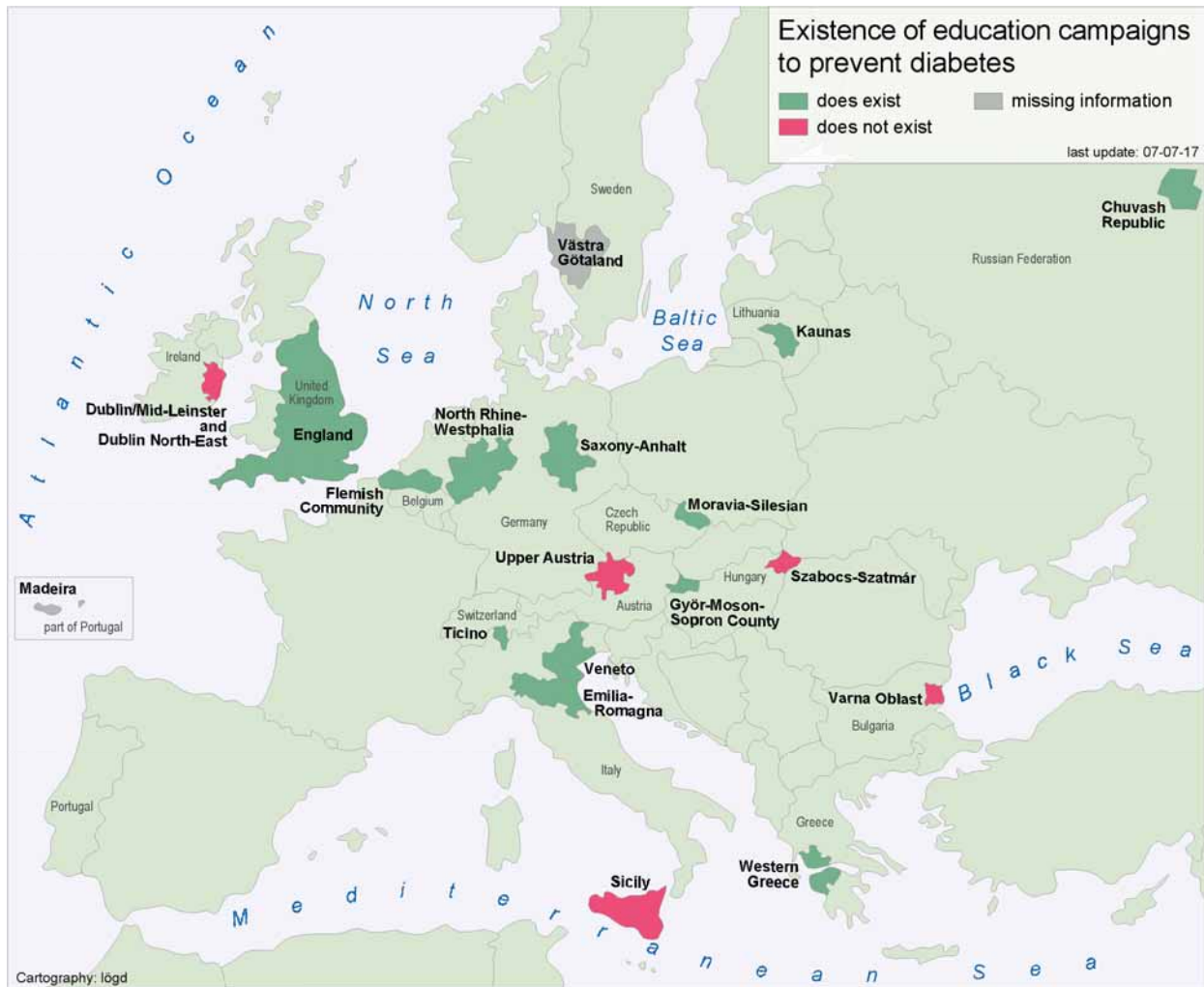
6.3.1 Prevention and screening

6.3.1.1 Education campaigns to prevent diabetes and diabetes risk factors

Due to the growing number of diabetics, the health systems worldwide are faced with considerably higher expenses for diabetes services as diabetes is a chronic disease. Against the background of a continuously growing number of diabetics, special education campaigns for the prevention of diabetes will gain in importance. It can be stated that of 19 regions interviewed, 12 regions, i.e. the Flemish Community (BE), Ticino (CH), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Western Greece (EL), Győr-Moson-Sopron County (HU), Emilia-Romagna (IT), Veneto (IT), Kaunas (LT), Chuvash Republic (RU) and England (UK) offer special education campaigns for the prevention of diabetes. It should in addition be pointed out that in Upper-Austria (AT), Varna-Oblast (BG), Szabolcs-Szatmár-Bereg (HU), Dublin/Mid-Leinster and Dublin/North-East (IE) and Sicily (IT) no special education programmes for the prevention of diabetes have been implemented (see illus. 19).¹⁰⁶

¹⁰⁶ Missing information: Madeira (PT) and Västra Götaland (SE).

Illus. 19: Existence of education campaigns to prevent diabetes (type II)

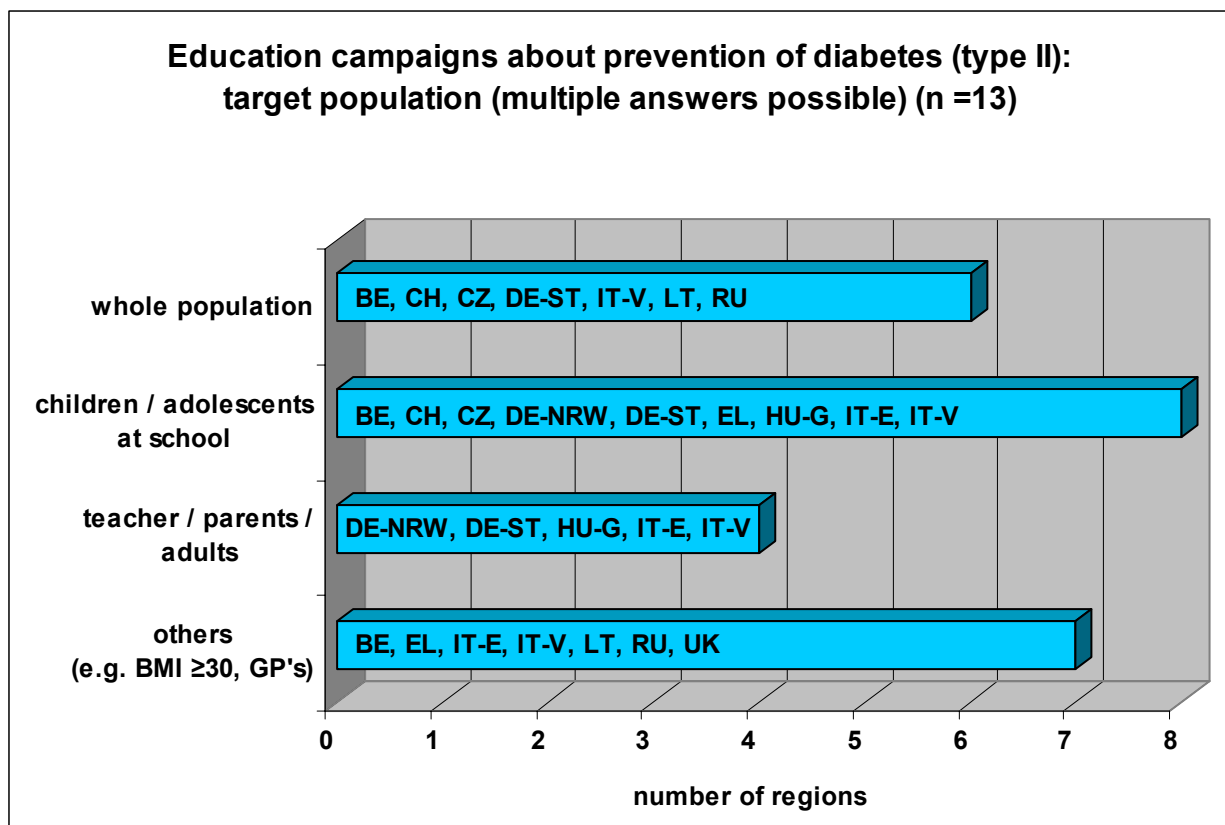


Measures in the field of prevention are particularly well suited to considerably reduce risk factors such as overweight and hyperlipaemia which contribute to the development of diabetes (type II). Specific lifestyle actions can help to minimise risk factors and thus to reduce the individual risk of contracting the disease. For these reasons, a look should be taken at the range of specific education campaigns offered for the prevention of diabetes risk factors. It becomes apparent that all those regions which offer education campaigns for the prevention of diabetes also provide education campaigns for the prevention of diabetes risk factors, such as for example obesity.

6.3.1.2 Target population of education programmes/campaigns

When looking at the target groups for the prevention of diabetes (type II), a high degree of heterogeneity can be observed (see illus. 20).

Illus. 20: Target population of education campaigns (multiple answers possible)



In some regions, education campaigns are addressed to the whole population. It is, moreover, noticeable that in particular children and adolescents at school are being targeted by the education programme. No special education programmes/campaigns have been established in Upper Austria (AT), Varna-Oblast (BG), Szabolcs-Szatmár-Bereg (HU), Dublin/Mid-Leinster and Dublin/North-East (IE) and Sicily (IT).¹⁰⁷ But parents/legal guardians and teachers (as multipliers) are also intended to be reached by the different education programmes and/or campaigns.

¹⁰⁷ Missing information: Madeira (PT) and Västra Götaland (SE).

6.3.1.3 Information and education for socio-economic subgroups

A conspicuous feature revealed by the project is that none of the regions interviewed has found an ideal solution to inform socio-economic subgroups about the prevention of diabetes (type II). Instead, the regions pointed out to the problem that the “normal population” was hardly being reached and that therefore there were almost no possibilities to comprehensively inform socio-economic subgroups such as for example migrants. It can in general be said that in those cases where information was passed on, this was done by physicians, mass media or information brochures. In Upper-Austria (AT), Varna-Oblast (BG), Szabolcs-Szatmár-Bereg (HU), Dublin/Mid-Leinster and Dublin/North-East (IE) and Sicily (IT) no special education programmes to prevent diabetes have been implemented.¹⁰⁸

6.3.1.4 Special regional diabetes screening programme

A revealing insight is given by statements pertaining to specific *regional* diabetes screening programmes. Such a programme has exclusively been implemented in Emilia-Romagna (IT). All other regions involved in the project have no such regional diabetes screening programme.¹⁰⁹

6.3.1.5 Examination interval

The results obtained in answer to the question about the intervals of the examinations (screening) for diabetes (type II) detection are very telling. Ten regions involved in the project have fixed examination intervals for the detection (screening) of diabetes (type II). In the Flemish Community (BE), Dublin/Mid-Leinster and Dublin/North-East (IE), Sicily (IT-E) and Ticino (CH) no such programmes have been initiated.¹¹⁰ The examination intervals differ in terms of frequency and are either held every three years, every two years or annually. What is important for the timeframe is above all the patient’s age and whether or not there might be risk factors for him/her. So for example in North Rhine-Westphalia (DE), women up to the age of 35 years who have given birth to a “big baby” (i.e. a child with a birth weight of 4,000 g and more) are examined for diabetes every three years. At the age of 35 and older, they are screened every two years. In Western-Greece (EL), patients with “normal” results at the last

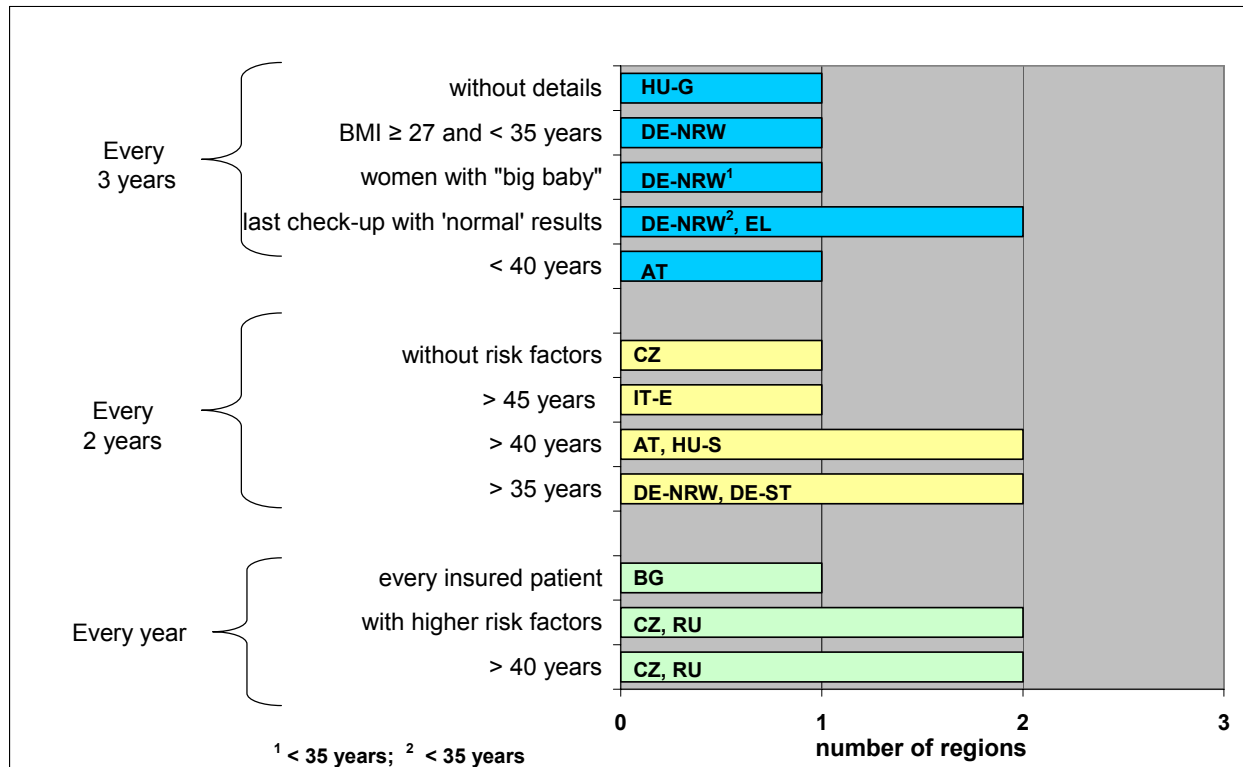
¹⁰⁸ Missing information: Madeira (PT) and Västra Götaland (SE).

¹⁰⁹ Missing information: Western Greece (EL), Vento (IT), Madeira (PT) and Västra Götaland (SE).

¹¹⁰ Missing information: Veneto (IT), Madeira (PT) and Västra Götaland (SE).

check-up are screened for diabetes every three years. Moravia-Silesia (CZ), on the other hand, screens patients without risk factors every two years. Patients in Moravia-Silesia (CZ) and in Chuvash Republic (RU) with a higher risk of falling ill due to risk factors are screened every year.

Illus. 21: Examination interval for the detection (screening) of diabetes (type II)



There are no restrictions for diabetes screening in Varna-Oblast in Bulgaria; here every patient can have diabetes screening once a year.

6.3.1.6 Detection examination of pregnant women

Gestational diabetes is a disease which is increasing worldwide and one of the most frequent complications during pregnancy. (Linn/Lang 2006: 196) Gestational diabetes is defined as hyperglycaemia which is first recognised during pregnancy. Symptoms of gestational diabetes are similar to type II diabetes. Gestational diabetes is most often diagnosed through prenatal screening, rather than reported symptoms.¹¹¹ In Germany, the expected frequency of gestational diabetes is up to 6% of all pregnancies. This corresponds to almost 50.000 cases per

¹¹¹ <http://www.who.int/mediacentre/factsheets/fs312/en/index.html> (21.06.2007).

year. Diagnosing this disease is important since it is related to increased morbidity of mother and child.

Gestational diabetes usually goes away after pregnancy. But once women have had gestational diabetes, their chances are 2 in 3 that it will return in future pregnancies. In a few women, however, pregnancy uncovers diabetes type I or diabetes type II. It is hard to tell whether these women have gestational diabetes or have just started showing their diabetes during pregnancy. These women will need to continue diabetes treatment after pregnancy. Many women who have gestational diabetes go on to develop diabetes type II years later. There seems to be a link between the tendency to have gestational diabetes and diabetes type II. Gestational diabetes and type II diabetes both involve insulin resistance. Certain basic life-style changes may help prevent diabetes after gestational diabetes.¹¹²

Screening examination for gestational diabetes is carried out on pregnant women in all interviewed European regions with the exception of England (UK), Dublin/Mid-Leinster and Dublin/North-East (IE) and Sicily (IT) where this examination is not done in a methodical way through a screening programme.¹¹³

6.3.2 Treatment and care

Since diabetes is a chronic disease, special attention should be attached to treatment and care in order to avoid long-term damage.

6.3.2.1 Implementation of regional integrated care programmes

With regard to integrated care programmes for diabetes, a look at the regional level gives interesting insights. Currently, six regions have implemented such a programme. These regions include North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Emilia-Romagna (IT), Veneto (IT), Kaunas (LT) and England (UK). In addition it should be said that such a programme is planned in Upper-Austria (AT).¹¹⁴

A look within country borders shows that for regional integrated care programmes for diabetes (type II) no differences can be observed between the two German regions. At the

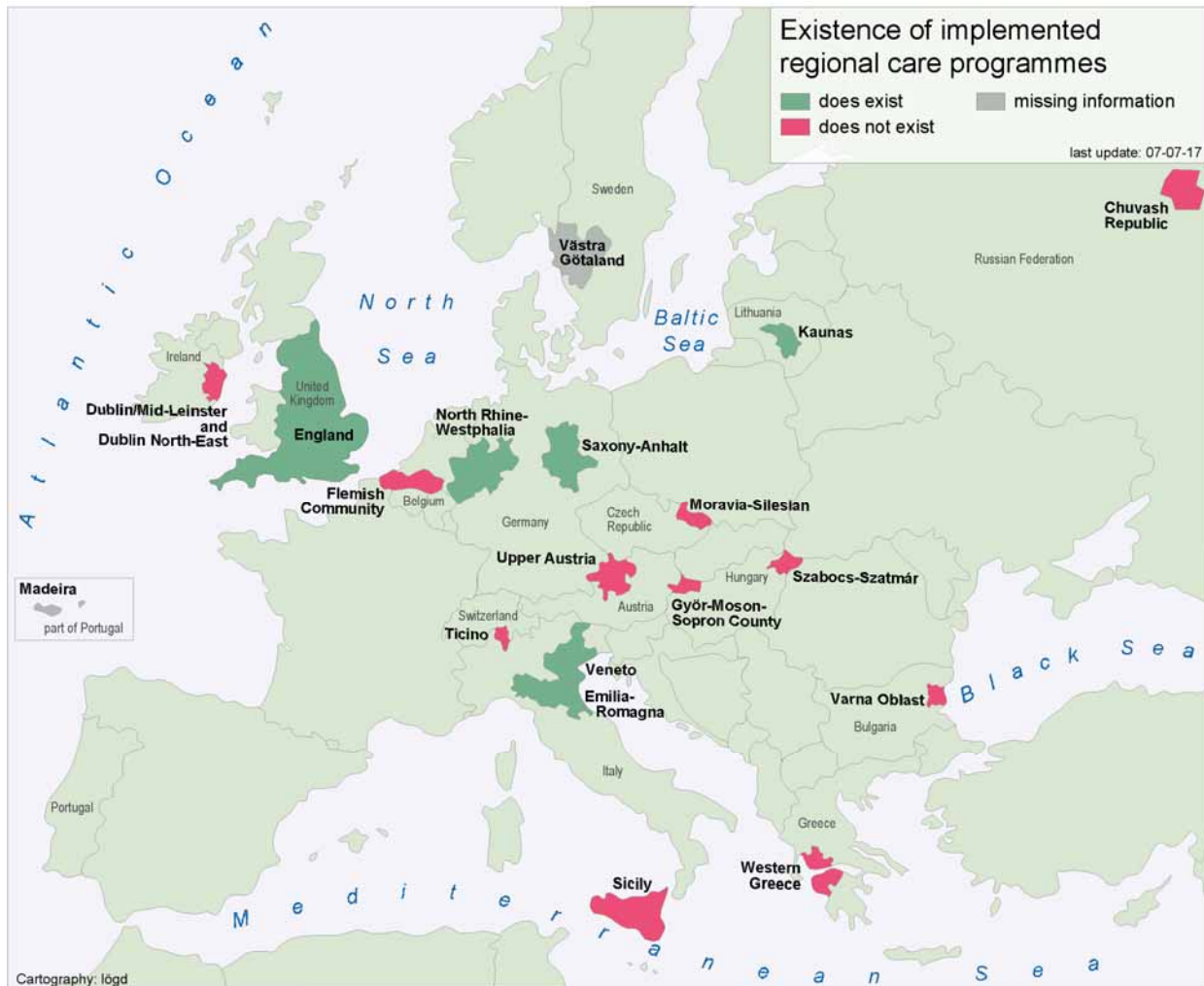
¹¹² American Diabetes Association <http://www.diabetes.org/gestational-diabetes.jsp> (17th July 2007).

¹¹³ Missing information: Veneto (IT), Madeira (PT) and Västra Götaland (SE).

¹¹⁴ Missing information: Madeira (PT) and Västra Götaland (SE).

moment, the Italian regions still differ but harmonisation is intended, particularly since such a programme is planned in Sicily (IT).

Illus. 22: Existence of regional care programmes



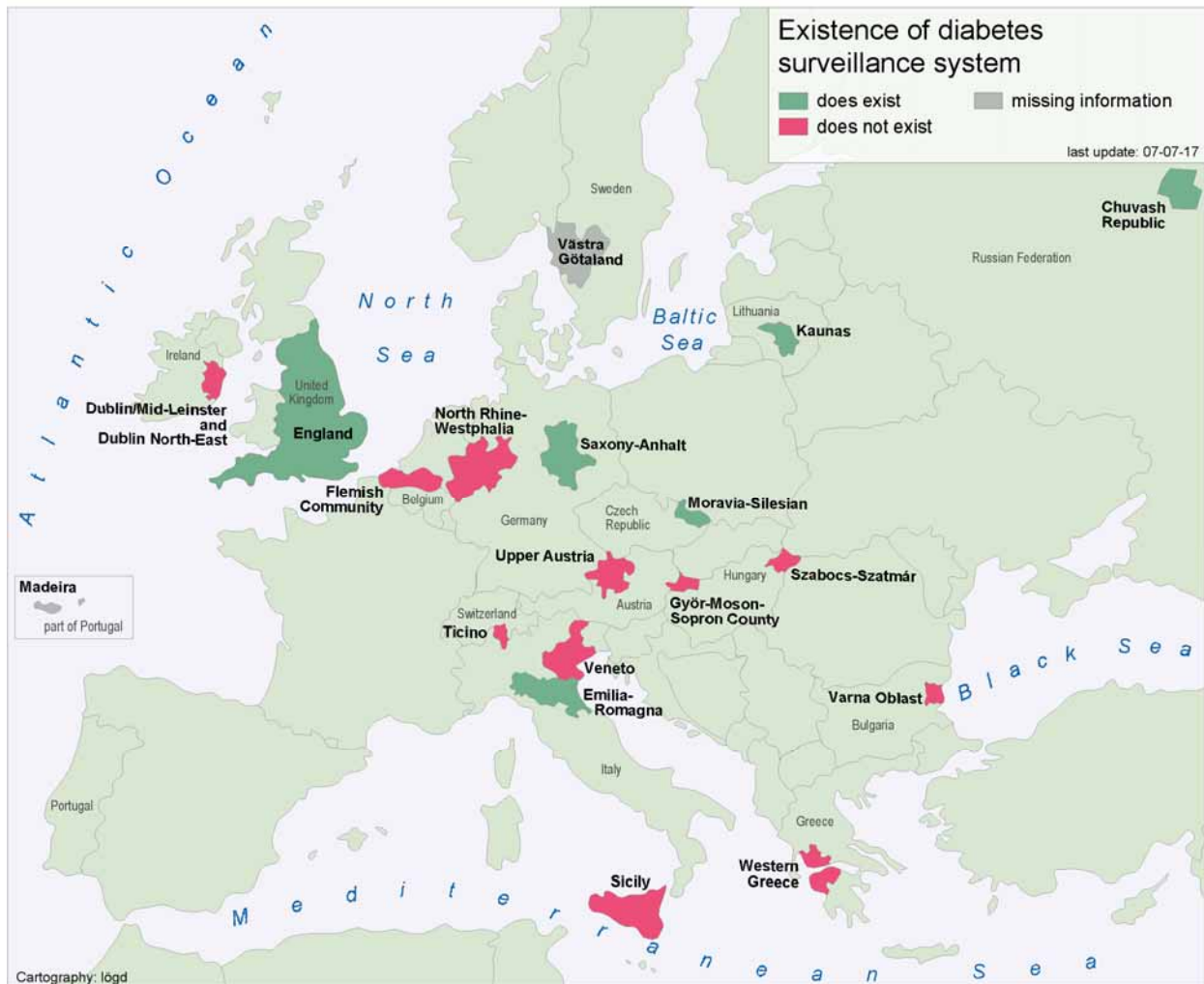
6.3.2.2 Establishment of a diabetes surveillance system

The project shows that only six regions have installed a diabetes surveillance system. These include the regions of Chuvash Republic (RU), Moravia-Silesia (CZ), Saxony-Anhalt (DE), Emilia-Romagna (IT), Kaunas (LT) and England (UK).¹¹⁵ It is therefore foreseeable that in this field a lot of catching up will have to be done to establish the corresponding systems. What is also interesting in this context is the difference between two regions within the same country. A diabetes surveillance system has for example been implemented in Saxony-Anhalt

¹¹⁵ Missing information: Madeira (PT) and Västra Götaland (SE).

(DE), whereas North Rhine-Westphalia has no such system. Regional differences can also be observed in Italy. Emilia-Romagna (IT) has installed such a system, whereas Sicily (IT) and Veneto (IT) are lacking this system. But in Veneto (IT), the regional commission is in the process of defining a system of surveillance.

Illus. 23: Existence of a diabetes surveillance system



6.3.2.3 Examination intervals

Medical care for diabetes mellitus patients is provided at various levels of the health care system. In addition to general medical treatment provided in doctors' practices and hospitals, diabetes-specific services are sometimes offered for the patients concerned in order to avoid or at least postpone the onset of late complications of the disease such as loss of sight or am-

putation of limbs. “Over time, diabetes can damage the heart, blood vessels, eyes, kidneys, and nerves.”¹¹⁶

6.3.2.3.1 Eye examination

Diabetic retinopathy is the most frequent micro-vascular complication in patients with diabetes mellitus. (Hammes 2006) After more than 20 years of diabetes, 60 - 80 % of all diabetes (type II) patients suffer from damage to the retina caused by diabetes. Recognising diabetic retinopathy as early as possible is therefore very important, particularly since the early stages pass without symptoms. (Hammes 2006) “Diabetic retinopathy is an important cause of blindness, and occurs as a result of long-term accumulated damage to the small blood vessels in the retina. After 15 years of diabetes, approximately 2% of people become blind, and about 10% develop severe visual impairment.”¹¹⁷ Advanced stages of diabetic retinopathy are the most frequent causes for loss of sight among adults between 20 - 74 years of life. (Hammes 2006)

The project has shown that all regions that responded to the question (n = 17) promote/reimburse the costs of annual eye examinations.¹¹⁸ This observation should, however, be qualified by saying that Dublin/Mid-Leinster and Dublin/North-East (IE) have not yet implemented an organised screening programme for diabetic retinopathy although such a programme is currently being planned.

6.3.2.3.2 Foot examination

The diabetic foot syndrome is one of the most frequent complications of diabetes mellitus. The incidence rate of diabetes-related amputations is estimated at 6-8/1,000 diabetics/year. (Risse 2006) This means that with regard to long-term treatment, pathological changes to the foot have to be reckoned with for every diabetes patient. (Risse 2006)

“Diabetic neuropathy is damage to the nerves as a result of diabetes, and affects up to 50% of people with diabetes. Although many different problems can occur as a result of diabetic neuropathy, common symptoms are tingling, pain, numbness, or weakness in the feet

¹¹⁶ <http://www.who.int/mediacentre/factsheets/fs312/en/index.html> (21.06.2007).

¹¹⁷ <http://www.who.int/mediacentre/factsheets/fs312/en/index.html> (21.06.2007).

¹¹⁸ Missing information: Madeira (PT) and Västra Götaland (SE).

and hands. Combined with reduced blood flow, neuropathy in the feet increases the chance of *foot ulcers* and eventual *limb amputation*.’’¹¹⁹

The project has revealed that in 15 of the 19 participating regions, annual foot examinations are being promoted and/or examination costs reimbursed. In England (UK) foot examination is not generally part of the annual check.¹²⁰ In Dublin/Mid-Leinster and Dublin/North-East (IE) this is not promoted; access to podiatry services is limited and this service is free for lower income groups and patients aged 65 years and older. In England foot examinations are not generally part of annual checks.

6.3.2.4 Support of self-help groups by official institutions

An important question to investigate into was whether self-help groups of diabetics are supported by official institutions. The project has shown that self-help groups are supported in 14 regions. Only Moravia-Silesia (CZ), Szabolcs-Szatmár-Bereg (HU) and Sicily (IT) do not provide this support. Valid statements on the extent and kind of support provided can unfortunately not be made because of the multi-faceted possibilities of providing support.

6.3.2.5 Monitoring patient satisfaction regarding care provision

The patients’ satisfaction with the health services provided was examined in ten regions. These include Upper-Austria (AT), Moravia-Silesia (CZ), North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Győr-Moson-Sopron County (HU), Emilia-Romagna (IT), Veneto (IT), Kaunas (LT) and Chuvash Republic (RU).¹²¹ It should, however, be said that the patients’ satisfaction was only partly monitored.

6.3.3 Diabetes examination and screening programmes as part of the political agenda

As already mentioned, the number of diabetics is increasing worldwide, leading to the question as to how far examination and screening programmes have already been established as part of the political agenda. Currently, such programmes have become an integral part of the

¹¹⁹ <http://www.who.int/mediacentre/factsheets/fs312/en/index.html> (21.06.2007).

¹²⁰ Missing information: Madeira (PT) and Västra Götaland (SE).

¹²¹ Missing information: Madeira (PT) and Västra Götaland (SE).

political agenda only in Moravia-Silesia (CZ), Western-Greece (EL), Szabolcs-Szatmár-Bereg (HU), Emilia-Romagna (IT), Kaunas (LT) and Chuvash Republic (RU).¹²²

6.3.4 Discussion of the analysis of the responses from the participating regions¹²³

It is apparent from the analysis in the preceding paragraphs that the responses showed many differences in the policy, organisation and management of diabetes screening, treatment and care programmes in the participating regions. These differences may be explained to some degree by differences in health systems in operation within the regions e.g. publicly funded versus health insurance systems, or by the socio-political or socio-economic background and culture of the different regions.

However, there may also be differences in regions within the same country operating within the same national environment, e.g. regarding the installation of a diabetes surveillance system. Why should this be so? It may signal the degree of autonomy exerted by a given region. Just as there may be differences of approach between regions of different countries so also there may be differences between autonomous regions within the same country.

It is clear from the analysis of the responses of the regions that although there are differences, a majority may have given a similar response to a particular question thus constituting what might be regarded as a “norm”. The important question from the Ben RHM II perspective is: Can this “norm” be regarded as representing *good practice* that might be emulated by other regions and, if so, how does it equate/relate to one of the evidence-based interventions and policies selected for the reference frameworks?

Another question that occurs from the results of the analysis is: Did the open question method used in the interviews always obtain the right information?

Applying these two questions to the results of the analysis of the responses, a number of observations can be made.

When asked about special education campaigns or programmes for the prevention of diabetes, 12 of the 17 regions that responded said that they have implemented them whereas 5 regions said they have no such campaigns or programmes in place.

The reference framework for diabetes includes a number of related actions: implementation of education programmes; implementation of anti-obesity programmes; information about consequences of unhealthy lifestyles; provision of evidence-based informa-

¹²² Missing information: Veneto (IT), Madeira (PT) and Västra Götaland (SE).

¹²³ Author: Kieran Hickey, Health Service Executive, Dublin.

tion; addiction prevention programmes; health promotion campaigns; lifestyle oriented prevention campaigns (e.g. campaigns on healthy food).

Given the continuously growing number of diabetics, preventive measures aimed at reducing the risk factors for diabetes through lifestyle or other actions seem to be an almost essential part of the armament of any public health authority in the battle against diabetes. Evidence-based preventive measures shown to contribute to a reduction in risk factors such as obesity and hyperlipaemia therefore assume a particular significance.

Because of the significance of such preventive measures, the analysis of the responses from the regions that had implemented education campaigns about the prevention of diabetes were further analysed in terms of target population. It was hoped that this would be of interest to all regions but that it would be particularly informative for those regions that had not yet implemented any campaigns.

The further analysis showed that campaigns in the 12 regions have a number of different target populations: the whole population – 7 regions; children/adolescents at school – 9 regions; teachers/parents/adults – 5 regions; others e.g. persons at risk (BMI ≥ 30) and GPs – 7 regions.

Only 1 region provides campaigns for all four target groups; 3 regions provide them for three of the target groups; 7 regions provide them for two target groups; 1 region provides a campaign for one target group.

None of the regions that responded has found a way to comprehensively inform socioeconomic subgroups about the prevention of diabetes and some regions point out that the 'normal population' is hardly being reached.

The reference framework for diabetes includes broadly based screening programmes looking for metabolic and cardiovascular risk factors and for early disturbances of carbohydrate metabolism particularly in middle age.

Surprisingly, the analysis of the responses from the regions shows that only 1 region has implemented a specific regional screening programme for diabetes. Further information on the reasons for this would be interesting but was not asked for in the interview questionnaire.

The responses do show that detection examinations for diabetes (type II) diagnosis are habitually carried out in 10 regions and that this is not done in the other 4 regions that responded. The examination may be done during doctor visits, preventive check-up or other circumstances and the selection criteria are generally related to individual risk of diabetes.

The examination intervals used differ in terms of frequency and may be at yearly, two or three yearly intervals depending on age or specific risk factors.

Screening of pregnant and/or pregnant overweight women for gestational diabetes was shown by the responses to be carried out in 13 regions but not in the other 3 regions that responded.

The reference framework indicates: General screening, preferably one-step screening should be offered to each pregnant woman; Screening for overweight pregnant women. Yet, it is interesting to note from the analysis of responses that diabetes examination and screening programmes are not part of the political agenda in 10 of the 16 regions that responded. This can be regarded as a very revealing statistic.

One of the largest differences between regions to emerge from the analysis of the responses concerns the installation of a diabetes surveillance system. Only 6 regions have a surveillance system and the other 11 regions that responded do not have such a system, although it is being planned in 1 region at least. There are also differences between regions in Italy where 2 of 3 regions have such a system and in Germany where 1 of the 2 regions has a system in operation.

The provision of a diabetes surveillance system is not included in the reference framework.

Since diabetes is a chronic disease, special attention needs to be paid to treatment and care services in order to avoid long-term damage to patients and minimise the growing burden on the health services. The responses show that only 6 of the regions that responded currently have integrated care programmes and 11 regions do not have such programmes.

The reference framework for diabetes includes the provision of Disease Management Programmes/Integrated Care so this is clearly an area for examination by a number of regions.

Two areas of significance in avoiding or postponing complications of diabetes are annual eye examination and foot examination for people with diabetes.

The analysis shows that all 17 of the regions that responded reimburse the cost of annual eye examinations although a retinopathy-screening programme as such may not be in place in all regions.

The analysis of responses also shows that 15 of the 17 regions that responded promote, and/or reimburse the cost of annual foot examination.

The reference framework for diabetes includes: Annual foot exams among people with diabetes; Dilated/annual eye exam.

The analysis reveals that official institutions in 14 of the 17 regions that responded support self-help groups of diabetics. It also revealed that monitoring of patient satisfaction is in partial operation in 10 of the 17 regions that responded.

7. Results of the rapid appraisal using reference frameworks

7.1 Analysis of the three tracers

To rapidly appraise the regional health managements of measles, breast cancer and diabetes (type II), the Project Secretariat asked the participants to indicate which interventions from the developed reference frameworks (see section 4.2.3) were carried out in their regions.

Once the information had been received, the applied interventions were counted for each setting and time dimension. Based on the total number of the interventions from the reference frameworks, percentages were calculated. For a better overview, the following shades of colour were assigned to the resulting percentages.

0- 25%	26- 50%	51- 60%	61- 70%	71- 80%	81- 90%	91- 100%
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7.1.1 Measles

Out of nineteen regions participating in the project, thirteen participants identified the interventions from the reference frameworks applied in their region with regard to measles. After calculating the percentages of implemented interventions and assigning colours, significant differences between the regions were established.

For example, Moravia-Silesia (CZ) had implemented almost all the interventions recommended in the reference frameworks, while Ticino (CH) had carried out only a small number of them. Important differences in the implementation of interventions were also revealed within a country. While Saxony-Anhalt (DE) registered a considerable number of first-dose interventions, North Rhine-Westphalia (DE) reported few interventions with regard to the first dose.

Illus. 24a: Rapid appraisal of measles interventions (part a)

Ticino (CH)

	Individual/ Immediate Setting	Population	Social System
First Dose	5/12 (42%)	3/11 (27%)	7/15 (47%)
Second Dose	3/6 (50%)	0/2 (0%)	0/1 (0%)
Children with Measles	1/1 (100%)		3/10 (30%)

Upper Austria (AT)

	Individual/ Immediate Setting	Population	Social System
First Dose	7/12 (58%)	1/11 (9%)	7/15 (47%)
Second Dose	4/6 (67%)	0/2 (0%)	1/1 (100%)
Children with Measles	0/1 (0%)		6/10 (60%)

Moravia-Silesia (CZ)

	Individual/ Immediate Setting	Population	Social System
First Dose	12/12 (100%)	8/11 (73%)	15/15 (100%)
Second Dose	6/6 (100%)	2/2 (100%)	1/1 (100%)
Children with Measles	1/1 (100%)		10/10 (100%)

North Rhine-Westphalia (DE)

	Individual/ Immediate Setting	Population	Social System
First Dose	6/12 (50%)	1/11 (9%)	7/15 (47%)
Second Dose	4/6 (67%)	2/2 (100%)	1/1 (100%)
Children with Measles	1/1 (100%)		4/10 (40%)

Saxony-Anhalt (DE)

	Individual/ Immediate Setting	Population	Social System
First Dose	7/12 (58%)	8/11 (73%)	13/15 (87%)
Second Dose	4/6 (67%)	1/2 (50%)	1/1 (100%)
Children with Measles	1/1 (100%)		10/10 (100%)

Szabolcs-Szatmár-Bereg (HU)

	Individual/ Immediate Setting	Population	Social System
First Dose	8/12 (67%)	5/11 (45%)	9/15 (60%)
Second Dose	3/6 (50%)	2/2 (100%)	0/1 (0%)
Children with Measles	1/1 (100%)		7/10 (70%)

Illus. 24b: Rapid appraisal of measles interventions (part b)

England (UK)			
	Individual/ Immediate Setting	Population	Social System
First Dose	8/12 (67%)	7/11 (64%)	11/15 (73%)
Second Dose	4/6 (67%)	1/2 (50%)	1/1 (100%)
Children with Measles	0/1 (0%)		3/10 (30%)

Madeira (PT)			
	Individual/ Immediate Setting	Population	Social System
First Dose	10/12 (83%)	9/11 (82%)	10/15 (67%)
Second Dose	6/6 (100%)	2/2 (100%)	1/1 (100%)
Children with Measles	1/1 (100%)		7/10 (70%)

Varna-Oblast (BG)			
	Individual/ Immediate Setting	Population	Social System
First Dose	7/12 (58%)	2/11 (18%)	10/15 (66%)
Second Dose	5/6 (83%)	0/2 (0%)	1/1 (100%)
Children with Measles	1/1 (100%)		10/10 (100%)

Western Greece (EL)			
	Individual/ Immediate Setting	Population	Social System
First Dose	8/12 (67%)	7/11 (64%)	11/15 (73%)
Second Dose	4/6 (67%)	1/2 (50%)	1/1 (100%)
Children with Measles	0/1 (0%)		3/10 (30%)

Emilia-Romagna (IT)			
	Individual/ Immediate Setting	Population	Social System
First Dose	7/12 (58%)	9/11 (82%)	11/15 (73%)
Second Dose	5/6 (83%)	2/2 (100%)	1/1 (100%)
Children with Measles	1/1 (100%)		10/10 (100%)

Dublin/Mid-Leinster &/North-East (IE)			
	Individual/ Immediate Setting	Population	Social System
First Dose	6/12 (50%)	7/11 (64%)	11/15 (73%)
Second Dose	3/6 (50%)	2/2 (100%)	1/1 (100%)
Children with Measles	1/1 (100%)		8/10 (80%)

Illus. 24c: Rapid appraisal of measles interventions (part c)

Flemish Community (BE)			
	Individual/ Immediate Setting	Population	Social Sys- tem
First Dose	8/12 (67%)	8/11 (73%)	10/15 (66%)
Second Dose	6/6 (100%)	1/2 (50%)	1/1 (100%)
Children with Measles	1/1 (100%)		7/10 (70%)

7.1.2 Breast cancer

With regard to breast cancer, thirteen participants identified the interventions from the reference frameworks implemented in their own regions. With this information, percentages were calculated and shades of colours were assigned in accordance with the methodology described in section 4.2.3.2.

Considerable differences were established concerning the implementation of breast cancer interventions. Out of eleven regions which sent information for the rapid appraisal of breast cancer interventions, North Rhine-Westphalia (DE) and Dublin/Mid-Leinster and Dublin/North-East (IE) reported a large number of the interventions recommended in the reference frameworks.

On the other hand, Ticino (CH) and Madeira (PT) had implemented only a few of the recommended interventions.

Illus. 25a: Rapid appraisal of breast cancer interventions (part a)

North Rhine-Westphalia (DE)			
	Individual/ Immediate Setting	Population	Social System
Undiagnosed	4/5 (80%)	6/7 (86%)	9/10 (90%)
Diagnosed with Cancer	8/10 (80%)	3/3 (100%)	12/15 (80%)

Dublin/Mid-Leinster &/North-East (IE)			
	Individual/ Immediate Setting	Population	Social System
Undiagnosed	4/5 (80%)	6/7 (86%)	8/10 (80%)
Diagnosed with Cancer	8/10 (80%)	3/3 (100%)	12/15 (80%)

Szabolcs-Szatmár-Bereg (HU)

	Individual/ Immediate Setting	Population	Social System
Undiagnosed	4/5 (80%)	5/7 (71%)	8/10 (80%)
Diagnosed with Cancer	6/10 (60%)	3/3 (100%)	5/15 (33%)

Ticino (CH)

	Individual/ Immediate Setting	Population	Social System
Undiagnosed	1/5 (20%)	1/7 (14%)	6/10 (60%)
Diagnosed with Cancer	8/10 (80%)	0/3 (0%)	4/15 (27%)

Illus. 25b: Rapid appraisal of breast cancer interventions (part b)

Madeira (PT)

	Individual/ Immediate Setting	Population	Social System
Undiagnosed	5/5 (100%)	4/7 (57%)	4/10 (40%)
Diagnosed with Cancer	3/10 (30%)	0/3 (0%)	3/15 (20%)

Moravia-Silesia (CZ)

	Individual/ Immediate Setting	Population	Social System
Undiagnosed	4/5 (80%)	4/7 (57%)	10/10 (100%)
Diagnosed with Cancer	8/10 (80%)	3/3 (100%)	8/15 (53%)

Emilia-Romagna (IT)

	Individual/ Immediate Setting	Population	Social System
Undiagnosed	3/5 (60%)	5/7 (71%)	6/10 (60%)
Diagnosed with Cancer	6/10 (60%)	1/3 (33%)	9/15 (60%)

England (UK)

	Individual/ Immediate Setting	Population	Social System
Undiagnosed	4/5 (80%)	3/7 (43%)	6/10 (60%)
Diagnosed with Cancer	8/10 (80%)	2/3 (66%)	6/15 (40%)

Western Greece (EL)

	Individual/ Immediate Setting	Population	Social System
Undiagnosed	4/5 (80%)	3/7 (43%)	6/10 (60%)
Diagnosed with Cancer	8/10 (80%)	2/3 (66%)	6/15 (40%)

Veneto (IT)

	Individual/ Immediate Setting	Population	Social System
Undiagnosed	1/5 (20%)	6/7 (86%)	7/10 (70%)
Diagnosed with Cancer	4/10 (40%)	0/3 (0%)	6/15 (40%)

Upper Austria (AT)				Varna-Oblast (BG)			
	Individual/ Immediate Setting	Population	Social System		Individual/ Immediate Setting	Population	Social System
Undiagnosed	3/5 (60%)	3/7 (43%)	7/10 (70%)	Undiagnosed	4/5 (80%)	3/7 (43%)	8/10 (80%)
Diagnosed with Cancer	7/10 (70%)	2/3 (66%)	9/15 (60%)	Diagnosed with Cancer	8/10 (80%)	2/3 (66%)	5/15 (33%)

Illus. 25c: Rapid appraisal of breast cancer interventions (part c)

Flemish Community (BE)			
	Individual/ Immediate Setting	Population	Social System
Undiagnosed	4/5 (80%)	6/7 (86%)	6/10 (60%)
Diagnosed with Cancer	4/10 (40%)	0/3 (0%)	4/15 (27%)

Significant intra-national differences in breast cancer management were also confirmed. Although Emilia-Romagna (IT) and Veneto (IT) reported a similar number of interventions from the reference frameworks with regard to the undiagnosed level of the settings “population and social system”, Veneto (IT) had implemented fewer interventions in the individual/immediate setting than Emilia Romagna (IT).

With regard to the “diagnosed with cancer dimension”, Emilia-Romagna (IT) had implemented a greater number of the recommended interventions than Veneto (IT).

7.1.3 Diabetes (type II)

Concerning the health management of diabetes (type II), eleven project participants identified the interventions from the reference frameworks applied in their own region. In addition, information for the rapid appraisal from the region of Styria, Austria, was also delivered by the participant of Upper-Austria.

After calculating the percentages of implemented interventions and assigning colours, significant differences among the regions were identified. For example, it was confirmed that Moravia-Silesia (CZ) had implemented most of the interventions from the reference frame-

works, while Dublin/Mid-Leinster and Dublin/North-East (IE) had carried out only a few of them.

Illus. 26a: Rapid appraisal of diabetes (type II) interventions (part a)

Madeira (PT)				Moravia-Silesia (CZ)			
	Individual/ Immediate Setting	Population	Social System		Individual/ Immediate Setting	Population	Social System
Primary Prevention	1/1 (100%)	4/5 (80%)	4/6 (67%)	Primary Prevention	1/1 (100%)	4/5 (80%)	6/6 (100%)
Screening	2/4 (50%)	2/6 (33%)	0/4 (0%)	Screening	4/4 (100%)	5/6 (83%)	4/4 (100%)
Secondary Prevention	2/4 (50%)	1/1 (100%)	2/3 (66%)	Secondary Prevention	4/4 (100%)	1/1 (100%)	3/3 (100%)
Tertiary Prevention	4/7 (57%)	0/3 (0%)	3/4 (75%)	Tertiary Prevention	7/7 (100%)	3/3 (100%)	4/4 (100%)

Dublin/Mid-Leinster &/North-East (IE)				Flemish-Community (BE)			
	Individual/ Immediate Setting	Population	Social System		Individual/ Immediate Setting	Population	Social System
Primary Prevention	0/1 (0%)	3/5 (60%)	2/6 (33%)	Primary Prevention	0/1 (0%)	3/5 (60%)	2/6 (33%)
Screening	1/4 (25%)	0/6 (0%)	0/4 (0%)	Screening	3/4 (75%)	1/6 (17%)	0/4 (0%)
Secondary Prevention	2/4 (50%)	0/1 (0%)	0/3 (0%)	Secondary Prevention	3/4 (75%)	1/1 (100%)	3/3 (100%)
Tertiary Prevention	3/7 (43%)	1/3 (33%)	2/4 (50%)	Tertiary Prevention	6/7 (86%)	3/3 (100%)	2/4 (50%)

In contrast to Germany and Italy where significant intra-national differences in the health management of measles and breast cancer were confirmed, the two regions of Austria did not show any major differences in the health management of diabetes (type II).

The only difference could be established for the tertiary prevention dimension in the population setting. While Styria (AT) had realised three of the three recommended interventions, Upper-Austria reported only two.

Illus. 26b: Rapid appraisal of diabetes (type II) interventions (part b)

	Saxony-Anhalt (DE)		
	Individual/ Immediate Setting	Population	Social System
Primary Prevention	1/1 (100%)	3/5 (60%)	5/6 (83%)
Screening	3/4 (75%)	6/6 (100%)	3/4 (75%)
Secondary Prevention	4/4 (100%)	1/1 (100%)	3/3 (100%)
Tertiary Prevention	7/7 (100%)	3/3 (100%)	3/4 (75%)

	Styria (AT)		
	Individual/ Immediate Setting	Population	Social System
Primary Prevention	1/1 (100%)	4/5 (80%)	3/6 (50%)
Screening	3/4 (75%)	4/6 (67%)	2/4 (50%)
Secondary Prevention	4/4 (100%)	1/1 (100%)	3/3 (100%)
Tertiary Prevention	7/7 (100%)	3/3 (100%)	3/4 (75%)

	Szabolcs-Szatmár-Bereg (HU)		
	Individual/ Immediate Setting	Population	Social Sys- tem
Primary Prevention	0/1 (0%)	2/5 (40%)	1/6 (17%)
Screening	2/4 (50%)	3/6 (50%)	2/4 (50%)
Secondary Prevention	2/4 (50%)	1/1 (100%)	1/3 (33%)
Tertiary Prevention	6/7 (86%)	1/3 (33%)	2/4 (50%)

	Upper Austria (AT)		
	Individual/ Immediate Setting	Population	Social System
Primary Prevention	1/1 (100%)	4/5 (80%)	3/6 (50%)
Screening	3/4 (75%)	4/6 (67%)	2/4 (50%)
Secondary Prevention	4/4 (100%)	1/1 (100%)	3/3 (100%)
Tertiary Prevention	7/7 (100%)	2/3 (66%)	3/4 (75%)

Illus. 26c: Rapid appraisal of diabetes (type II) interventions (part c)

Varna-Oblast (BG)				Western Greece (EL)			
	Individual/ Immediate Setting	Population	Social Sys- tem		Individual/ Immediate Setting	Population	Social System
Primary Prevention	0/1 (0%)	5/5 (100%)	3/6 (50%)	Primary Prevention	1/1 (100%)	3/5 (60%)	4/6 (67%)
Screening	3/4 (75%)	5/6 (83%)	4/4 (100%)	Screening	4/4 (100%)	5/6 (83%)	3/4 (75%)
Secondary Prevention	2/4 (50%)	1/1 (100%)	0/3 (0%)	Secondary Prevention	4/4 (100%)	1/1 (100%)	2/3 (66%)
Tertiary Prevention	7/7 (100%)	3/3 (100%)	4/4 (100%)	Tertiary Prevention	6/7 (86%)	3/3 (100%)	3/4 (75%)

Emilia-Romagna (IT)				England (UK)			
	Individual/ Immediate Setting	Population	Social System		Individual/ Immediate Setting	Population	Social System
Primary Prevention	1/1 (100%)	5/5 (100%)	4/6 (67%)	Primary Prevention	1/1 (100%)	3/5 (60%)	4/6 (67%)
Screening	4/4 (100%)	5/6 (83%)	2/4 (50%)	Screening	4/4 (100%)	5/6 (83%)	3/4 (75%)
Secondary Prevention	3/4 (75%)	1/1 (100%)	3/3 (100%)	Secondary Prevention	4/4 (100%)	1/1 (100%)	2/3 (66%)
Tertiary Prevention	7/7 (100%)	2/3 (66%)	3/4 (75%)	Tertiary Prevention	6/7 (86%)	3/3 (100%)	3/4 (75%)

7.1.4 Conclusions

When filling in the reference frameworks for a region with the colours, it can immediately be recognised in which dimensions and settings the region does well and in which there is potential for implementing further interventions.

Nevertheless, there are disadvantages of using the coloured presentations for appraising existing health management systems. If a policy or intervention is only implemented in a part of the region or implemented not very effectively, it can be counted as implemented. In addition, the rapid appraisal does not say much about the success of the implementation. Thus, a comparably minor policy or intervention which has been implemented might darken

the colour shade of a cell, indicating a more comprehensive health management approach than that of another region. The other region, however, might indeed have implemented fewer but rather effective policies and interventions.

Although there are limitations to the rapid appraisal method, the advantages of the method are clear. The method is relatively easy to use and, compared to the little effort, very beneficial and helpful. It can immediately be seen which areas policy makers should examine more closely to improve the health management in their region. Also regions can be compared against each other. However, a ranking of the regions exclusively based on the rapid appraisal method is not advisable due to the limitations mentioned above.

Therefore, the rapid appraisal method can be recommended to policy makers and public health researchers interested in comparing regions from different countries and performing intra-national analyses aimed at verifying the variability of regional health strategies and interventions from a country.

7.2 Case study – Measles in North Rhine-Westphalia¹²⁴

The following is a practical example of applying the “Evidence-based reference framework” which shall contribute to achieving the objective of eliminating measles in Europe by the year 2010.

In 2005, WHO Europe reconfirmed the objective formulated as early as in 1983 of eradicating measles and rubella as well as preventing congenital rubella infection and fixed a strategy plan for the years 2005 up to 2010. Since the start of the programme, the Federal Republic of Germany has also declared its willingness to provide an active contribution to achieving this objective. In 2002, the Health Ministers’ Conference reaffirmed that all German states would cooperate with all countries of WHO Europe in realizing the long-term objective of eradicating measles altogether.

Since the year 2001, the number of annually reported cases of measles has shown a clear downward trend. In 2004, only 28 cases were reported in NRW, in the whole of Germany no more than 122 cases. This trend has, however, been reversed over the last two years. Nationally, 780 cases of measles were reported in 2005 and in 2006 even 2.281 cases. In 2005, North Rhine-Westphalia registered 34 cases and in 2006 even 1.726 cases. These high figures in 2006 were almost exclusively caused by a huge outbreak in NRW.

¹²⁴ Author: PD Dr Matthias Schröter, Institute of Public Health, North Rhine-Westphalia, Münster (Germany).

A total of 263 cases needed hospital treatment. Forty-one cases of pneumonia, 39 cases of otitis media and 7 cases of meningitis and/or encephalitis were registered. Thus the frequency of encephalitis/meningitis as the most serious complication accounted for 1/247 notified cases. Unfortunately in January 2007, measles claimed the first victim. Due to a congenital immunodeficiency, a two-year-old boy could not be immunised and contracted the disease as early as in March 2006. He developed severe encephalitis in the course of which he finally died. Meanwhile, a second child who also suffered from severe prolonged encephalitis has died.

The outbreak occurred despite continuously increasing immunisation coverage rates in NRW over the last years. Based on school entrance surveys it has been observed that both the first dose immunisation rate and even more strongly the second dose immunisation rate are continuously increasing. The average first dose immunisation rate has reached the targeted objective of 95% whereas the rate for the second dose is still clearly below the value of 95%. As expected, the number of measles cases clearly decreased with increasing immunisation rates. It was not before the outbreak in 2006 that this trend was once again reversed. This development gives rise to the assumption that higher immunisation rates in children alone will not be sufficient for reaching the objective of measles eradication in the short run.

For this reason, the “evidence-based reference framework” worked out as part of the Ben RHM II project was used to determine which further useful and effective measures could be established. This framework is a summary of measures supported by literature and expert opinions and suited for a long-term strategy of measles eradication. These measures are distinguished by different events (first dose immunisation, second dose immunisation and disease). Moreover, different action levels are analysed: The level of the individual, the level of the total population and the level of the overall social system.

An analysis of the situation in NRW clearly shows that above all at the population level only few measures have been realised, i.e. only one of 13 possible measures. With regard to the different points in time which are being looked at, measures are above all inadequate in the field of first dose immunisation. At the population level, only one of 11 possible measures has presently been implemented, at the level of the individual no more than 6 of 12 possible measures and at the level of the overall health care system only 7 of 15 possible measures. According to this estimation, various recommendations for action can be given, of which four important measures will be described in greater detail.

7.2.1 Individual reminder

During the outbreak, together with the local health authorities and the Robert Koch Institute, the Institute for Public Health, NRW (Iögd) carried out a detailed examination at a school where more than 50 cases of measles had erupted. As part of the examination, the parents of those children who had not been immunised against measles were interviewed for possible reasons and causes for not having their children immunised.

According to this admittedly small-scale survey, an individual reminder would have had a possible benefit in at least 38% of the cases. If the reminder is combined with information material on the risks of measles disease and the benefit of the immunisation, the benefit to be expected might even be higher. After all, 75% of the parents who quite consciously refrained from having their children immunised justified their behaviour with the fear of side effects or with the opinion that measles are a harmless disease.

7.2.2 Establishment of vaccination campaigns

The Standing Immunisation Committee (STIKO) presently recommends a combined measles, mumps and rubella immunisation of two doses which should be administered up to the end of a child's 24th month of life. A catch-up campaign which could be aimed at having older children and adolescents without immunisation protection immunised does not exist at the moment. As already shown, the immunisation rate for school beginners has been continuously rising for some years now.

An analysis of the age distribution of the outbreak in NRW reveals that the age groups mainly hit by the disease were those between 5 and 20 years. More than 60% of all cases fell into this age group. This shows that there seem to be considerable gaps in the immunisation coverage rate for this age group. It has therefore to be feared that despite rising immunisation rates in small children the expected decline in the number of diseases will only be very slow if adolescents and young grown-ups are not included in the immunisation programmes.

7.2.3 Education of possible multipliers

It is not only the family doctor who has an influence on the immunisation behaviour of parents and children. From what we know, midwives have a very pronounced influence on young

parents. But often particularly midwives feel reserved about immunisations, an attitude which could be changed through further training and information measures. Teachers and educators also play an important role in the children's health education and often serve as an example. Unfortunately, teachers themselves are often not immunised and are therefore no good example to their pupils. During the above-described measles outbreak, two schools were for example closed for some days because a great number of teachers had not been immunised against measles and because it also could not be clarified if the teachers had been ill with measles during their childhood.

7.2.4 Bonus system for parents

A financial incentive is certainly suited to motivate many parents who are undecided about immunisation to think about this issue critically and perhaps have their children immunised. Such a bonus system could for example consist of cost reductions for medical examinations when the child enters kindergarten, provided the child has been immunised. An alternative would be to include parents into the bonus system of their health insurance company if they have their child immunised.

With 1,715 cases last year, NRW has seen the biggest measles outbreak since introduction of the Infectious Disease Control Act (IfSG) in 2001. Seven children fell ill with encephalitis or meningitis and two children have died up to now. Against the background of this outbreak, the measures established in NRW did not seem to be sufficient in order to reach the objective of WHO Europe and to eradicate measles up to the year 2010. The work carried out under the Ben RHMII project has led to defining important further measures for NRW which could help to still achieve this objective.

7.2.5 Conclusions

Based on these results a comprehensive concept has already been drawn up and has become the subject of a political agreement process. The Ben RHM II has thus already contributed to the effective improvement of health management within a region. This can be a paradigm how the reference frameworks and the results of Ben RHM II in general can be utilised to improve the public's health in Europe.

8 Analysis of the health performance indicators

As described in section 4.2.4, the Steering Group selected the following epidemiological parameters as health performance indicators to assess the performance of regional health managements:

Measles:

- 1st Uptake dose (percentage)
- 2nd Uptake dose (percentage)
- Incidence (per 100.000)
- Mortality (per 100.000)
- Hospitalisation (percentage of cases)

Breast cancer:

- Incidence (per 100.000 women)
- Mortality (per 100.000 women)
- Fatality (percentage of cases)
- 5-year survival rate (percentage of women diagnosed with breast cancer)
- 10-year survival rate (percentage of women diagnosed with breast cancer)
- Participation in mammography screening (percentage of women aged 50-69 years old)
- Detection (per 100.000 women screened)

Diabetes (type II):

- Incidence (per 100.000)
- Prevalence (per 100.000)
- Participation in education programmes (percentage of diabetics)
- Hospitalisation (percentage of diabetics)

Once the health performance indicators had been selected, the participating regions were asked towards the end of 2005 to complete tables containing the indicators from the year 1996 to 2005 with regional data.

The Project Secretariat regularly reminded the participants about the delivery of the tables per telephone and Internet. The Project Secretariat informed the regions in 2007 that the

tables with the health performance indicators could only be considered for benchmarking and the final report if they had been received by June 15th 2007. After this date, no further data could be accepted due to the fact that good practice models had to be identified and the report to be written.

The majority of the regions delivered information on the indicators. From the 19 participating regions, Győr-Moson-Sorpon (HU) and Västra-Götaland (SE) did not return epidemiological information. For the requested years, Western-Greece (EL) reported data but the majority of them for the national level. A region which also delivered national information was Dublin/Mid-Leinster and Dublin/North-East (IE).

However, it is important to note that from the received information not all the years were covered by the regions and that not all data received corresponded to the health performance indicators selected by the Steering Group. Major differences in the way regional information is calculated and reported were identified (the information sent by each region can be taken from annex 5. The main differences and shortages of information are described in the following.

8.1 Measles

For the first and second dose of measles vaccination, the World Health Organisation recommends to provide every child with a first vaccination dose by his or her 12 months of life and to give all children from 9 months to 15 years old a second opportunity.

With regard to the data received, before June 15th 2007 no epidemiological information concerning measles was received from Chuvash Republic (RU), Győr-Moson-Sorpon (HU) and Västra-Götaland (SE). Concerning the *first-dose indicator*, Kaunas (LT) and Western-Greece (EL) did not report any kind of regional information for the requested years. While Western-Greece (EL) delivered information but at the national level, Kaunas (LT) did not deliver any first-dose information at all. They informed us that the data were neither available at the regional nor at the national level.

Based on the information received at the regional level, significant differences were confirmed regarding the way the first-dose information was handled and reported by the regions. Not all data corresponded to the first-dose indicator selected by the Steering Group. Not all first-dose data were calculated based on the population aged 12 months recommended by WHO for the first dose. For example, for the year 1999, Flemish Community (BE) reported a first-dose uptake but based on a study for young children.

Another example is North Rhine-Westphalia (DE), which calculates the first-dose uptake rate as a percentage of all school-entry children with vaccination certificate book having at least one vaccination (one or more uptakes).

With regard to the *2nd dose uptake* indicator, for the years 1999 to 2005 two regions did not provide any regional information concerning this indicator: Western-Greece (EL) and Sicily (IT). While Western-Greece (EL) provided national data instead of regional data, Sicily (IT) did not provide any information at all.

Important differences were also established concerning the calculation of this parameter. Not all data corresponded to the second-dose indicator selected by the Steering Group. None second-dose data were based on the population aged 9 months to 15 years old as recommended by WHO. One example is Varna-Oblast (BG). This region reported that children not immunised with a second dose vaccine in 1998 and 2002 had been included in the total number liable to immunisation and had been immunised in the following year (1999 and 2003 respectively).

With regard to the *measles incidence* indicator, for the years 1999 to 2005 Western-Greece (EL) and Flemish Community (BE) reported that no information was available at the regional level. Western-Greece (EL) delivered national information instead of regional data. The rest of the participants delivered regional information. Incidence data were reported as a rate per 100.000 inhabitants. Confirmed and registered cases of measles were also reported by some participants.

With regard to *measles mortality*, Upper-Austria (AT) and the three regions from Italy (IT-E, IT-S, IT-V) did not provide any information for the regional level for the requested years. Nevertheless, national data were reported in the cases of Italy and Greece.

The *measles hospitalisation* indicator is the proportion of individuals diagnosed with measles who were hospitalised in relation to the total number of individuals diagnosed with the illness. With regard to this indicator, expressed as percentage of cases, no information was reported by the regions of Emilia-Romagna (IT), Veneto (IT) and Ticino (CH). On the other hand, England (UK) and Flemish Community (BE) informed us that such hospitalization data were not available at the regional level for the requested years. Numbers of hospitalization cases were also reported by Greece and Sicily.

8.2 Breast cancer

No epidemiological information concerning breast cancer was received from four of the participating regions. Concerning *breast cancer incidence*, measured in new cases per 100.000 individuals, Sicily (IT) delivered national information. Western-Greece (EL) and Saxony-Anhalt (DE) informed the Ben RHM II Secretariat that for the years 1999 to 2005 no such information was available at the regional level. Emilia-Romagna (IT) and England (UK) delivered sub-national data in which the regions are only partially considered.

The information sent by Emilia-Romagna (IT) for example does not consider the province of Piacenza. The data delivered by England (UK) include only the Thames Region.

Instead of regional information, national data on *breast cancer mortality* was received for the cases of Western-Greece (EL) and Kaunas (LT) for the requested years. Regarding this indicator, no regional information was provided by England (UK).

With regard to the *breast cancer fatality* indicator expressed as percentage of cases, no information was provided by England (UK). On the other hand, Dublin/Mid-Leinster (IE), Flemish Community (BE), North Rhine-Westphalia (DE) and Western-Greece (EL) informed us that such data were not available at the regional level for the years 1999 to 2005.

With regard to the *mammography screening participation* indicator defined by the Steering Group as the percentage of women aged 50 to 69 years old participating in mammography screening, six regions provided this kind of information for a certain number of years. There were other regions which sent data but based on a different group population. For example, Dublin/Mid-Leinster and Dublin/North-East (IE) calculated the participation rate in mammography screening for women aged 50 to 64 years old. On the other hand, Szabolcs-Szatmár-Bereg (HU) estimated this rate based on the female population aged 45 to 65 years old.

North Rhine-Westphalia (DE), Western-Greece (EL) and Saxony-Anhalt (DE) informed us that for the years 1999 to 2005 no such information was available at the regional level.

Upper-Austria (AT) pointed out that mammography screenings were done in the region but failed to differentiate by type of screening. Ticino (CH) informed us that they were not able to provide this kind of information since there was no screening programme in the region.

With regard to the *breast cancer detection* indicator, measured in detected cases per 100.000 women screened, only Emilia-Romagna (IT), Flemish Community (BE), Szabolcs-Szatmár-Bereg (HU), Veneto (IT) and Moravia-Silesia (CZ) reported this specific indicator but only for some years. Other regions delivered detection data but per 1,000 women screened. These regions were Dublin/Mid-Leinster and Dublin/North-East (IE) and England (UK).

Concerning the *5-year survival rate* (as percentage of women diagnosed with breast cancer), a significant shortage of information was confirmed. Only two regions from all participants, Sicily (IT) and Varna-Oblast (BG), delivered this precise information for all years from 1999 to 2005.

Eight participants, including Upper-Austria and England, sent related information for some years. However, the indicator of England is a regional approximation since the indicator only refers to the Thames Region.

With regard to the *10-year survival rate* (as percentage of women diagnosed with breast cancer), a significant shortage of information also was confirmed. Six participants let the Secretariat know that for the years 1999 to 2005 the indicator was not available at the regional level. Nine other regions did not deliver any kind of information on the 10-year survival rate. Only Emilia-Romagna (IT) reported relative information for the year 2005, based on the number of cases from 1990 to 1994.

8.3 Diabetes (type II)

With regard to the three project tracers, the greatest lack of regional data was identified for information related to diabetes (type II). Six participants did not deliver regional information concerning diabetes. Two of them let the Secretariat know that they were unable to send this information because diabetes-related data were not systematically collected.

Concerning the regions which sent some information related to diabetes, it is important to note that the majority of them provided aggregated data referring to both types of diabetes.

It should be mentioned that additional diabetes data were delivered to the Project Secretariat. For example, Veneto sent the paper “Monitoring the occurrence of diabetes mellitus and its major complications: the combined use of different administrative databases” from Stefano Brocco et al. (2007), while Chuvash Republic (RU) delivered, in addition to some BEN indicators, mortality data per 1,000 population; structure of mortality for patients with

diabetes; average life expectancy with diabetes regarding age and gender; and the average life expectancy with diabetes from the beginning of the illness regarding age and gender. Moravia-Silesia (CZ) also delivered additional diabetes-related data. The region sent the Project Secretariat information regarding diabetic nephropathy, diabetic retinopathy and diabetic foot for the years 1996 to 2005.

Concerning *diabetes (type II) incidence*, measured as new cases per 100.000 population, only two regions, Moravia-Silesia (CZ) and Szabolcs-Szatmár-Bereg (HU), supplied this type of information. Other incidence estimates of diabetes type II were also received for Veneto (IT) and Italy. Incidence information on both types of diabetes was sent by Flemish Community (BE), Varna-Oblast (BG) and England (UK).

With regard to *diabetes (type II) prevalence*, defined as the number of cases per 100.000 population, only Moravia-Silesia (CZ) and Szabolcs-Szatmár-Bereg (HU) provided data satisfying these specifications and exclusively on diabetes type II.

Dublin/Mid-Leinster (IE) also delivered prevalence information on diabetes type II. They sent this type of information for two population groups: the 50-60-year-old population for the year 1998 and for the population aged 20 years old and older for 2005.

Other prevalence estimates pertaining to diabetes type II were sent by North Rhine-Westphalia (DE), Upper-Austria (AT), Chuvash Republic (RU), Veneto (IT), Greece and Italy. Prevalence information on both types of diabetes was sent by Flemish Community (BE), Varna-Oblast (BG) and England (UK).

The *diabetes (type II) hospitalisation* indicator is the proportion of individuals diagnosed with diabetes (type II) who were hospitalised in relation to the total number of diabetics. With regard to this indicator, expressed as percentage of diabetics, only England (UK) provided this type of information. Varna-Oblast (BG) calculated this indicator for both types of diabetes. North Rhine-Westphalia (DE), Saxony-Anhalt (DE), Flemish Community (BE) and Veneto (IT) sent other hospitalisation estimates. Information for the national level in relation to hospitalisation was also received from Sicily (IT), Upper-Austria (AT) and Western-Greece (EL).

With regard to *participation in education programmes*, measured as the percentage of diabetics participating in education programmes, only two regions provided us with the corresponding information: Moravia-Silesia (CZ) and Upper-Austria (AT). Moravia-Silesia (CZ) delivered data on this specific indicator from 1996 to 2004, while Upper-Austria (AT) reported national data in absolute numbers for the year 1999.

8.4 Conclusions

After conducting the analysis of the health performance indicators, it can be concluded that the regional data situation is very heterogeneous. A great number of the health performance indicators do not exist or are not available at the regional level. Comparing the situation among the three tracers, indicators on measles are well available, indicators on diabetes not at all. The main reason why many of the information were not available was because the data are not collected systematically.

Comparing the situation within countries a heterogenous situation could be observed as well when considering regions from one country as the availability of data also differs between the regions in one country. For example, data on breast cancer incidence is available in just one of the two participating German regions. North Rhine-Westphalia (DE) collects this type of incidence information for the years 1996 to 2003, while Saxony-Anhalt (DE) does not have these data for the same years.

It already becomes obvious that good health policy which is based on evidence and works on the basis of data is hardly possible in many of the regions – not to mention inter-regional benchmarking where the regions can learn from other regions.

9 Identification of good practice

Among the aims of the “Benchmarking Regional Health Management II (Ben RHM II)” project is the identification of good practice models of health management within the regional health systems. Good practices are activities or processes that will assist us to reach a superior performance in one’s own organisation or system (Wilson 2004). The goal of benchmarking is the collection of comparative data in diverse key areas that make comparisons amongst systems meaningful.

To make comparisons amongst the participating regions which allow the identification of those practices which could improve the health management systems of the regions, the Steering Group developed a methodology based on the analysis instruments of the project (reference frameworks, health performance indicators, in-depth interviews, etc).

9.1 Methodology

Since the benchmarking methodology as such is more likely to be found in the industrial or manufacturing sectors (Crandelta International 2004), no specific health management methodology has up to now been developed which we could apply without any reservations in the course of the project. A methodology has therefore been developed by the Steering Group and further refined in the course of the project.

Because of the relevance of the health performance indicators for the formulation and assessment of health policies, the Steering Group agreed that the identification of good practices should be based on the analysis of the health performance indicators selected by the Steering Group (see chapters 8 and 4.2.4).

The analysis of the indicators would be the first approach, the political approach, of the identification of good practices. With this approach, policy makers could get a picture about the relevance of the diseases in their own regions.

The second approach is an examination approach. The reference frameworks, in-depth interviews and organigraphs of the regions should be examined and compared to identify the actions, initiatives and programmes developed by the regions which had positive health outcomes.

Regarding the first approach to identify good practice models, only those data available on the regional level and which precisely satisfy the HPIs selected by the Steering Group (see chapter 8) were considered in the good practice analysis. Data available at the national level were not considered in the study. The rationale behind this is that, in accordance with the Steering Group, these are exactly the HPIs that have to be implemented in the regions to assess the performance of the health management and that helps policy makers to improve their health policies.

On July 9th and 10th 2007, the Steering Group met at the Institute of Public Health NRW (lögD) to identify good practice models. For each project tracer, the Steering Group adopted the following procedure: in a first step, the regional data received from the participants on the health performance indicators selected by the Steering Group were reviewed to select a year in order to perform a more-in-detail analysis. The year was a recent year – as it is a criterion for good policy making and good health governance to draw on recent data – and chosen according to the availability of regional data.

In a second step, once the year had been selected, the relevance of the indicators was re-examined to identify which of them should be further employed because they better reflect the disease burden and could be used by policy-makers in the formulation and evaluation of health programmes and interventions related to the disease and are thus of utmost importance as criteria for identifying good practices.

In a third step, it was defined which optimal values the identified health performance indicators should have to achieve health and well-being among the population. For example, the optimal value for the “first-dose uptake” of immunisation against measles should be 95%, because, in accordance with the Field Guidelines for Measles Elimination from the World Health Organisation (2004), at least 95% of the population must be vaccinated to eliminate measles.

In a fourth step, Ben RHM II regions with optimal or even better indicator values were identified for a final analysis. Using the second examination approach, in a fifth and last step, the information taken from the organigraphs, reference frameworks and in-depth interviews, from the identified regions with optimal values, will be examined and compared to recognise good practice.

9.2 Measles

9.2.1 First approach: analysis of indicators

a. Analysis of data availability

When examining the information delivered by the regions with regard to the health performance indicators defined by the Steering Group, it was confirmed that out of 19 participants three had not sent any kind of information on measles. Using the data received from the 16 remaining regions, a rapid review was performed to select the year for the good practice analysis.

After confirming data availability for the majority of indicators for the year 2005, that year was chosen by the Steering Group as a basis for the measles analysis. Apart from this pragmatic selection criterion, it was important to use the most recent year since for communicable diseases rapid reporting to policy makers is of major importance. The availability of most recent data is thus essential for good practice in measles health management. Hence, using the year 2005 is also an implicit selection criterion for good practice.

For the first and second dose of measles vaccination, the World Health Organisation (2007) recommends to provide every child with a first vaccination dose by his or her 12th month of age and to give all children between 9 months and 15 years of age a second opportunity.

With regard to the information received, eight regions sent data for the year 2005 which satisfied the definition for the 1st dose indicator of the Steering Group covering the one-year-old population recommended by WHO for the first dose (the information received from the regions with regard to the Health Performance Indicators is available in annex 5).

Regarding the year 2005, one participant (England, UK) informed us that they did not have any available data on the first-dose indicator defined by the Steering Group. Western Greece (EL) supplied national information.

Table 11: Measles 2005: Availability of regional data regarding the health performance indicators selected by the Steering Group

Health Performance Indicators Selected by the Steering Group	AT - Upper-Austria	BE - Flemish	BG - Varna-Oblast	CH - Ticino	CZ - Moravia-Silesia	DE - NRW	DE - ST	EL - Western-Greece	HU-S Szabolcs-Szatmár	IE - Dublin/Mid-Leinster	IT-E Emilia-Romagna	IT-S Sicily	IT-V Veneto	LT - Kaunas	PT - Madeira	UK - England
1st Uptake Dose (percentage)	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported
2nd Uptake Dose (percentage)	not available or not reported	available	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported	available	not available or not reported
Incidence (per 100.000)	not available or not reported	not available or not reported	available	available	available	available	available	not available or not reported	available	not available or not reported	available	available	available	available	available	not available or not reported
Mortality (per 100.000)	not available or not reported	not available or not reported	available	available	available	available	available	not available or not reported	available	not available or not reported	not available or not reported	not available or not reported	not available or not reported	available	available	not available or not reported
Hospitalisation (percentage of cases)	not available or not reported	not available or not reported	available	not available or not reported	available	not available or not reported	not available or not reported	not available or not reported	available	available	not available or not reported	not available or not reported	not available or not reported	available	available	not available or not reported

■ available ■ not available or not reported

With regard to the 2nd dose, nine regions sent data on the indicator selected by the Steering Group. Of the remaining participants, three regions, Western-Greece (EL), Sicily (IT) and Ticino (CH) did not provide any regional information for the year 2005 with regard to the second-dose uptake.

On the other hand, England (UK) and Dublin/Mid-Leinster and Dublin/North-East (IE) informed us that they did not have any available second-dose information for that particular year. Regarding the age between 9 months and 15 years as recommended by the World Health Organisation for the second vaccination, there was no region which reported 2nd dose data for that specific population group. While North Rhine-Westphalia (DE) delivered data as percentage of all school-entrance children with a vaccination certificate book showing that they had received complete vaccination protection (two or more uptakes), Upper Austria (AT) sent second-dose data for the year 2005, but for three different population groups.

With regard to measles incidence, England (UK), Western-Greece (EL), Upper-Austria (AT) and Flemish Community (BE) reported that for the year 2005 they did not have any available information on the defined indicator. With regard to measles mortality, half of the regions supplied data on the indicator selected by the Steering Group for the year 2005. Regarding the measles hospitalisation indicator, only six participants provided corresponding information.

Having analysed the availability of data, the Steering Group re-examined the relevance of the five health performance indicators concerning measles. The group decided that all indi-

cators should be further used since they were important for the evaluation of the disease burden and for the formulation of measles-related health policies and interventions.

It was confirmed that only four regions had supplied available information on the five measles health performance indicators selected by the Steering Group. These were Varna-Oblast (BG), Moravia-Silesia (CZ), Szabolcs-Szatmár-Bereg (HU) and Madeira (PT) (see table 12).

b. Quantitative analysis of the data

In accordance with the Field Guidelines for Measles Elimination from the World Health Organisation (2004), at least 95% of the population must be vaccinated to interrupt transmission and hence eliminate measles. Based on this guideline and the consensus of the Steering Group, the Group defined the optimal values of the selected indicators as follows:

Optimal Values of Measles:

- 1st uptake dose: 95%
- 2nd uptake dose: 95%
- Incidence: 0 cases
- Mortality: 0 cases
- Hospitalisation: 0 cases

Considering the optimal values for the five health performance indicators selected by the Steering Group, Varna-Oblast (BG) reported lower uptake rates than the rates set by the Steering Group (see next table), Madeira (P) presented a considerable low fist uptake, while Moravia-Silesia (CZ) had achieved optimal values for four of the five indicators. Only Szabolcs-Szatmár-Bereg (HU) reported optimal values for all indicators. The region even reported greater uptakes than the optimal.

Table 12: Measles 2005

Health Performance Indicators Selected by the Steering Group	BG - Varna-Oblast	CZ - Moravia-Silesia	HU-S Szabolcs-Szatmár	PT - Madeira
1st Uptake Dose (percentage)	93,00	97,45	99,80	77,90
2nd Uptake Dose (percentage)	90,00	94,14	99,80	95,90
Incidence (per 100.000)	0,00	0,00	0,00	0,00
Mortality (per 100.000)	0,00	0,00	0,00	0,00
Hospitalisation (percentage of cases)	0,00	0,00	0,00	0,00

Because of the values reported by the mentioned regions, only Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ) were considered for the second approach of the analysis to identify good practice.

9.2.2 Second approach: analysis of additional information

In order to identify good practice models, the organigraphs, in-depth interviews and reference frameworks from Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ) were examined to recognise similarities among these regions.

a. Organigraphs

Basing on the analysis of the organigraphs and system descriptions from the section 5.1.16, it was verified that in Szabolcs-Szatmár-Bereg (HU) and in Moravia-Silesia (CZ), the organigraphs and system descriptions show one chain through which there is downward transmission from national Ministry level to regional and local levels, of a measles immunisation policy or programme, including vaccination schedules decided by the Ministry nationally, and another chain through which there is upward transmission of surveillance data to national level (see section 5.1.16 for the definition of chain).

b. In-depth interviews

Examining the information from the in-depth interviews, similarities among Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ) were confirmed with regard to the measles policies and interventions conducted in the regions. For example, both regions keep registers about vaccinated persons and adverse reactions. Moreover, children in these two regions receive their first measles immunisation dose at the same point in time and both regions use

MMR vaccine. Funds for measles vaccination are in both regions provided by the national budget. Another feature shared by both regions is the fact that both have a specific immunisation law and that measles elimination is part of the current political agenda.

c. Reference frameworks

What is now interesting is a look at the reference frameworks of the regions of Moravia-Silesia (CZ) and Szabolcs-Szatmár-Bereg (HU). It was verified that these regions conducted similar measures/interventions in the health management of measles (the interventions carried out in each region are marked in yellow in the illus. 27 and 28).

When looking at the measures/interventions carried out within the individual/immediate setting, it turns out that the following measures are carried out in both regions: coverage with 1st dose, individual reminder, documentation of immunisation for parents (passes, certificates etc.), documentation of immunisation for Primary Care Physician (IT, patient files etc.), obligation to immunise, home-visiting interventions, easy/cheap access to vaccination/reduction of out of pocket costs for vaccination, education of agents in shared facilities about the benefits/risks of vaccination, coverage with 2nd dose, individual reminder, documentation of immunisation (passes, certificates etc.) and identification of contacts.

At population level, the following interventions/measures are carried out in the two regions: invitation/reminder/recall system, strategies to immunise marginal groups/sub-groups (e.g. gypsies, unregistered migrants, refugees), special strategies for lower socio-economic groups, educational measures about benefits/risks of vaccination, local authorities offer information/counselling, invitation/reminder system and strategies to immunise sub-groups.

When looking at the social system, at the legislative and professions, it becomes obvious that both regions implement the following interventions/measures: legislation/law on infectious diseases, strategy for measles elimination, national/regional immunisation plan with defined targets, implementation of WHO-immunisation guidelines, sentinels, drug law, licensing of vaccine, producer is obligated to cold-chain logistics (product liability), strategy for quality assurance in place and regular review, development of strategy, rapid communication of cases and coordination of health services, obligation to report cases, surveillance of uptake rates, vaccination register, register of severe adverse reactions, Health reporting, implementation of surveillance guidelines of WHO and vigorous case investigation and laboratory confirmation.

Illus. 27: Reference framework – measles - interventions implemented for measles immunisation and elimination – Moravia-Silesia (CZ)

<i>Action Level: "Policies and Interventions Aiming at ..."</i>				Overall Goals: Measles eradication <i>[Incidence]</i> & Reduction of deaths by measles <i>[Mortality]</i> Strategic Points <i>[Indicators]</i>
	the Individual / Immediate Setting	the Population	the Social System, the Legislative, Professions	
Time	First Dose <ul style="list-style-type: none"> Coverage with 1st dose Individual reminder Documentation of immunisation for parents (passes, certificates etc.) Documentation of immunisation for Primary Care Physician (IT, patient files etc.) (Obligation to immunise) Home-visiting interventions Easy/cheap access to vaccination/Reduction of out of pocket costs for vaccination Bonuses for parents Education of agents in shared facilities about benefits/risks of vaccination Pre-school nursery/kindergarten/school entry screening Motivation of parents/teachers to identify non-immunised children Offering vaccination 	<ul style="list-style-type: none"> Invitation/reminder/recall system Strategies to immunise marginal groups/sub-groups (e.g. gypsies, unregistered migrants, refugees) Special strategies for lower socio-economic groups Establishment of campaigns: <ul style="list-style-type: none"> Catch-up Follow-up Focal Awareness raising campaigns Educational measures about benefits/risks of vaccination Local authorities offer information/counselling Multi-media information resource availability (e.g. e-health) Agenda-setting in the media 	<ul style="list-style-type: none"> Legislation/Law on Infectious diseases Strategy for measles elimination National/regional immunisation plan with defined targets Implementation of WHO-immunisation guidelines Sentinels Incentives for Primary Care Physicians Guaranteed reimbursement of vaccination for Primary Care Physicians Educative measures concerning risks/benefits of immunisation Education of multipliers Risk-communication Drug Law Licensing of vaccine Producer is obligated to cold-chain logistics (product liability) Strategy for quality assurance in place and regular review and development of strategy Serological survey 	<ul style="list-style-type: none"> >95% Coverage with 1st dose <i>[Uptake rate 1st dose]</i> Reduce complications <i>[Hospitalisation rate]</i> Improve measles immunisation surveillance Promote 2nd opportunity for immunisation Improve motivation of Primary Care Physicians and parents Improve education of health professionals Improve knowledge of population regarding risks/benefits of immunisation Maintain public confidence in vaccine safety Maintain high quality of vaccine Establish evaluation of programmes Identify non-immunised persons
	Second Dose <ul style="list-style-type: none"> Coverage with 2nd dose Individual reminder Documentation of immunisation (passes, certificates etc.) Pre-school nursery/kindergarten/school entry screening Motivation of parents/teachers to identify non-immunised children with second dose Offering vaccination with second dose 	<ul style="list-style-type: none"> Invitation/reminder system Strategies to immunise sub-groups 	<ul style="list-style-type: none"> Information of doctors about second dose 	<ul style="list-style-type: none"> >95% Coverage with 2nd dose <i>[Uptake rate 2nd dose]</i> Raise uptake rate of second dose Identify persons not-immunised with 2nd dose
	Children with Measles <ul style="list-style-type: none"> Identification of contacts 		<ul style="list-style-type: none"> Rapid communication of cases and coordination of health services Improvement of skills in professionals to detect and to communicate cases Participation in „Measles and Rubella Laboratory Network“ Establishment of national reference laboratory Obligation to report cases Surveillance of uptake rates, vaccination register Register of severe adverse reactions Health reporting Implementation of surveillance guidelines of WHO Vigorous case investigation and laboratory confirmation 	<ul style="list-style-type: none"> Prevent new infections Improve quality of diagnostics Strengthen/Improve measles surveillance

Illus. 28: Reference framework – measles - interventions implemented for measles immunisation and elimination – Szabolcs-Szatmár-Bereg (HU)

<i>Action Level: "Policies and Interventions Aiming at ..."</i>				Overall Goals: Measles eradication <u>[Incidence]</u> & Reduction of deaths by measles <u>[Mortality]</u> Strategic Points <u>[Indicators]</u>
	the Individual / Immediate Setting	the Population	the Social System, the Legislative, Professions	
Time	First Dose <ul style="list-style-type: none"> Coverage with 1st dose Individual reminder Documentation of immunisation for parents (passes, certificates etc.) Documentation of immunisation for Primary Care Physician (IT, patient files etc.) (Obligation to immunise) Home-visiting interventions Easy/cheap access to vaccination/Reduction of out of pocket costs for vaccination Bonuses for parents Education of agents in shared facilities about benefits/risks of vaccination Pre-school nursery/kindergarten/school entry screening Motivation of parents/teachers to identify non-immunised children Offering vaccination 	<ul style="list-style-type: none"> Invitation/reminder/recall system Strategies to immunise marginal groups/sub-groups (e.g. gypsies, unregistered migrants, refugees) Special strategies for lower socio-economic groups Establishment of campaigns: <ul style="list-style-type: none"> Catch-up Follow-up Focal Awareness raising campaigns Educational measures about benefits/risks of vaccination Local authorities offer information/counselling Multi-media information resource availability (e.g. e-health) Agenda-setting in the media 	<ul style="list-style-type: none"> Legislation/Law on Infectious diseases Strategy for measles elimination National/regional immunisation plan with defined targets Implementation of WHO-immunisation guidelines Sentinels Incentives for Primary Care Physicians Guaranteed reimbursement of vaccination for Primary Care Physicians Educative measures concerning risks/benefits of immunisation Education of multipliers Risk-communication Drug Law Licensing of vaccine Producer is obligated to cold-chain logistics (product liability) Strategy for quality assurance in place and regular review and development of strategy Serological survey 	<ul style="list-style-type: none"> >95% Coverage with 1st dose <u>[Uptake rate 1st dose]</u> Reduce complications <u>[Hospitalisation rate]</u> Improve measles immunisation surveillance Promote 2nd opportunity for immunisation Improve motivation of Primary Care Physicians and parents Improve education of health professionals Improve knowledge of population regarding risks/benefits of immunisation Maintain public confidence in vaccine safety Maintain high quality of vaccine Establish evaluation of programmes Identify non-immunised persons
	Second Dose <ul style="list-style-type: none"> Coverage with 2nd dose Individual reminder Documentation of immunisation (passes, certificates etc.) Pre-school nursery/kindergarten/school entry screening Motivation of parents/teachers to identify non-immunised children with second dose Offering vaccination with second dose 	<ul style="list-style-type: none"> Invitation/reminder system Strategies to immunise sub-groups 	<ul style="list-style-type: none"> Information of doctors about second dose 	<ul style="list-style-type: none"> >95% Coverage with 2nd dose <u>[Uptake rate 2nd dose]</u> Raise uptake rate of second dose Identify persons not-immunised with 2nd dose
	Children with Measles <ul style="list-style-type: none"> Identification of contacts 		<ul style="list-style-type: none"> Rapid communication of cases and coordination of health services Improvement of skills in professionals to detect and to communicate cases Participation in „Measles and Rubella Laboratory Network“ Establishment of national reference laboratory Obligation to report cases Surveillance of uptake rates, vaccination register Register of severe adverse reactions Health reporting Implementation of surveillance guidelines of WHO Vigorous case investigation and laboratory confirmation 	<ul style="list-style-type: none"> Prevent new infections Improve quality of diagnostics Strengthen/Improve measles surveillance

9.2.3 Preliminary conclusions

The analysis to identify good practice in the health management of measles was limited because of a lack of quantitative information. After examining the availability of regional data, only four participants could be considered for the analysis. They were taken into account since they were the only regions which presented actual information concerning the health performance indicators selected by the Steering Group. *Of the four participants, only Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ), both members of cluster 2 (see chapter 4.2.5), reported optimal values for the indicators.* They presented high uptake rates and no measles cases for the year 2005. After examining the information from the organigrams, in-depth interviews and reference frameworks, similarities among these two regions were confirmed. Both regions keep registers about vaccinated persons and adverse reactions; children in these two regions receive their first measles immunisation dose at the same point in time and both regions use MMR vaccine. Another feature shared by both regions is the fact that both have a specific immunisation law and that measles elimination is part of the current political agenda. Moreover, in Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ) there is an individual reminder, an invitation system and home-visiting interventions are carried out. Both have obligatory immunisation. This is most probably a promoting factor for the health outcome.

These interventions, the interventions from the reference frameworks which are carried out in both regions, as well as the other similarities among the regions, could be considered as aspects making good practice in the health management of measles since they are conducted in both regions and both regions presented optimal health outcomes. Nevertheless, because of a shortage of information, a definitive correlation between the health outcomes and the interventions/programmes carried out in both regions could not be established.

9.3 Breast cancer

9.3.1 First approach: analysis of indicators

a. Analysis of data availability

Based on the information delivered by the regions on the health performance indicators defined by the Steering Group, it was established that of the 19 participating regions four had not sent any information related to breast cancer (the received data regarding the indicators is

available in annex 5). Using the data received from the 15 remaining regions, a rapid review was conducted to select the year for the good practice analysis. When reviewing the data, a shortage of information was confirmed. Trying to cover as many indicators and regions as possible, the Steering Group selected the year 2005 as the basis for the good practice analysis on breast cancer.

Table 13: Breast cancer 2005: Availability of regional data regarding the health performance indicators selected by the Steering Group

Health Performance Indicators Selected by the Steering Group	AT - Upper-Austria	BE - Flemish	BG - Varna-Oblast	CH - Ticino	CZ - Moravia-Silesia	DE - NRW	DE - ST	EL - Western-Greece	HU-S Szabolcs-Szatmár	IE - Dublin/Mid-Leinster	IT-E Emilia-Romagna	IT-S Sicily	IT-V Veneto	LT - Kaunas	UK - England
Incidence (per 100.000 women)															
Mortality (per 100.000 women)															
Fatality (percentage of cases)															
Participation in mammography screening (percentage of women aged 50-69 years)															
Detection (per 100.000 women screened)															
5-year survival rate (percentage of women diagnosed with breast cancer)															
10-year survival rate (percentage of women diagnosed with breast cancer)															

■ available
 ■ not available or not reported

In relation to breast cancer incidence, only two regions, Varna-Oblast (BG) and Szabolcs-Szatmár-Bereg (HU), provided regional information for the year 2005 on the indicator selected by the Steering Group. Regarding breast cancer mortality, seven participants provided information available on the selected indicator. With regard to the breast cancer fatality indicator expressed as percentage of cases, only Sicily (IT), Szabolcs-Szatmár-Bereg (HU) and Varna-Oblast (BG) provided available data for the year 2005.

With regard to the mammography screening participation indicator defined by the Steering Group as percentage of women aged 50 to 69 years old participating in mammography screening, five regions provided information for the year 2005 based on this specific population group (see Section 8 for more details about this indicator). Regarding breast cancer detection, measured in detected cases per 100.000 women screened, only Szabolcs-Szatmár-

Bereg (HU), Moravia-Silesia (CZ) and Veneto (IT) supplied this specific indicator for the selected year.

Concerning the 5-year survival rate (as percentage of women diagnosed with breast cancer), three regions delivered available information for 2005. These regions were Emilia-Romagna (IT), Sicily (IT) and Varna-Oblast (BG). With regard to the 10-year survival rate, only Emilia-Romagna (IT) provided data for the year 2005.

After analysing the availability of data, the Steering Group re-examined the relevance of the seven health performance indicators regarding breast cancer. Because of their importance by determining the burden disease and assessing the performance of the health management with regard to breast cancer, the Group decided that the following indicators should be further used: incidence, participation in mammography screening and 5-year survival rate.

Based on these three indicators, it was confirmed that none of the participants had provided information on all indicators. Nevertheless, Varna-Oblast (BG), Emilia-Romagna (IT) and Sicily (IT) supplied data on most of the selected indicators.

b. Quantitative analysis of the data

According to the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis (European Commission 2006), the desirable proportion of women invited to attend screening is 75%. This participation rate and two further breast cancer indicators were considered by the Steering Group for the identification of good practice. The Steering Group defined the following optimal values for the selected indicators:

Optimal values of breast cancer:

- Incidence: the lower the better
- 5-year survival rate: the higher the better
- Participation in mammography screening: 75%

Three regions supplied information on most of the selected indicators. These regions were Varna-Oblast (BG), Emilia-Romagna (IT) and Sicily (IT).

Table 14: Breast cancer: 2005

Health Performance Indicators Selected by the Steering Group	BG - Varna-Oblast	IT-E Emilia-Romagna	IT-S Sicily
Incidence (per 100.000 women)	92,50	n/a	n/a
Participation in mammography screening (percentage of women aged 50-69 years)	n/a	72,50	39,30
5-year survival rate (percentage of women diagnosed with breast cancer)	73,20	87,00	98,00 75,00

n/a = not available

Taking optimal indicator values as the basis, only Varna-Oblast (BG) and Emilia-Romagna (IT) were considered for the further identification of good practice for breast cancer since Sicily (IT) recorded low participation rates in mammography screening programmes.

9.3.2 Second approach: analysis of additional information

a. Organigraphs

In looking at treatment and care services for breast cancer it seems from the organigraphs and system descriptions (section 5.2.15), that in Varna-Oblast (BG) and Emilia-Romagna (IT), there is a programme of integrated care in operation.

With regard to the information and education of health professionals, the organigraphs and system descriptions show that Varna-Oblast (BG) and Emilia-Romagna (IT) refer to provision of information and education for health professionals regarding mammography screening.

b. In-depth interviews

The analysis of the in-depth interviews about breast cancer shows that the two regions of Varna-Oblast (BG) and Emilia-Romagna (IT) report breast cancer cases at the regional level. Moreover, both regions have integrated care programmes. Likewise, Disease-Management-Programmes have been implemented in both regions.

c. Reference frameworks

Analysing the information received regarding the reference frameworks, it was verified that Varna-Oblast (BG) and Emilia-Romagna (IT) conducted similar measures/interventions in the health management of breast cancer (the interventions carried out in each region are marked in yellow in the illus. 29 and 30).

When analysing the measures/interventions from the reference frameworks which are being carried out in the individual/immediate setting, it becomes apparent that Emilia-Romagna (IT) and Varna-Oblast (BG) share common characteristics when it comes to the following interventions/policies: access to information on factors causing breast cancer and genetic determinants of breast cancer for persons at risk and their families, informed consent with high standard information, information about alternative strategies, psycho-social care, treatment of patients by interdisciplinary teams in dedicated breast centres, psycho-social counselling, offer of follow-up care and cures are financed by health insurances.

When concentrating on the population level, it can be seen that the only intervention regarding this setting which is carried out in both regions is the promotion measure via local authorities, PCPs etc.

A look at the social system, at the legislative and professions reveals that both regions implement the following interventions/policies: initiation and support of research, breast centres have possibilities for triple assessment (clinical, mammogram, biopsies), education of physicians and the political community regarding the risks and benefits of mammography screening, education of technicians/radiologists, establishment of cancer/breast-cancer registers, policies and initiatives to train breast cancer workforce, establishment of specialised centres (with defined minimum number of primary therapy), establishment of internationally recognised performance indicators (e.g. mastectomy rates) and improvement of psycho-social competence of health professionals.

Illus. 29: Reference framework – breast cancer - screening and care – Emilia-Romagna (IT)

		<i>Action Level: "Policies and Interventions Aiming at ..."</i>			Overall Goal: Reach 30% reduction in breast cancer mortality [<i>Mortality</i>], [<i>Detection rate</i>], [<i>5-year survival rate</i>]; [<i>10-year survival rate</i>]; [<i>Fatality</i>]; [<i>Incidence</i>] Strategic Points <i>[Indicators]</i>
		The Individual / Immediate Setting	The Population	The Social System, the Legislative, Professions	
<i>Time</i>	Undiagnosed	<ul style="list-style-type: none"> • Access to information on factors causing breast cancer and genetic determinants of breast cancer for persons at risk & their families • Initiation and promotion of manual breast self-examination • Easy access to mammography screening programmes for women 50-69 years • Informed consent with high standard information • Respecting right not to know 	<ul style="list-style-type: none"> • Availability of genetic counselling and testing for women from families with breast cancer history • Self-awareness campaigns • Area-wide mammography screening programme according to EUREF • Identification and invitation of eligible women (every two/three years) • Invitation system for mammography screening • Agenda-Setting in the media • Promotion via local authorities, PCPs etc 	<ul style="list-style-type: none"> • Establishments of seals of approval for trustworthy information • Initiation and support of research • Reimbursement of non-mammography breast examinations by physicians (ultrasound, manual) • Clear strategy according to EUREF guidelines • Establishment of specialised breast centres according to EUREF guidelines • Breast centres have possibilities for triple assessment (clinical, mammogram, biopsies) • Education of physicians and the political community regarding the risks and benefits of mammography screening • Education of technicians/radiologists • Establishment of cancer/breast-cancer registers • Obligatory reporting 	<ul style="list-style-type: none"> • Educate persons about factors causing breast cancer • Improve scientific knowledge about factors causing breast cancer • Support other examination methods than mammography • Raise self-awareness • Extend mammography screening: participation rate >70% among women between 50-69 years [<i>Participation rate</i>] • Increase the validity and accuracy of mammograms reading • Reduce unnecessary biopsies • Raise the acceptability of mammography screening • Promote mammography screening programmes in public • Improve the screening education of professionals • Improve surveillance • Set ethical standards for screening
	Diagnosed with Cancer	<ul style="list-style-type: none"> • Information about alternative strategies • Active offer of additional conversations according to patients' needs • Psycho-social care • Treatment of patients by interdisciplinary teams in dedicated breast centres • Empowerment of patients to encourage to exercise their rights in participation • Access of patients to information assessing the quality of the care provider • Psycho-social counselling • Offer of follow-up care • Home-help is reimbursed by health insurances • Cures are financed by health insurances 	Mutual-help groups (should): <ul style="list-style-type: none"> • be supported (by physicians etc.) • participate in development and quality assurance of health/disease management programmes • Establishment of psychological support centres 	<ul style="list-style-type: none"> • Training the competence of communication of health professionals (doctors, nurses) • Development of DMPs/Integrated Care • Policies & initiatives to train breast cancer workforce • Establishment of specialised centres (with defined minimum number of primary therapy) • Certification of centres (according to EUSOMA) • Establishment of internationally recognised performance indicators (e.g. mastectomy rates) • Improvement of competence of physicians, nurses, staff etc. to communicate with patients • Consideration of psychological factors in guidelines • Improvement of psycho-social competence of health professionals • Implementation of guidelines for rehabilitation • Improvement of ambulant rehabilitation • Establishment of severely handicapped passes (and other benefits) • Cosmetic implants are covered by insurance • Resource allocation for breast cancer research • Strategy to integrate research outcomes into care programmes/practice 	<ul style="list-style-type: none"> • Improve responding of care to individual needs • Monitor patient satisfaction • Improve education of professionals • Improve quality of care • More involvement of mutual-help groups • Promote patient education • Involve patients in decision-making process • Improve quality of life • Assure follow-up • Improve rehabilitation • Give research high priority

Illus. 30: Reference framework – breast cancer - screening and care - Varna-Oblast (BG)

		<i>Action Level: "Policies and Interventions Aiming at ..."</i>			Overall Goal: Reach 30% reduction in breast cancer mortality [<i>Mortality</i>], [<i>Detection rate</i>], [<i>5-year survival rate</i>]; [<i>10-year survival rate</i>]; [<i>Fatality</i>]; [<i>Incidence</i>] Strategic Points <i>[Indicators]</i>
		The Individual / Immediate Setting	The Population	The Social System, the Legislative, Professions	
<i>Time</i>	Undiagnosed	<ul style="list-style-type: none"> Access to information on factors causing breast cancer and genetic determinants of breast cancer for persons at risk & their families Initiation and promotion of manual breast self-examination Easy access to mammography screening programmes for women 50-69 years Informed consent with high standard information Respecting right not to know 	<ul style="list-style-type: none"> Availability of genetic counselling and testing for women from families with breast cancer history Self-awareness campaigns Area-wide mammography screening programme according to EUREF Identification and invitation of eligible women (every two/three years) Invitation system for mammography screening Agenda-Setting in the media Promotion via local authorities, PCPs etc. 	<ul style="list-style-type: none"> Establishments of seals of approval for trustworthy information Initiation and support of research Reimbursement of non-mammography breast examinations by physicians (ultrasound, manual) Clear strategy according to EUREF guidelines Establishment of specialised breast centres according to EUREF guidelines Breast centres have possibilities for triple assessment (clinical, mammogram, biopsies) Education of physicians and the political community regarding the risks and benefits of mammography screening Education of technicians/radiologists Establishment of cancer/breast-cancer registers Obligatory reporting 	<ul style="list-style-type: none"> Educate persons about factors causing breast cancer Improve scientific knowledge about factors causing breast cancer Support other examination methods than mammography Raise self-awareness Extend mammography screening: participation rate >70% among women between 50-69 years [<i>Participation rate</i>] Increase the validity and accuracy of mammograms reading Reduce unnecessary biopsies Raise the acceptability of mammography screening Promote mammography screening programmes in public Improve the screening education of professionals Improve surveillance Set ethical standards for screening
	Diagnosed with Cancer	<ul style="list-style-type: none"> Information about alternative strategies Active offer of additional conversations according to patients' needs Psycho-social care Treatment of patients by interdisciplinary teams in dedicated breast centres Empowerment of patients to encourage to exercise their rights in participation Access of patients to information assessing the quality of the care provider Psycho-social counselling Offer of follow-up care Home-help is reimbursed by health insurances Cures are financed b health insurance 	Mutual-help groups (should): <ul style="list-style-type: none"> be supported (by physicians etc.) participate in development and quality assurance of health/disease management programmes <ul style="list-style-type: none"> Establishment of psychological support centres 	<ul style="list-style-type: none"> Training the competence of communication of health professionals (doctors, nurses) Development of DMPs/Integrated Care Policies & initiatives to train breast cancer workforce Establishment of specialised centres (with defined minimum number of primary therapy) Certification of centres (according to EUSOMA) Establishment of internationally recognised performance indicators (e.g. mastectomy rates) Improvement of competence of physicians, nurses, staff etc. to communicate with patients Consideration of psychological factors in guidelines Improvement of psycho-social competence of health professionals Implementation of guidelines for rehabilitation Improvement of ambulant rehabilitation Establishment of severely handicapped passes (and other benefits) Cosmetic implants are covered by insurance Resource allocation for breast cancer research Strategy to integrate research outcomes into care programmes/practice 	<ul style="list-style-type: none"> Improve responding of care to individual needs Monitor patient satisfaction Improve education of professionals Improve quality of care More involvement of mutual-help groups Promote patient education Involve patients in decision-making process Improve quality of life Assure follow-up Improve rehabilitation Give research high priority

9.3.3 Preliminary conclusions

Like in the measles analysis, the identification of good practice for breast cancer also was limited because of a lack of quantitative information. After examining the data availability of the indicators selected by the Steering Group and their optimal values, only two regions could be considered for a further analysis. They were: Varna-Oblast (BG) and Emilia-Romagna (IT), which supplied information on two of the selected indicators for the year 2005. Nevertheless, it is important to mention that of the two indicators, only the 5-year survival rate was the common indicator reported by the two regions.

When examining the information from the organigraphs, in-depth interviews and reference frameworks, similarities among these two regions were confirmed. Both regions report breast cancer cases at the regional level. Moreover, Varna-Oblast (BG) and Emilia-Romagna (IT) have Disease-Management-Programmes implemented in the regions. With regard to the information and education of health professionals, the organigraphs and system descriptions show that Varna-Oblast (BG) and Emilia-Romagna (IT) refer to provision of information and education for health professionals regarding mammography screening.

These similarities and the interventions from the reference frameworks which are carried out in both regions could be examples of good practice in the health management of breast cancer. Nevertheless, they should be considered with caution since there are not sufficient data to confirm this. Because of a shortage of information, it is not possible thus to establish a definitive correlation between the health outcomes reported by the regions and the interventions/programmes carried out by them.

Concerning the identification of good practice for breast cancer based on the identified clusters, it was confirmed that this analysis was not possible to carry out because of the shortage of information already reported.

9.4 Diabetes (type II)



9.4.1 First approach: analysis of indicators

When analysing the information received from the regions on the health performance indicators defined by the Steering Group, a significant shortage of information concerning diabetes (type II) was identified (annex 5). When gathering diabetes-related data it is important to distinguish between diabetes (type I) and diabetes (type II).

Besides Győr-Moson-Sorpon (HU) and Västra-Götaland (SE); Madeira (P), Kaunas (LT), Ticino (CH) and Emilia-Romagna (IT) provided no regional information on diabetes (type II). Kaunas (LT) and Ticino (CH) informed us that they were not able to send this type of information since data about diabetes are not systematically collected. The Steering Group selected the year 2004 as the basis for the good practice analysis. 2005 was not chosen because for this year even more information was lacking than for the year 2004. Nevertheless, it was established that the information on the health performance indicators of 2004 was not useful for the identification of good practice regarding diabetes (type II).

Table 15: Diabetes (type II) 2004: Availability of regional data on health performance indicators selected by the Steering Group

Health Performance Indicators Selected by the Steering Group	AT - Upper-Austria	BE - Flemish	BG - Varna-Oblast	CZ - Moravia-Silesia	DE - NRW	DE - ST	EL - Western-Greece	HU-S Szabolcs-Szatmár	IE - Dublin/Mid-Leinster	IT-S Sicily	IT-V Veneto	RU - Chuvash	UK - England
Incidence (per 100.000)													
Prevalence (per 100.000)													
Hospitalisation (percentage of diabetics)													
Participation in education programmes (percentage of diabetics)													

 available  not available or not reported

Due to the unavailability of quantitative data in 2004 (see table 15), the first approach of the analysis to identify good practice for diabetes (type II) was not possible to conduct.

9.4.2 Second approach: analysis of additional information

Since the data from the health performance indicators regarding diabetes (type II) were not useful to make comparisons to identify good practice models, it was decided to use the rapid appraisal method (see section 7) to meaningfully compare the participating regions and facilitate the recognition of possible good practice.

Observing the coloured matrixes from the section 7, one verified that Moravia-Silesia (CZ), Emilia-Romagna (IT) and Saxony-Anhalt (DE) implemented the majority of the evidence-based interventions recommended in the reference frameworks. To identify common charac-

teristics shared by the three regions regarding the health management of diabetes (type II), the interventions from the reference frameworks implemented by the regions were examined.

Verifying that Moravia-Silesia (CZ) exclusively informed on the number of interventions they carry out in each setting of the reference frameworks, it was decided to consider only Emilia-Romagna (IT) and Saxony-Anhalt (DE) for a further analysis.

a. Organigraphs

Of Emilia-Romagna (IT) and Saxony-Anhalt (DE), only an organigraph for diabetes (type II) was received from the first region. No organigraph or system description for diabetes (type II) was received from Saxony-Anhalt (DE).

b. In-depth interviews

Due to the analyses of the in-depth interviews it was confirmed that both regions have implemented education campaigns to prevent diabetes and diabetes risk factors. Emilia-Romagna (IT) is, however, the only region which has implemented a special regional diabetes screening programme. Whereas in Emilia-Romagna (IT), examinations for the detection (screening) of diabetes (type II) for the population aged 45 years and over are held at two-year intervals, Saxony-Anhalt (DE) already starts with these examinations for the 35-year-old and older population, hence 10 years earlier. Both regions have moreover implemented a regional integrated care programme and both regions have a diabetes surveillance system.

c. Reference frameworks

When looking at the measures/interventions which are being carried out in the individual/immediate setting, it can be noticed that the number and kind of the interventions carried out are very similar to each other. These regions for example share the following characteristics: community-oriented prevention/setting approaches, social-medical counselling, check-ups for people who see doctors for other reasons, general screening, preferably one-step screening should be offered to each pregnant woman, offer of patient education/seminars about self-care and lifestyle, involvement of patients and families in planning the delivery of care and education of patients' families about self-care and lifestyle, patient training, offer of seminars (smoking, alcohol, overweight), screening for complications, management of long term and fatal complications, annual foot exams among people with diabetes, treatment of elevated blood pressure and dilated/annual eye exam (the interventions carried out in each region are marked in yellow in the illus. 31 and 32).

At the population level, both regions consider and/or have implemented the following interventions: information about consequences of unhealthy lifestyles, Health promotion campaigns, lifestyle oriented prevention campaigns (e.g. campaigns on healthy food), motivating measures to increase participation in health check ups in target groups, regular health check-ups for people with family history in diabetes, screening in individuals with abdominal adiposity (men), hypertriglyceridaemia (women), hypertension, and parental diabetes history, broadly based screening programmes looking for metabolic and cardiovascular risk factors and for early disturbances of carbohydrate metabolism particularly in middle-age groups, information campaigns, provision of education programmes for patients, mutual-help groups (should) be supported (by physicians etc.) and strategy for detection and management of long-term and fatal complications.

With regard to the social system, the legislative and professions, the regions of Emilia-Romagna (IT) and Saxony-Anhalt (DE) have the following interventions in common: implementation of education programmes, creation of living conditions that promote healthy living (e.g sidewalks to motivate people in cities to walk, healthy food in schools etc.), impact on cultural lifestyle habits (taxations, prohibitions etc.), consumer protection laws (e.g. nutritional information, financing of preventive check-ups, improvement of competence of physicians, nurses, staff etc. to communicate with patients, training of competence of communication of health professionals (doctors, nurses), DMPs/Integrated care, assurance of insulin provision (different types, sufficient insulin), assurance of test strips provision and raising awareness of health professionals.

Illus. 31: Reference framework – diabetes (type II) – primary prevention, screening, secondary and tertiary prevention – Emilia-Romagna (IT)

		<i>Action Level</i>			Overall Goals: Reduce diabetes-related deaths Strategic Points <i>[Indicators]</i>
		The Individual / Immediate Setting	The Population	The Social System, the Legislative, the State, Professions	
<i>Time</i>	Primary Prevention	<ul style="list-style-type: none"> Community oriented prevention / setting approaches 	<ul style="list-style-type: none"> Information about consequences of unhealthy lifestyles Provision of evidence based information Addiction prevention programmes Health promotion campaigns Lifestyle oriented prevention campaigns (e.g. campaigns on healthy food) 	<ul style="list-style-type: none"> Implementation of anti-obesity programmes Implementation of education programmes Creation of living conditions that promote healthy living (e.g. sidewalks to motivate people in cities to walk, healthy food in schools etc.) Establishment of seals of approval for trustworthy information Impact on cultural lifestyle habits (taxations, prohibitions etc.) Consumer protection laws (e.g. nutritional information) 	<ul style="list-style-type: none"> Reduce cases of diabetes <i>[Prevalence]</i> Prevent new cases of diabetes <i>[Incidence]</i> Improve the education of the population about lifestyle dependent health risks Promote healthier lifestyles
	Screening	<ul style="list-style-type: none"> Social-medical counselling Check-ups for people who see doctors for other reasons General screening, preferably one-step screening should be offered to each pregnant woman. Screening for overweight pregnant women 	<ul style="list-style-type: none"> Motivating measures to increase participation in health check ups in target groups People from 35 years on: regular health check-ups: urine, glucose, blood pressure, weight, blood lipids Regular health check-ups for people with family history in diabetes Screening in individuals with abdominal adiposity (men), hypertriglyceridaemia (women), hypertension, and parental diabetes history. Broadly based screening programmes looking for metabolic and cardiovascular risk factors and for early disturbances of carbohydrate metabolism particularly in middle-age groups Information campaigns 	<ul style="list-style-type: none"> Financing of preventive check-ups Evidence based strategy in place for prevention of diabetes type 2, including monitoring and evaluation components Investment in professional development of workforce Provision of education programmes for professionals 	<ul style="list-style-type: none"> Raise uptake rate of medical, preventive check-ups Identify more persons at higher risk Identify more persons with diabetes Raise uptake of examinations for early detection Reduce mortality Improvement of the education of professionals Achieve pregnancy outcome in the diabetic women that approximates that of the non-diabetic woman Identify more pregnant women with diabetes
	Secondary Prevention	<ul style="list-style-type: none"> Promotion of self-testing Offer of patient education/seminars about self-care and lifestyle Involvement of patients and families in planning the delivery of care Education of patients' families about self-care and lifestyle 	<ul style="list-style-type: none"> Provision of education programmes for patients 	<ul style="list-style-type: none"> Improvement of competence of physicians, nurses, staff etc. to communicate with patients Training of competence of communication of health professionals (doctors, nurses) DMPs/Integrated Care 	<ul style="list-style-type: none"> Increase number of people with diabetes self-monitoring glucose Improve number of educated patients <i>[Participation rate in education programmes]</i> Involve more patients in decision-making process Reduce hospitalisation among people with diabetes <i>[Hospitalisation rate]</i> Improve responding of care to individual needs
	Tertiary Prevention	<ul style="list-style-type: none"> Patient training Offer of seminars (smoking, alcohol, overweight) Screening for complications Management of long term & fatal complications Annual foot exams among people with diabetes Treatment of elevated blood pressure Dilated/annual eye exam 	<ul style="list-style-type: none"> Mutual-help groups (should): be supported (by physicians etc.) participate in development and quality assurance of health/disease management programmes Strategy for detection and management of long-term & fatal complications 	<ul style="list-style-type: none"> Assurance of insulin provision (different types, sufficient insulin) Assurance of test strips provision Raising awareness of health professionals Incentives for health professionals to detect complications 	<ul style="list-style-type: none"> Raise degree of health literacy and information about the disease/disease-management among people with diabetes More involvement of mutual-help groups Assuring tertiary prevention Reduce cases of complications: diabetic renal failure; foot ulcers; limb amputations; respiratory complications; blindness, cardiovascular diseases etc.

Illus. 32: Reference framework – diabetes (type II) – primary prevention, screening, secondary and tertiary prevention – Saxony-Anhalt (DE)

		<i>Action Level</i>			Overall Goals: Strategic Points [Indicators]
		The Individual / Immediate Setting	The Population	The Social System, the Legislative, the State, Professions	
<i>Time</i>	Primary Prevention	<ul style="list-style-type: none"> Community oriented prevention / setting approaches 	<ul style="list-style-type: none"> Information about consequences of unhealthy lifestyles Provision of evidence based information Addiction prevention programmes Health promotion campaigns Lifestyle oriented prevention campaigns (e.g. campaigns on healthy food) 	<ul style="list-style-type: none"> Implementation of anti-obesity programmes Implementation of education programmes Creation of living conditions that promote healthy living (e.g. sidewalks to motivate people in cities to walk, healthy food in schools etc.) Establishment of seals of approval for trustworthy information Impact on cultural lifestyle habits (taxations, prohibitions etc.) Consumer protection laws (e.g. nutritional information) 	<ul style="list-style-type: none"> Reduce cases of diabetes [Prevalence] Prevent new cases of diabetes [Incidence] Improve the education of the population about lifestyle dependent health risks Promote healthier lifestyles
	Screening	<ul style="list-style-type: none"> Social-medical counselling Check-ups for people who see doctors for other reasons General screening, preferably one-step screening should be offered to each pregnant woman Screening for overweight pregnant women 	<ul style="list-style-type: none"> Motivating measures to increase participation in health check ups in target groups People from 35 years on: regular health check-ups: urine, glucose, blood pressure, weight, blood lipids Regular health check-ups for people with family history in diabetes Screening in individuals with abdominal adiposity (men), hypertriglyceridaemia (women), hypertension, and parental diabetes history Broadly based screening programmes looking for metabolic and cardiovascular risk factors and for early disturbances of carbohydrate metabolism particularly in middle-age groups Information campaigns 	<ul style="list-style-type: none"> Financing of preventive check-ups Evidence based strategy in place for prevention of diabetes type 2, including monitoring and evaluation components Investment in professional development of workforce Provision of education programmes for professionals 	<ul style="list-style-type: none"> Raise uptake rate of medical, preventive check-ups Identify more persons at higher risk Identify more persons with diabetes Raise uptake of examinations for early detection Reduce mortality Improvement of the education of professionals Achieve pregnancy outcome in the diabetic women that approximates that of the non-diabetic woman Identify more pregnant women with diabetes
	Secondary Prevention	<ul style="list-style-type: none"> Promotion of self-testing Offer of patient education/seminars about self-care and lifestyle Involvement of patients and families in planning the delivery of care Education of patients' families about self-care and lifestyle 	<ul style="list-style-type: none"> Provision of education programmes for patients 	<ul style="list-style-type: none"> Improvement of competence of physicians, nurses, staff etc. to communicate with patients Training of competence of communication of health professionals (doctors, nurses) DMPs/Integrated Care 	<ul style="list-style-type: none"> Increase number of people with diabetes self-monitoring glucose Improve number of educated patients [Participation rate in education programmes] Involve more patients in decision-making process Reduce hospitalisation among people with diabetes [Hospitalisation rate] Improve responding of care to individual needs
	Tertiary Prevention	<ul style="list-style-type: none"> Patient training Offer of seminars (smoking, alcohol, overweight) Screening for complications Management of long term & fatal complications Annual foot exams among people with diabetes Treatment of elevated blood pressure Dilated/annual eye exam 	<ul style="list-style-type: none"> Mutual-help groups (should): be supported (by physicians etc.) participate in development and quality assurance of health/disease management programmes Strategy for detection and management of long-term & fatal complications 	<ul style="list-style-type: none"> Assurance of insulin provision (different types, sufficient insulin) Assurance of test strips provision Raising awareness of health professionals Incentives for health professionals to detect complications 	<ul style="list-style-type: none"> Raise degree of health literacy and information about the disease/disease-management among people with diabetes More involvement of mutual-help groups Assuring tertiary prevention Reduce cases of complications: diabetic renal failure; foot ulcers; limb amputations; respiratory complications; blindness, cardiovascular diseases etc.

9.4.3 Preliminary conclusions

In particular the data regarding the health performance indicators on diabetes (type II) at the regional level shows that in this respect much remains to be done to achieve comparable regional data in future. When considering the fact that according to WHO estimates a considerable increase in diabetics worldwide has to be expected, arrangements should be made for the foreseeable future so that in future this “dark spot” will not exclude any analyses at the regional level (WHO 2006).

When collecting data on diabetes, care should be taken to distinguish between diabetes (type I) and diabetes (type II). This distinction will help to adequately consider both patient groups and to collect valid and reliable data. According to the CDC Foundation (2006), the proportion of the population hit by diabetes (type I) presently amounts to about five or ten percent of all diagnosed cases and type 2 diabetes affects 90 to 95 percent of people with diabetes.

It remains to be stated that due to the analysis performed only first steps towards comprehensive benchmarking in the health management of diabetes (type II) could be carried out. Among others, education campaigns to prevent diabetes and diabetes risk factors, integrated care programmes and a diabetes surveillance system, were identified as common interventions in the analysed regions. However, they could not be verified as good practice since the significant shortage of information. Therefore, many improvements are still required when it comes to collecting diabetes-related data.

9.5 Conclusions

The developed method to identify good practice is a recommendable tool for the benchmarking of health management approaches. The method can and should be further applied in other regional projects. With it is possible to show where health management is successful and gives other regions hints with what regions to compare themselves for improving their health managements. With the help of the Reference Frameworks, it becomes clear what interventions and policies contribute to good practice.

Yet, the results of the identification of good practice show some deficits in the health management of the three tracers in the participating regions: the data held and provided in the region is insufficient for good health management – at least when we consider the Health Performance Indicators the Steering Group had identified and defined for good health manage-

ment. Policy makers would need a better basis of data to make sound decisions for a good health governance.

The results have further shown that the good practice identified in measles health management was both within one cluster (namely cluster 2). An originally intended goal to identify good practice for each of the clusters was not possible due to lacking data of quantitative information of the Health Performance Indicators.

To conclude, with the help of the developed methodology we could identify first good practices and have received many hints how the health management in the participating regions could be improved. For a deeper insight into European health management systems, benchmarking studies should be encouraged. Benchmarking processes amongst regions should also be stimulated using further tracers to identify where health managements could be improved.

10 Discussion

10.1 Relevance of the methodology of Ben RHM II

The developed and implemented range of different methods provided us with the chance of combining various approaches over a certain period of time.

Thanks to the *organigraphs* it was possible to look into and to compare various management systems with the help of the three examined tracers “measles, breast cancer and diabetes (type II)”, including their functions and ways of decision making from the national, regional and up to the local level. A comparison of the organigraphs by tracers shows that the regions adopt different approaches at the different levels. *It has been shown that in practice those regions do well whose organigraphs reflect simple structures.* Health management, in particular, tends to be hindered through complex structures rather than promoted – irrespective of the disease which is at stake. In addition, the information given in the in-depth interviews clearly illustrated the steps and measures already being taken up to now in the various European regions in the fields of prevention, treatment and follow-up care of patients.

The research work conducted led to three *reference frameworks* for the health management of measles, breast cancer and diabetes (type II) and to a refined method of applying these references frameworks to rapid appraisal. This method is more efficient because it uses relative numbers assigned to colour shades. Thus a graphic presentation of a region can stand

on its own and be informative – no comparison with a graphic presentation of the respective reference framework is needed. Through the colour shade, the “rapid appraisal” or so-called reference frameworks provide a quick overview of presently valid expert recommendations as well as of the measures carried out in their own region. They moreover allow a direct comparison of the measures/policies implemented in their own regions with the measures taken by other European regions. The reference frameworks show the assets in regional health management and also reveal areas in regional and national healthy policy which might require further actions.

In the course of the project it has also been revealed that through these different methodological approaches different actions and measures in the health management of the participating regions can be identified. The structures and processes within the different health management systems within Europe have been laid open. They can and could be used for a comparison providing the responsible researchers and policy makers with information on how well the health management system in their region is doing, aspects which might require further improvements and where concrete comparisons with other regions are recommendable. Such a complete overview will help them to gain information on the position and standing of their own region since from these data recommendations for the further development at the local, regional and national level can be derived.

This research project allows all parties involved not only to consider the practices in their own regions but at the same time also provides information beyond national and local borders. The key contacts also allow to get in touch with the main contact partners in the individual regions, facilitating the exchange of views among experts. A lively exchange of opinions among all parties involved and interested in the project should thus become possible in the various health organisations after completion of the project.

The project has quite clearly shown that each disease must be considered and evaluated by itself because the health management systems are very differently organised. With the help of an organigraph alone, no valid general statements can be made on the corresponding health management system of the region.

In general it can be said that the project “Benchmarking Regional Health Management II (Ben RHM II)” provides profound insights into the activities already implemented in health management. A great deal of information about effective, successful and promising measures and treatment services would never have come to our notice if we had not applied these manifold research methods.

10.2 Lessons learned from the analysis of good practice

The analysis of good practice in the Ben RHM II project shows remarkable results. On the one hand, statistical data are collected, evaluated and analysed. On the other hand, those measures and actions are identified which are actually being implemented by the interviewed European regions.

To identify good practice methods, only data available at the regional level should be used. Data only available at the national level were not considered for the study.

It has been shown in the course of the project that many data are being collected at the national level and not at the regional level. To turn the argument on its head, this means that no good health policy can be implemented at the regional level if corresponding data are not available. To put it in a nutshell, this can be summarised in the following words: “You cannot manage what you cannot measure”.

It turns out that some regions have no responsibility for the regional data but that some regions manage this kind of data very well. But not all regions have the tools for this.

An additional problem revealed by the project consists in the fact that there is no health data law which means that there is no legal basis to get data.

In general it can be said that “good practice” is not possible without good data. It has through our study in numerous cases and with the help of specific regions been shown that regional data are urgently required for implementing specific actions and recommendations for action at the regional level and for analysing them with respect to their evidence.¹²⁵ It remains to be stated that presently no data have been collected on the successes of specific measures at the regional level and been analysed with regard to their evidence.

All in all it has to be stated that the methods for collecting data at the national and also at the regional level have to be further improved. If more regional data are available, the “good practice” approach can provide an incentive for increasingly comparing and learning from each other. The analysis of the three tracers “measles, breast cancer and diabetes (type II)” can thus serve as a basis for getting an insight into further diseases and their immanent care systems.

Yet some good practices and hints on good practice could be identified. Regions can learn for their health management by referring to the reference framework, by doing rapid appraisal, comparing their Organigraphs and by further researching in the first insights on

¹²⁵ Exemplarisch ist hier zu nennen: European guidelines for quality assurance in breast cancer screening and diagnosis (2006).

good practice. Ben RHM II has thus significantly contributed to the opportunity of improving health management of European regions.

11 Perspectives

11.1 Complementarity with other EU Projects¹²⁶

Ben RHM II is one of several projects established on the basis of the European Community action programme in the field of public health. This programme forms an essential part of the Community's health strategy and is aiming at three main objectives.

1. To improve information and knowledge with emphasis on promoting public health and health systems; a comprehensive system for collecting, analysing and evaluating data and knowledge should be developed.
2. To enhance the ability of the Community to respond rapidly and coherently to health threads; surveillance and early-warning mechanisms should be developed and strengthened.
3. To reduce premature death and illnesses; health promotion activities and measures to reduce or eliminate health risks should be developed.

Especially the first bullet comprises several tasks which correspond to the four steps of the public health action cycle: Assessment of a situation, development of policies to influence the situation, implementation of policies and evaluation of the results which form a new situation and start the cycle again. For each of these steps there are some projects which look at specific aspects and deliver solutions for parts of the whole system. In addition there are projects which coordinate the individual projects and bring the results together.

Community health policy is not restricted to the formulation of regulations which are to be implemented in the Member States. Community health policy is also aimed at supporting the Member States providing information and methods and tries to improve the harmonisation within the European Community by regional funding beyond the national level. For this purpose it is important to identify regions which are responsible for health policy and thus able to influence the health system or to perform health promotion. For the funding and pro-

¹²⁶ Author: Dr Wolfgang Hellmeier, Institute of Public Health North Rhine-Westphalia, Bielefeld (Germany).

motion of regions data and information on the regional level are necessary. Therefore some of the projects are dealing with regions and the respective data.

11.2 Projects in the environment of Ben RHM II

To highlight the relationships of some of the projects, they will be presented according to their task and to the step of the public health action cycle to which they contribute.

11.2.1 Development of indicators, identification of data, check of the availability of data

These tasks clearly form the basis of the assessment of public health. Without data, which for reasons of comparability must be based on common definitions, policies or situations cannot be assessed.

Four projects have laid their emphasis on these objectives:

- ECHIM: European Community Health Indicators Monitoring
- ISARE: Health Indicators in the European Regions
- EURO-URHIS: European Urban Health Indicator System
- EUPHID: European Health Promotion Indicators Development

The aim of ECHIM is the provision of relevant, valid and comparable health data for the EU and the Member States as well as for sub-national regions. The deliverables of ECHIM are a list of indicators with definitions and information about data availability. The list provides an overview of accepted indicators and their definitions which can and should be used for the calculation of indicators in European public health projects. The work of ECHIM is based on the list of indicators which were produced by the ECHI projects (European Community Health Indicators) and a permanent communication with all other projects which are working on new indicators. If projects develop indicators, which are meaningful for the information needs of health policy and public health and if the definition is clear and data available, these indicators can be included into the ECHI list.

ISARE dealt with regional data throughout Europe. A part of the project was the identification of regions which are in the position to perform health policy and where data are available. These regions differ very much within the Member States and they do not corre-

spond to any one of the levels defined by EUROSTAT (NUTS). From the identified regions a set of core indicators, which were seen as important for regional health policy, were collected and a website with the indicators and some analyses was established. The work of ISARE is becoming more and more important because the structural funds of the Community will deal with aspects of public health and therefore need regional health indicators.

EURO-URHIS is dealing with a system of health indicators for urban areas. The outcome of the project will be an overview of urban health problems and information on the activities which are carried out at the urban level within the Member States. In this context indicators which are useful for urban public health will be selected. In a first step, the ECHI list will be checked for appropriate indicators; if some important aspects are not covered yet in ECHI, new indicators will be proposed.

EUPHID has the aim of establishing a common set of European Health Promotion Indicators.

11.2.2 Design and construction of health information systems

Data and indicators are only useful if they are available and if they are presented in a way which a policy maker or a policy consultant can read and use easily. There are two projects dealing with these aspects.

EUPHIX: European public health information system and ENHIS II: Environmental health information system.

EUPHIX is developing a prototype for a sustainable web-based health information system for the EU. The deliverables are a functional web application, structured information on selected topics, comprising tables, graphs and textual descriptions and assessments as well as links to external information related to the topic presented. In addition, a network for the maintaining of the system after the end of the project will be developed.

ENHIS II has similar aims as EUPHIX with the emphasis on environment and health. Therefore the indicators are different to those in EUPHIX and reports on health impact assessment play an important role.

11.2.3 Development of methods and tools for the assessment of public health projects and policies

These projects rely on the results of the former and deal with the assessment and the evaluation of some aspects of public health.

HIA: Health Impact Assessment is aimed at identifying different HIA methods in the EU and at assessing the hindering and promoting factors of the different methods. The deliverables are a documentation of HIA activities and some good practice examples for a harmonised application in the EU.

PIA PHR: Policy impact assessment of public health reporting analyses the current practice of public health reporting and its policy impact on the different levels of the Member States. The needs of the users of public health reports will be identified and the comparison of the current practice versus the needs will show discrepancies which will be used for the development of a tool box for public health reporting which will meet the needs of the users.

EUREGIO: Evaluation of cross-border activities in the European Union deals with the collection and assessment of activities in the field of public health where regions in different Member States are involved. The deliverables are a list of projects and an assessment combined with good practice examples and hints on how to improve the effectiveness of such projects.

Ben RHM II also belongs to this group because it looks at the health systems in different regions, provides a method for a rapid appraisal and an assessment of the performance.

These projects go beyond assessment, as the methods and results can be used for policy development, evaluation and in parts for the assurance of policies and programmes.

11.2.4 Relationships between the projects

The projects which are mentioned here are linked together in different ways. The first group of projects produces the basis for the further work by providing a list of standardised and available indicators which can be used by other projects. Especially ECHIM as the coordinating project contributes to comparable data and study results. To maximise the usefulness of ECHIM, all projects should cooperate in two ways. First, each project should use ECHIM indicators as far as possible, second, if additional indicators are developed, they should be sent to ECHIM in order to discuss if they are important enough and data availability is good enough throughout the EU to include the indicator in the ECHI list.

The information systems rely on the ECHI list for the presented data and they develop and establish systems which provide information which meets the needs of the users in terms of presentation and in terms of contents using ECHI indicators. These projects can benefit a lot from the results of HIA and PIA but they can also give input to these projects by controlling the acceptance of their contents and by identifying those which are used very often. This knowledge can be used for the construction of guidelines and good examples.

Ben RHM II has built on the results of many of the described projects, especially IS-ARE which identified the regions which are important for public health. But the results of Ben RHM II can also promote other projects as the results of Ben RHM II show that standardised data for the EU and especially regional data are important and that they can be used by the policy makers of each region in EU for their own health policy.

11.3 Lessons learned from Ben RHM II for the “Method of Open Co-ordination” (OMC)¹²⁷

The “open method of co-ordination“ (OMC) was established for national social policies amongst the Member States (European Council 2000). It represents a new policy approach agreeing common targets/guidelines and indicators for evaluation that are not legislatively binding. It supports cooperation and the exchange of good practice. OMC will be discussed also for application in the health sector but concrete experiences do not exist so far. Therefore it would be worthwhile to ask how the experiences of the Ben RHM II project can give impetus to OMC. Based on proposed indicators and reference frameworks, Ben RHM II provides targets where the participating regions benchmark how far they reach good practice goals. The project can be used and applied for chronic diseases, for instance, or screening programmes. It concurs, by carrying out processes and management approaches which could be identified as good practice, with the general direction of OMC. But the project makes a step forward and helps to identify those areas where structures and processes can be improved to reach the agreed targets. Moreover the project shows the importance of valid and reliable comparable data for defined indicators – a prerequisite for OMC.

The experiences of Ben RHM II show that methodological problems exist in comparing the data, due to the fact that the necessary data for the defined indicators is not available in different regions/countries (not routinely reported) or, because it is based on different health systems, and not appropriate benchmarking. Based on that experience, a prerequisite

¹²⁷ Author: Dr Reli Mechtler, University of Linz, Departement of Health System Research (Austria).

for applying OMC in the health sector is that there has to be a prior focus and agreement not only on targets and indicators but also on the operationalization. It will also be necessary to consider the national historical peculiarities of health systems when interpreting the data.

11.4 Ben RHM II – and the future work of the Regions for Health Network in Europe¹²⁸

Since its inception in 1992, the members of the WHO Regions for health network (RHN) have committed themselves to strengthen the focus of work on health at the regional level. Today the network unites 29 regions from 18 countries in Europe from diverse geographical, political and historical landscapes. This diversity of membership serves as an important base for cross cutting policy programme work both within WHO/EURO and externally with partners such as the EU. This diversity and flexibility is demonstrated by RHNs active role in several EU funded projects such as ECHI (European Community Health Indicators); ISARE (Indicateurs de santé des Régions Européennes-Health Indicators in the European regions) and Ben RHM II.

The RHN will continue to align its work with that of WHO; more specifically, working towards WHO/Europe's country strategy 2005-2009, dedicated to strengthening health systems on a country by country basis. WHO/EURO efforts to strengthen health systems are based on our common values (Health for All update, the Ljubljana Charter on Reforming Health Care, Ljubljana Conference, 1996) and that health is a human right. In line with this strategy is the WHO framework for strengthening health systems that looks at the overall goals and key functions. The aim of this framework is to help the countries and regions to analyze their own performance, obtain an understanding of factors that contribute to performance, improve performance and better respond to needs and expectations of citizens.

The Ben RHM II project is demonstrative of the need to better understand health systems (their functions and goals) where a comparison of the health systems of 19 European regions has shed light on the structures, processes and results at the regional level in Europe. The intention of RHN is to use the results of Ben RHM II to help improve the potential of performance-based governance at the regional level. Furthermore, the report of the Ben RHM II will be presented as part of documentation at the upcoming WHO European Ministerial Conference on Health Systems in June 2008 in Tallinn, Estonia.

¹²⁸ Author: Shouka Pelaseyed, Focal Point for Regions for Health Network (RHN), WHO Regional Office for Europe, Copenhagen (Denmark).

Thus RHN will continue to gear its projects towards the health systems strategy in order to strengthen the evidence base at the regional level in Europe. This will support the body of evidence on the work of health systems as well as provide some insight into the implications of decentralization and recentralization of health systems in Europe. It is hoped that methodological approaches such as the reference framework and analysis of health performance indicators from Ben RHM II will be applied to future project work as well. These act as useful tools in providing regional level policy-makers with overview and determine the possibility of the need for further action. This in turn, will help to reinforce the importance of health actions at the regional level for the improvement of population health status.

12 Conclusions

The Ben RHM II project aimed at producing more transparency between the regional health systems in Europe, at identifying “good practice“ models, and at establishing a platform allowing the regions to learn from each other and to promote cooperation among the Member States.

In the participating European regions, a number of different positive approaches supporting the health management systems in an effective way could be identified. Using the outcomes of the analysis, we were able to show that there is no single ideal way of proceeding in the fields of prevention, treatment and follow-up care. The outcomes of Ben RHM II show that with regard to the three examined diseases many different approaches and regulations have been established in European health care provision. It is moreover revealed that not only regions with different national borders differ in prevention, treatment and follow-up care but also regions within national borders.

Whereas the organigraphs served to describe the different national, regional and local levels in health management with the help of three tracers, the in-depth interviews provided a lot of interesting and revealing information reflecting the wide variety of the corresponding health management systems.

The reference frameworks are helpful in two ways. They give an overview of effective and feasible interventions and policies for the health management approach of the respective tracers. This helps policy makers to develop the health management system in their regions or countries. Additionally, they can serve as the basis for a rapid appraisal method for health plans or for the analysis of the health management approaches and structures already existing.

As such, they can be a starting and endpoint of the health policy cycle: in the beginning, to set up health plans and organise health management systems – as shown in the case study (chapter 7.2) – and then later on to evaluate existing health management systems. The reference frameworks in general provide a good possibility for orientation. They are, however, not suited for the exclusive conduct of evaluations.

Due to our research results it is urgently recommended to further improve the collection of health-relevant data at the regional level so that not only data at the national level but also at the regional level are comparable with each other. This would be beneficial to all participating regions in that they could carry out their own interregional comparisons in addition to regional comparisons. It can in general be stated, that without regional health performance indicators no efficient and effective health policy can be implemented. It is however not sufficient to only compare indicators. Our project has further shown that clustering is a good tool to compare regions meaningfully. At the same time it has to be stated that the clustering method used for this research project is well suited for application and recommended for other projects. Under this project a clustering method was developed and used for working on the results obtained. The method can be used for other research projects and be further improved.

The “Benchmarking Regional Health Management II (Ben RHM II)” project shows political decision makers various successful fields of action for the implementation of relevant measures for the health management of the three tracers.

Finally it has to be said that due to these different results obtained from the organigraphs, in depth-interviews, health performance indicators and reference frameworks first important steps towards comprehensive benchmarking in health management could be taken. Even if “good practice“ examples could be established (e.g. the regions Szabolcs-Szatmár-Bereg (HU) and Moravia-Silesia (CZ), both members of cluster 2 can be considered examples of good practice for the management of measles prevention), an important outcome of this regional comparison consists in the fact that most of the participating regions still have serious deficits in providing quantitative health information.

To conclude, the “Benchmarking Regional Health Management II” project thus has delivered concrete methods, results and impulses for future benchmarking in this area to improve good health governance in Europe.

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