



Boosting Innovation and Cooperation in European Cancer Control

Key Findings from the European Partnership
for Action Against Cancer

Edited by

Jose M. Martin-Moreno
Tit Albreht
Sandra Radoš Krnel

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E-mail: info@ivz-rs.si

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and

World Health Organization on behalf of the European Observatory on Health Systems and Policies

Rue de l'Autonomie 4, B-1070 Brussels, Belgium

E-mail: info@obs.euro.who.int

Tel. +32 2 525 0935

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Contents

List of tables, figures and boxes	vii
Abbreviations	xi
Foreword <i>John F. Ryan</i>	xv
Preface <i>Marija Magajne</i>	xvii
Acknowledgements	xxi
Introduction to the present volume <i>Jose M. Martin-Moreno, Meggan Harris, Tit Albreht</i>	1
Chapter 1: Joint Action European Partnership for Action Against Cancer - EPAAC <i>Sandra Radoš Krnel, Tit Albreht, Jose M. Martin-Moreno</i>	9
Chapter 2: Rejuvenating the European Week Against Cancer: Working together to spread the word, 'Cancer is preventable!' <i>Wendy Yared, Kevin O'Hagan, Sabrina Paladini, Pavel Poc, Alojz Peterle, Matic Meglič, Tina Lipušček, Ana Šinkovec</i>	35
Chapter 3: Online social media as a tool to improve cancer prevention and health promotion <i>Matic Meglič, Aleš Lamut, Ana Šinkovec, Wendy Yared</i>	57
Chapter 4: Building European capacity and expertise in secondary cancer prevention: towards a common core curriculum for cancer screening <i>Ahti Anttila, Stephen P. Halloran, Florian A. Nicula, Alban Ylli, Nereo Segnan, David Ritchie, Dolores Salas Trejo, Ana Molina-Barceló, Marlou Bijlsma, Lawrence von Karsa</i>	87
Chapter 5: More than a European sound box: capitalising on the added value of the European perspective in cancer treatment <i>Josep M Borrás, Joan Prades, Jeanne-Marie Brechot, Sara Faithfull, Annalisa Trama, Paolo G. Casali</i>	117

Chapter 6:	Information for action: building a unified European Cancer Information System to bolster cancer control <i>Milena Sant, Riccardo Capocaccia, David Forman, Stefano Rosso, Annalisa Trama, Sabine Siesling, Renée Otter, Camilla Amati, Francesco De Lorenzo</i>	141
Chapter 7:	Towards innovative models to improve cancer research coordination and outcomes in Europe <i>Julio E. Celis, Anna Rouillard, Ingrid van den Neucker, Maria Ferrantini, Silvia Paradisi, Carlos Segovia, Teresa Corral, Rosana Peiró, Dolores Salas, Christine Berling, Fabien Calvo, Agnès Buzyn</i>	179
Chapter 8:	From 'on paper' to 'into action': development of National Cancer Control Programmes in the EU <i>Tit Albreht, Marjetka Jelenc, Lydia Gorgojo</i>	209
Chapter 9:	Summary and conclusions: the European Partnership for Action Against Cancer . . . Just the beginning <i>Jose M. Martin-Moreno, Tit Albreht, Sandra Radoš Krnel</i>	243
Index		265

List of tables, figures and boxes

Tables

Table 3.1	SWOT overview of EPAAC Online Social Gaming	79
Table 4.1	ESSM pilot course 19–23 November 2012 and 11–15 March 2013, delegates	95
Table 4.2	ESSM pilot course 19–23 November 2012 and 11–15 March 2013, faculty	96
Table 4.3	ESSM pilot course, abridged curriculum	97
Table 5.1	List of EPAAC associated and collaborating partners in health care	119
Table 6.1	Science- and policy-related hurdles to an ECIS	150
Table 6.2	EUROCHIP cancer indicators	152
Table 6.3	Agreed conclusions adopted by EUROCARE and IARC on common dissemination of cancer burden indicators	167
Table 6.4a–d	ECIS organisational options and considerations, by function	170
	Table 6.4a Database management	170
	Table 6.4b Data quality control	171
	Table 6.4c Data analysis	172
	Table 6.4d Individual data dissemination	173
Table 7.1	Priority areas for cancer research coordination	184
Table 8.1	General elements of NCCPs	218
Table 8.2	Structures for implementation and accountability in NCCPs	221
Table 8.3	Challenges in NCCP development and Member State responses	223
Table 8.4	Evaluation processes and indicators for NCCPs	227

Figures

Figure 2.1	Winning entry from the 2012 youth poster competition, by Claudio Pavione of Italy	46
Figure 2.2	Homepage of the CancerCode website as it appeared on 9 October 2011, in its original unchanged form, created during the previous EU-funded Europe Against Cancer programme ‘Last update July 2, 2003’.	47

Figure 3.1	Value chain for online social media campaign	66
Figure 3.2	I'm a Fan of Life Facebook landing page	69
Figure 3.3	Example of a game: Solve the rebus	70
Figure 3.4	Diachronic evolution of Facebook 'likes' from 1 Jan 2013 to 21 March 2013 (N=166 'likes')	74
Figure 3.5	Diachronic evolution of Facebook 'likes' from 22 March 2013 to 22 June 2013 (N=16828 'likes')	75
Figure 3.6	Sources of Facebook 'likes' in the period from 22 March 2013 to 22 June 2013	76
Figure 3.7	Demographics of EPAAC Facebook reach, 22 March 2013 to 22 June 2013	77
Figure 3.8	Facebook indicators on engagement and viral reach, 22 March 2013 to 22 June 2013	78
Figure 4.1	ESSM course Module 1 participants	90
Figure 4.2	Process of cancer screening	92
Figure 4.3	Evaluation of Module 2 of ESSM course by participating delegates	99
Figure 5.1	Age standardised five-year relative survival estimates for colorectal cancer in selected European countries, 1995–99	120
Figure 5.2	Age standardised five-year relative survival estimates for breast cancer in selected European countries, 1995–99	121
Figure 5.3	Network approaches by level of integration	126
Figure 6.1	Organigram of the European Network of Cancer Registries	155
Figure 6.2	CR coverage in EU and EEA/EFTA countries in 2007 and 2013	156
Figure 6.3	Adult and childhood cancer coverage participating in EUROCARE-5	160
Figure 8.1	Health system functions and goals	213
Figure 8.2	European NCCPs implemented before and after European Commission Communication on Action Against Cancer	217
Figure 8.3	EPAAC working structure on NCCPs	237

Boxes

Box 1.1	Associated and Collaborating Partners of the Health Promotion and Prevention Advisory Council	13
Box 1.2	Priorities for improving cancer care, Lisbon round table for better cancer care	20
Box 1.3	Pan-European actors in cancer information	27
Box 2.1	Steps to planning a smart flash mob	42
Box 2.2	Case study: Promotion of the European Code Against Cancer Poster Competition in Slovenia	45
Box 2.3	Case study: Raising prevention awareness at the National Level in the Czech Republic	49
Box 4.1	European Schools of Screening Management (ESSM) network, senior management team	91

Box 5.1	The Lombardy Cancer Network (ROL)	127
Box 5.2	The Catalanian Institute of Oncology Network (ICO)	128
Box 6.1	Definition of cancer information system	143
Box 6.2	Addressing policy-related obstacles to an ECIS	151
Box 6.3	Spotlight on cancer registries in Greece, Luxembourg and Bulgaria	158
Box 6.4	Overview of Cancer Registration in Europe questionnaire	159
Box 7.1	The cancer research funding landscape in 18 EU Member States	187
Box 7.2	Guiding principles for European coordination of cancer research	188
Box 7.3	INCa's national programme for early-phase therapeutic cancer research/ CLIP ² programme	191

Abbreviations

AC	Associated Countries (plural AC)
ACC	Alliance Against Cancer (Italy)
AIM	International Association of Mutual Benefit Societies
ANCR	Association of Nordic Cancer Registries
BMI	Body mass index
BSE	Breast self-examination
CBE	Clinical breast examination
CCC	Comprehensive Cancer Centres
CDM	Central data management
CEN	European Committee for Standardisation
CI5	Cancer Incidence in Five Continents
CIBER	Biomedical Research Centre Networks (Spain)
CIBERESP	Biomedical Research Centre Network for Epidemiology and Public Health
CLIP	INCa Accredited Centres for Early Phase Clinical Trials
CR	Cancer Registry
CRC	Colorectal cancer
CSiMC	Cancer Screening and Early Detection in Mediterranean Countries
CSISP	Centre for Public Health Research (Spain)
CWA	CEN Workshop Agreement
CWG	Core Working Group
DALY	Disability-adjusted life years
EACS	European Academy of Cancer Sciences
EAPC	European Association for Palliative Care
EAPC RN	European Association for Palliative Care Research Network
EBCSM	EUNICE Breast Cancer Screening Monitoring
ECCA	European Cervical Cancer Association
ECCO	European CanCer Organisation
ECDC	European Centre for Disease Prevention and Control
ECIS	European Cancer Information System
ECL	Association of European Cancer Leagues
ECN	European Cancer Network
ECO	European Cancer Observatory
ECHI	European Community Health Indicators
ECMC	Experimental Cancer Medicine Centre
ECPC	European Cancer Patient Coalition
EET Pipeline	European Embryonal Tumor Pipeline
EHIS	European Health Information Survey

EHMA	European Health Management Association
EIWH	European Institute for Women's Health
ELPA	European Liver Patients Association
EN	European Standard
ENCR	European Network of Cancer Registries
ENSP	European Network for Smoking Prevention
EOHSP	European Observatory on Health Systems and Policies
EONS	European Oncology Nursing Society
EPAAC	European Partnership Action Against Cancer
EPHA	European Public Health Alliance
EPIC	European Prospective Investigation into Cancer and Nutrition
ERA	European Research Area
ERI3 INSERM	Institut National de la Santé et de la Recherche Médicale
ESMO	European Society for Medical Oncology
ESPEN	European Society for Clinical Nutrition and Metabolism
ESSM	European Schools of Screening Management
EUCAN	National estimates at ECO
EUCERD	European Union Committee of Experts on Rare Diseases
EUNICE	European Cancer Information Network
EUREG	Registry data at ECO
EUREGHA	European Regional and Local Health Authorities
EUROCAN	European Platform for Translational Cancer Research
EUROCARE	Survival of cancer patients in Europe
EUROCHIP	European Cancer Health Indicator Project
EUROCIM	Downloadable data at ECO
EUROCOURSE	EUROpe against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research
EURORDIS	European Organisation for Rare Diseases
FAVO	Italian Federation of Volunteer-based Cancer Organisations
FIS	International Ski Federation
FIT	Faecal immunochemical test
FP6/FP7	Sixth and Seventh Framework Programme
FRANCIM	French Network of Cancer Registries
gFOBt	Guaiac Faecal Occult Blood test
GLOBOCAN	Global Burden of Cancer Study
GP	General practitioner
GRELL	Latin Language Registry Group
HAEMACARE	Cancer Registry Based project on Haematologic malignancies
HCR	Hellenic Cancer Registry
HES	Health Examination Surveys
HIS	Health Interview Surveys
HLY	Healthy Life Years
HOPE	European Hospital and Healthcare Federation
HR	High Resolution
HRT	Hormone Replacement Therapy
HTA	Health Technology Assessment

IACR	International Association of Cancer Registries
IAEA	International Atomic Energy Agency
IARC	International Agency for Research on Cancer
ICO	Catalonian Institute of Oncology
ICS	International Classification for Standards
IKNL	Comprehensive Cancer Centre (the Netherlands)
IMI	Innovative Medicine Initiative
INCa	Institut National du Cancer
INRC	National Institute for Research on Cancer (Italy)
INT	Istituto Nazionale dei Tumori
IT	Information technology
IPOS	International Psycho-Oncology Society
ISCIH	Institute of Health Carlos III
ISS	Istituto Superiore di Sanita
IVZ	National Institute of Public Health of the Republic of Slovenia
JA	Joint Action
JRC	Joint Research Centre
LEEP	loop electrosurgical excision procedure
LILT	Italian Cancer League
MAC	MEPs Against Cancer
MCL	Mantle Cell Lymphoma
MEP	Member of the European Parliament
MDT	Multidisciplinary team
NAT	European Union Committee of the Regions
NCCP	National Cancer Control Programme
NCI	National Cancer Institute (USA)
NCR	National Cancer Registry
NCRN	National Cancer Research Network (United Kingdom)
NEN	Netherlands Standardisation Institute
NGO	Non-governmental organisation
NRS	Numerical rating scale
OECD	Organisation for Economic Cooperation and Development
OECI	Organisation of European Cancer Institutes
PARENT	Cross-Border Patient Registries
PET	Positron emission tomographies
PGEU	Pharmaceutical Group of the European Union
PHC	Public Health Care
PM	Particulate matter
POC	Patterns of care
PRC	European Palliative Care Research Centre
PREDICT	Increasing the PaRticipation of the ElDerly in Clinical Trials
PROFILES	Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship
PROM	Patient Recorded Outcome Measure
ProTheTs	Prognostic and therapeutic targets in the Ewing's family of tumors
PSA	Prostate specific antigen

RARECARE	Surveillance of rare cancers in Europe
RCT	Randomised clinical trial
SEER	Surveillance Epidemiology and End Results
SFP	Smokefree Partnership
SHE	Schools for Health in Europe
SIOP	European Society for Paediatric Oncology
SIOPEN-R-NET	International Society of Paediatric Oncology European Neuroblastoma Research Network
SISS	Common information system in the Lombardy Cancer Network
SNHS	Slovene Network of Healthy Schools
SWOT	Strengths, weaknesses, opportunities and threats
TESSy	European Surveillance System
WCRF	World Cancer Research Fund
WG NCCPs	Working Group on National Cancer Control Programmes
WHO	World Health Organization
UEGF	United European Gastroenterology Federation
UEMO	European Union of General Practitioners
UICC	Union for International Cancer Control
UNFPA	United Nations Population Fund
VAZG	Flemish Agency for Health and Care
VP	Virtual Partnership

Foreword

Cancer represents a major burden for patients, health systems and society across the European Union. In 2012 alone, 2.6 million European citizens were newly diagnosed with cancer, and the estimated total number of cancer deaths in the European Union in 2012 was 1.26 million. For over 25 years, the European Commission has contributed towards addressing the cancer challenge and remains committed to working with policymakers as well as experts in support of the Member States in the field of cancer, to better protect the health of European citizens.

Our cancer strategy focuses on clear areas of EU added value. As set out in the Commission Communication on Action against Cancer (2009), we are taking forward the development of guidelines for quality assurance in cancer screening, awareness-raising and prevention as well as facilitating coordination in research and collecting comparable data. These activities represent a concrete contribution by the European Commission to our common goal to tackle this disease more effectively, through information sharing, exchange of expertise and best practice. In support of the Commission strategy, the European Partnership for Action against Cancer Joint Action was launched to stimulate governments, academic and other non-profit organisations to join forces at EU level.

This publication presents the key outcomes of the work in the framework of the European Partnership. The approach of the Partnership is to bring together European stakeholders with a common aim and commitment to reduce cancer, focusing on actions that can be taken at EU level. In three years, with around 140 partners from across Europe, a considerable amount of work has been completed, covering a broad range of activities – from health promotion and cancer prevention to cancer related health care, from screening to research.

Cancer will remain high on the Commission's agenda in the coming years. Our ambitious goal, as set out in the 2009 Communication, is to reduce cancer incidence by 15% by 2020. By engaging relevant stakeholders across the European Union in a collective effort, this publication illustrates the political commitment of the partners and, in this sense, it is also an inspiration and guide for our future work.

I would like to express my gratitude to the Slovenian National Institute of Public Health for its leading role in the coordination of the European Partnership for Action against Cancer, as well as to all the partners for their valuable contributions and for their continuous engagement.

John F. Ryan

*Acting Director,
Public Health, Directorate-General for Health and Consumers,
European Commission*

Preface

The cancer burden in Member States of the European Union has been on the rise for well over 30 years, with further increases expected in light of projected population ageing. Politicians and experts in Europe have long been seeking models to help address this growing public health challenge. In the mid-1980s, the European Commission launched the Europe Against Cancer programme with the ambitious goal of achieving a 15% reduction in the expected number of deaths due to cancer by the year 2000. Although this very ambitious goal was eventually not fully achieved, the programme's contribution to improving cancer indicators and spurring advances in the field was significant. The results of the programme proved that pan-European cooperation brings about added value for cancer control.

Following the conclusion of the Europe Against Cancer programme, many experts, public health workers and policy planners looked for new models or frameworks that could encourage cooperation and partnership in an effort to prepare comprehensive policies and programmes to combat cancer. Several EU cancer control projects were implemented, and important acts were adopted, including the Council Recommendation on Cancer Screening in 2003¹. Given projections that cancer would soon become the leading cause of morbidity and mortality in Europe, it also remained an important issue for EU Member States. Though cancer was an important challenge to health systems in all countries, indicators also demonstrated important inequalities between Member States of the enlarged EU.

In this context, Slovenia took over the half-year Presidency of the Council of the European Union in 2008 (the first to do so among the 12 newcomers that joined the EU in 2004), addressing cancer as the main topic in the field of health. The renewed focus on this issue on the political agenda granted opportunities to intensify efforts in reducing the burden of cancer across Europe. Together with the European Observatory on Health Systems and Policies, the Slovenian Ministry of Health and the National Institute of Public Health organised an ambitious agenda during its semester of Council leadership, including a high-level conference in Brdo under the title, 'The Burden of cancer – How can it

¹ Council of the European Union. Council Recommendation of 2 December 2003 on cancer screening (2003/878/EC). Off J Eur Union 2003;(L 327):34–38.

be reduced?’ This event provided a stage for the launch of the book *Responding to the challenge of cancer in Europe*², and soon after followed a special issue of the *European Journal of Cancer*, devoted to the state of the art of cancer control in Europe³. In 2009, the policy summary *Fighting Against Cancer Today* was released⁴.

The main policymaking institutions of European Union supported this line of action, consecrating cancer control as a major public health priority for the European Union and its Member States. The European Parliament was the first to pass a resolution in April 2008⁵, drawing attention to the rising cancer burden in the enlarged EU-27 and entreating the Commission to take vigorous action to support cancer control. Just two months later, at the Employment, Social Policy, Health and Consumer Affairs Council meeting in Luxembourg, the Council produced its own Conclusions⁶, urging the Commission to take vigorous action in supporting Member States’ efforts to strengthen cancer prevention and care.

On this basis, the European Commission proposed the European Partnership for Action Against Cancer (EPAAC) for the period 2009–2013 (with the main work performed from 2011 to 2013) to support Member States in their efforts to tackle cancer by providing a framework for identifying and sharing information, capacity and expertise in cancer prevention and control and by engaging relevant stakeholders across the EU in a collective effort⁷. The Council reiterated its political support in its *Conclusions on Action Against Cancer*⁸, adopted in 2010 under the Belgian Presidency. It welcomed the Commission’s initiative of setting up a Joint Action to take the Partnership forward and encouraged the active participation of all Member States in the Joint Action.

The work of the Partnership is being co-financed by the EU Health Programme. A general objective is to contribute to reducing the cancer burden in the

2 Coleman MP, Alexe DM, Albrecht T, McKee M, editors. *Responding to the challenge of cancer in Europe*. Institute of Public Health of the Republic of Slovenia: Ljubljana, 2008.

3 Coebergh JW, Albrecht T, editors. *Cancer control in Europe: State of the art in 2008 (Special issue)*. *Eur J Cancer* 2008;44: 1341–1476.

4 Martin-Moreno JM, Harris M, Garcia-Lopez E, Gorgojo L. *Fighting Against Cancer Today: A policy summary*. Institute of Public Health of the Republic of Slovenia: Ljubljana, 2009.

5 European Union: European Parliament, European Parliament resolution on combating cancer in the enlarged European Union, B6-0132/2008 / P6-TA-PROV(2008)0121, [document on the internet]. 2008 [cited 2013 Mar 11]. Available from: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P6-TA-2008-0121+0+DOC+XML+V0//EN>.

6 Council Conclusions on reducing the burden of cancer. Council of the European Union, 2876th Employment, social policy, health and consumer affairs Council meeting, Luxembourg, 10 June 2008.

7 Commission of the European Communities. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the on Action Against Cancer: European Partnership COM(2009) 291 Final. [document on the internet]. 2009 [cited 2013 Jun 15]. Available from: <http://eur-lex.europa.eu/Notice.do?mode=dbl&lang=en&clhmlang=en&clng1=en,en&clng2=bg,cs,da,de,el,en,es,et,fi,fr,hu,it,lt,lv,mt,nl,pl,pt,ro,sk,sl,sv,&val=497223:cs>

8 Council of the European Union. Council conclusions on action against cancer. 3032nd General Affairs Council meeting. Brussels, 13 September 2010. Brussels, Belgium: Press Office of the Council of the European Union; 2010. 5021/09

European Union by actions in the areas of health promotion and prevention, screening and early diagnosis, cancer-related health care, coordination of cancer research, cancer information and data, and National Cancer Control Programmes. The National Institute of Public Health in Slovenia has assumed the challenging role of leader of the EPAAC Joint Action, mobilising 36 associated partners from across Europe and over 100 collaborating partners from around the world.

The European Partnership for Action Against Cancer brings together the efforts of different stakeholders in a joint response to prevent and control cancer. While the Commission had proposed a range of actions, EPAAC partners later outlined concrete actions. The selected examples of cooperation and collaboration featured in this book strengthen the assertion that there is added value when Member States work together to tackle cancer under the coordination and with the support of European institutions, and all stakeholders in the wider cancer community stand to benefit from European collaboration towards the achievement of joint goals.

Marija Magajne

*Acting Director
National Institute of Public Health of the Republic of Slovenia;
Ljubljana, Slovenia*

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Introduction to the present volume

Jose M. Martin-Moreno,^{a,b} Meggan Harris,^{a,c} Tit Albreht^d

This brief introduction will present the basic rationale, scope, aims and structure of the book *Boosting innovation and cooperation in European cancer control: key findings from the European Partnership for Action Against Cancer*. The volume describes a small but significant sample of the innovative activities that have been underway for the past three years under the European banner and will hopefully represent one more foundational stone in our countries' joint efforts to control cancer. We hope that future work is bolstered by both its spirit of cooperation and solidarity as well as by the potential and promise that it chronicles.

Before presenting the book itself, we would like to briefly place it within the context from which it springs. We will broadly examine the role of European institutions in national health systems and how EU authorities exert influence on public health policy, providing a conceptual backdrop to the Partnership's actions in cancer control. Finally, we will frame the present volume within the larger push to expand access to services and raise standards and quality throughout all EU Member States.

Health policy in Europe

In general, health care itself (like the overwhelming majority of social services) is firmly established as a national competency. European authorities cannot impose a particular model of care, interfere in financial arrangements between providers and patients, or dictate what a country's portfolio of health services must include. Yet, the role of European institutions, legislation and priorities – as well as cross-border issues between EU Member States – cannot be overlooked. Article 168 of the Treaty on the Functioning of the European

^a University of Valencia; Valencia, Spain

^b University Clinical Hospital; Valencia, Spain

^c European Observatory on Health Systems and Policies; Brussels, Belgium

^d National Institute of Public Health of the Republic of Slovenia; Ljubljana, Slovenia

Union establishes clear competencies for the European Union in public health matters. EU policy should improve public health, prevent diseases and health threats, and combat major health scourges by promoting research. Community action complements national policies, and the Union encourages cooperation between Member States in the field of health. Through the health strategy, the EU plays an important role in improving public health in Europe, and in so doing provides added value to Member State actions while fully respecting the responsibilities of the Member States for the organisation and delivery of health services and health care. (1)

While the European project began with the principal objective of achieving a common market for shared economic development, it has gradually become clear that no national economy can develop independently of social concerns. The EU must not only try to ensure a level playing field for individual economic competitors (including those in the health industry), it is also concerned with competing globally with the United States, Japan and other innovation-based societies, attracting private investments in research and development to strengthen European universities and centres of excellence and provide high-paying jobs for its top professionals. Likewise, it is interested in raising and lengthening the productivity of the European workforce and ensuring the sustainability of government services. In all of these matters, public health stands out as an essential driver of economic activity as well as a guarantor of social and political stability.

At the same time, the European vision of solidarity depends on the effective and equitable provision of social services throughout the territory. The freedom of movement principle, which applies to goods, services and people, has broad implications for health care, as it requires a certain floor to be established with regards to quality, safety and standards. The *Directive on the application of patients' rights in cross-border healthcare* (2) consolidates EU policy for residents who seek health care outside their home country's borders, but it creates new dilemmas for European institutions in terms of enforcement and guarantees for citizens, and for individual Member States with regard to administration, legislation and the allocation of resources. The directive increases the need to produce European standards, quality requirements and evaluation tools (such as quality assurance schemes), with important implications for both medical goods (drugs and medical devices) and services (clinical practice and professional training). The management of rare diseases and the creation of cross-border cooperative initiatives to address them efficiently has also been a hot topic of discussion, as these examples of European added value strengthen the European Union's legitimacy and bring important benefits to its citizens.

Thus, there are multiple factors which exert pressure on the EU to make inroads into social competencies in the form of setting norms, regulations and standards. However, binding directives and regulations that incur on national sovereignty usually meet resistance from Member States and the EU legislative chambers that represent them, so European institutions rely on soft law such as recommendations and communications as well as other leverage-creating instruments including grants, projects, policy dialogues, forums, platforms and – more recently – European pilot quality assurance schemes, to advance the priorities set by the Council through its rotating presidency. These policies, exemplifying the EU's commitment to the values of solidarity, participation and excellence, have an important role in capacity building among NGOs, citizen platforms, investigators and other issue-driven groups. They help to shape national policy agendas by setting priorities for the EU as a whole, supporting studies to draw attention to disparities between Member States and highlighting best practices. In contrast to the inevitable complexities surrounding the formulation of EU legislation on health matters, governments, NGOs, health advocates, professional associations and patients universally welcome the provision of funding for priority areas.

This EU action also helps, in a practical way, to reconcile the divergence between the principal European legislative and political agenda (which remains focused on the economy) and the objectives and values laid out in subsequent European treaties and documents, including the Charter of Fundamental Rights (3). It also encourages coordination in areas where multiplication of efforts could be avoided, for instance in the development of health care guidelines. Perhaps just as importantly, European initiatives such as these reach out to both experts and policymakers, providing pro-active knowledge-brokering pathways that help to transfer best practice and innovative policies to other regions and countries in the EU.

European institutions have thus carved an important and irreplaceable niche for the EU in health competencies through programmes that include the Health Strategy 2008–2013, the EU Health Programmes of 2008–2013 and 2014–2020, and the Horizon 2020 programme, and through recommendations and guidelines, for example on cancer screening and on different issues related to major chronic diseases. The EU has also spearheaded more specific health-related initiatives, for example on rare cancers (Rarecarenet and EUCERD), health professional networks (CANCON) and healthy ageing (European Innovation Partnership on Active and Healthy Ageing), among many others. In many of these areas, Member States may not be required to *act*, but they are compelled to *reflect*, and this activity in and of itself draws attention to a given issue.

Shining the European spotlight on cancer: the European Partnership for Action Against Cancer

The European Partnership for Action Against Cancer (EPAAC) is one of many examples of EU-led action in public health and in cancer control. While the launch was publicly applauded, the Partnership was privately seen with some apprehension among the cancer research and integrated care community. On the one hand, there was concern that the EU would be unable to really devote the necessary resources towards funding something of this scale and to invest the political will to ensure its success, not only in the short and medium term, but also in the long term. After all, past projects, including Europe Against Cancer, had been allowed to expire despite huge success in lowering cancer risk and mortality (the programme, which ran from 1987 to 2000, was credited with the avoidance of nearly 100,000 cancer deaths [4]). On the other hand, and most positively, the launch of EPAAC also spurred a good deal of enthusiasm and hope among cancer control advocates, who saw a clear opportunity for expanding European action.

The final budget allocated to the project was approximately 6.3€ million (with just half of that coming directly from Executive Agency for Health and Consumers). The amount was a drop in the bucket given the great need for concerted action in the field, but enough to fund a few valuable pilot programmes that might plant the seed for future work to be carried out by Member States and other stakeholders. The underlying idea was to create a real partnership, catalysing the collective energy of everyone by generating mechanisms to facilitate synergies between and among different groups.

Delivering innovation: scope, aims and structure of the EPAAC book

The conceptual foundation of the current volume was conceived to help address the communication challenges inherent to all projects of the size and scope of EPAAC. This book will complement the comprehensive reports released by each project area (most of which will be available online) in order to showcase the valuable, ongoing work in cancer control. The themes we have aimed to develop – innovation and cooperation – represent the defining strengths of European cancer research and policy, and everything from the chosen topics to the narrative style answer to those criteria. In this exercise, innovation is understood to mean the practical and novel application of evidence-based programmes to solve the specific challenges associated with cancer control at the policy level.

Challenging the leaders of each thematic area to home in on one or two activities of outstanding value, we have sought to create an editorial format that deepens, rather than broadens, readers' understanding of this endeavour. Authors were asked to tell the firsthand story of these activities, allowing EPAAC's European added value to shine through the voices of a wide range of participants who have invested their time, skills and passion to this cause, from professionals to policymakers to patients. These individuals have been tireless in their dedication and commitment to finding common solutions to the hydra-headed problem of cancer, and so this book also serves to give them prominence as champions of a struggle that affects us all.

The narrative approach we have taken also answers to one of the intrinsic qualities that define innovation: the scientific exploration of uncharted territory, where existing evidence may act as a guide, but never a map, to progress that is still unfolding. The activities showcased in this book have, as yet, few concrete results to report; they were chosen not because of their proven impact on the challenges facing cancer control at a European level, but because they show promise and reason for optimism in the face of a public health problem of immeasurable proportions.

Needless to say, the approach we have taken – expansive rather than concise, selective rather than comprehensive, and emphasizing ongoing projects rather than completed activities – is not apt for reflecting all of the many and varied actions carried out under the wider EPAAC umbrella. The book is neither a comprehensive report of all the EPAAC activities, nor a collection of studies sharing the rigorous evidence gained from the experience. The full reports, to be disseminated upon completion of EPAAC, will fulfil that function, providing a complete account of all work performed and including the close participation of all partners whose work has helped to make EPAAC such a round success. Moreover, many of the specific developments generated through EPAAC will be disseminated in other formats, especially in scientific and specialised journals. In that regard, the EPAAC Editorial Board has taken exploratory steps to identify potential topics, and has pledged to support efforts to generate additional publications on the work done during the Joint Action.

However, we believe that the lack of evidence presented is not a reflection on the value of the activities. Innovation is, by definition, somewhat untested, and a certain induction period is required in order to observe the impact and evolution of actions implemented over time. Thus, this book 'only' aims to provide a unique and frank account of the unfolding learning processes underway, taking a snapshot of the dynamic and innovative work made possible by EPAAC. By highlighting specific examples of innovation and cooperation, we want to illustrate the added value that European action gives

to cancer control initiatives and generate ideas on synergetic collaboration that are feasible on a practical level.

Our book includes one chapter for each main topic area. Authors were urged to recount their groups' activities in the first person, in the hopes that a journalistic style would serve to document the valuable work being carried out. Although better cancer control in Europe is logically foremost in our mind as the ultimate goal of our work, this book is really about the Partnership itself: the dedicated participants who have made it what it is and the potential it illustrates in terms of establishing an institutional framework to foster cooperation among Member States and other stakeholders.

Indeed, we believe that EPAAC has tried to capture the best of what the EU has to offer Member States and citizens in this field. Initiatives such as this one have a unique role in bringing together a critical mass capable of tackling problems – such as rare tumours – that few Member States can handle on their own. Moreover, the diversity of approaches in dealing with a common challenge – a defining quality of European policies on most every issue – can only be exploited by drawing from all of those experiences in order to formulate innovative, collective policies capable of addressing complex, evolving problems. EPAAC has enabled this process in the field of cancer control, resulting in a promising array of initiatives targeted to improving prevention and care for millions of citizens. We are proud to have had the privilege of taking part and convinced that our work can make a difference.

Given the importance that cancer has to European public health, we hope to draw in a diverse readership, including national and European policymakers, health professionals, citizens and patients. Without the proactive coordination and collaboration of all of these groups, the work described would not have been possible. Perhaps more important, without their concerted efforts, the fight against cancer in Europe will be destined to fail. To underline the relevance of EPAAC to all corners of society, we have included specific sections explaining the impact that its activities will have on Member States, patients, and other stakeholders in the cancer community.

We would also like to thank and explicitly recognise the praiseworthy efforts put forth by the authors who contributed to this volume, under severe time pressure and juggling a range of other professional commitments. It is a testament to their passion, enthusiasm and good will that this book was able to be produced at all. Our editorial team imposed considerable challenges on authors, starting with the imperative to choose only one or two topics out of a plethora of worthy activities to write about but also a timetable that allowed scant time to draft the text and revise it with the range of partners and collaborators

who participated in the activities, and a deadline that impeded authors from reporting the final results of their sub-projects. Yet, despite these limitations and the natural misgivings they gave rise to, we saw little reluctance to take on the challenge. On the contrary, the positive momentum generated from the start ended up motivating us, making the production of this book a truly satisfying and rewarding endeavour. Although it was not without the inevitable setbacks and complexities, these were met – almost without exception – with constructive suggestions on how to overcome them, generating a collective spirit of teamwork that made even the biggest challenges more manageable.

Ultimately, the commendable work carried out to produce this book is just one more in an abundance of arguments that support the continuation of the EPAAC spirit through other publications and synergetic partnerships between European stakeholders. The innovations presented in this book promise real progress in efforts to control cancer, but the results will be contingent on the follow-up and continued support provided by the European Commission, Member States and institutional partners. This point is especially important to emphasize in the context of the current financial crisis, which has strapped coffers both public and private to sometimes difficult extremes. It would be all too easy to allow the positive momentum generated over the past several years to fade, pointing to the work already carried out as evidence of European solidarity and commitment to public health. Yet, as this book illustrates through the stories of activities that are very much still *in medias res*, true solidarity is not measured by past accomplishments, but by steadfast and intelligent support for the long term. The Commission, Member States and other institutions must carefully examine the value of the sub-projects carried out under EPAAC, committing to continued action where this could bring clear benefits to health systems and patients.

If any public health challenge deserves such consistent and resolute support, it is cancer. Difficult to prevent and expensive to treat, cancer remains a wicked problem for most health systems, with no silver bullet, secret formula or magic solution on the horizon. Progress will be slow and painstaking, with missteps, obstacles and false hopes. Even as we take two steps forward in one area, we may fall back one in another (5).

However, Europe does collectively have the tools, resources and expertise to make clear and measurable progress (6), also through resource-saving activities coordinated by the Commission in the areas of competence (Art. 168 of the Treaties). Ground-breaking examples include the running activities on cancer registries and the development of guidelines, where the Commission (and the Joint Research Centre in particular) supports and works to add a European dimension to these instruments. EPAAC is an example of how this progress

looks. Although the European Union (as the embodiment of true political, economic and cultural unity) remains an incomplete project, precariously balanced upon shifting sands and subject to changing winds, it is still the last, best hope for progress for millions of citizens both within and outside its borders. Despite the hardships of recent times, and the disagreements of all times, this is true in the economic sphere, and it is true in the social sphere. We hope that the present volume provides a glimmer of what is possible when European minds meet to pursue a common goal, as we hope to continue this valuable work in the future.

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Chapter 1

Joint Action European Partnership for Action Against Cancer – EPAAC

Sandra Radoš Krnel,^a Tit Albreht,^a Jose M. Martin-Moreno^{b,c}

Structure and rationale of EPAAC

EPAAC is organised around five vertical and two horizontal topic areas, identified as important for the Joint Action in an advance consultation process. The vertical elements (health promotion and prevention; screening and early detection; health care; data and information; and research) encompass the entire span of cancer control and care. Two further horizontal topics were identified as cohesive: dissemination and National Cancer Control Programmes (NCCPs). Dissemination is essential to achieve the broader objectives of a Joint Action, in particular those of reaching out to patients and the general public. On the other hand, NCCPs organise all the relevant resources at the national level in order to improve cancer care and cancer control.

General objectives of the Joint Action and the timeline

In its communication laying out the objectives of EPAAC (COM [2009] 291final), the European Commission called for all Member States to have developed an NCCP by EPAAC's conclusion in 2013, as part of a push to achieve a 15% reduction in cancer incidence by 2020. NCCPs are public health programmes designed to ensure the centrally managed implementation and monitoring of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research. As an integrated

^a National Institute of Public Health of the Republic of Slovenia; Ljubljana, Slovenia

^b University of Valencia; Valencia, Spain

^c University Clinical Hospital; Valencia, Spain

approach that seeks innovative solutions to challenges associated with care pathways, continuity of care and multidisciplinary teams, NCCPs are increasingly seen as essential to optimising resource use, reducing the number of cancer cases and deaths, and improving quality of life for cancer patients.

While some EU Member States have extensive experience in NCCPs, having achieved substantial drops in incidence and mortality in their populations, other countries have only recently recognised the enormity of the cancer burden and its implications. This situation has led to stark inequalities throughout the European Community – differences which run contrary to the core principle of European solidarity and equality. Embodying the conviction that the EU's true added value lies in empowering Member States to help each other, EPAAC was conceived as a framework for identifying and sharing information, capacity and expertise in cancer prevention and control, in order to avoid scattered actions and the duplication of efforts. The partnership involved a wide range of stakeholders, all with concrete experiences and expertise to enrich the evidence base. It included medical and scientific research institutions with strong methodological development and production of assessments, industry representatives and non-governmental patient coalitions from all corners of the continent.

The main objective was to assist countries in developing NCCPs, but specific supportive activities were carried out in each vertical area:

- *Health promotion and prevention:* The European Week Against Cancer was revitalised to capitalise on proven strategies for communicating the European Code Against Cancer, a set of simple, evidence-based messages for cancer prevention. Work targeted specific groups, including young people, through a youth communication competition and social media.
- *Screening and early diagnosis:* Work focused on recommendations made by the Council of the EU, aiming to alleviate key barriers to screening access, increase quality and integrate programmes with other areas of early detection (e.g., health checks).
- *Health care:* Innovative network approaches were used to foster the exchange of best practices and develop consensual clinical guidelines for care.
- *Research:* Diverse stakeholders were engaged to achieve coordination of one third of research from all funding sources by 2013 in selected areas of cancer research.
- *Data and information:* Cancer information databases were mapped, and possibilities for constructing an information-sharing platform were explored.

EPAAC target groups

EPAAC was conceived to aid three principal target groups. The most direct target group comprises Member States, governmental and key non-governmental organisations, with EPAAC's main activities (e.g., formulation of clinical guidelines or access to cancer information) carried out to explicitly support these actors' missions. Secondly, scientific societies and professional associations stand to benefit directly from the facilitated exchange of best practices and expertise. In turn, these two groups serve European cancer patients and citizens, who, thanks to EPAAC, can expect better access to preventive services, treatment centres, therapies, palliative care and psycho-oncological support.

Methodology

Methodology varied depending on the specific objective, but in general, a major strength of the initiative lay in the added value of a European project. For many of the mapping and survey exercises, especially those contingent on high stakeholder participation, EU support was a decisive factor in determining a high response volume. Likewise, project leaders were able to fully utilize existing resources that already had the European brand, such as the European Week Against Cancer, and to enlist the active support of a broad range of European experts in the given subject areas. The diversity and quantity of stakeholder participants also guaranteed that work was carried out using the best existing evidence, from Europe and the world.

Project outcomes: a preliminary appraisal

Perhaps the most tangible outcome of the Joint Action has been the development – initially considered implausible or even impossible – of a National Cancer Control Programme in every EU Member State. Many of these plans will need adjustments down the line, but the very fact that they exist is an important victory for patients and cancer control advocates throughout the region because they mandate the establishment or strengthening of basic structures needed for cancer control (such as cancer registries) and create a mechanism for accountability.

Other outcomes are perhaps not as easily or immediately discernible, but they are no less important. Chief among these is the contribution that EPAAC has made towards maintaining cancer high on the list of priorities for European health systems. The continued dichotomy between European and Member State competencies in the area of public health means that EU action is largely ancillary to national or sub-national programmes; however, the EU role is by no means marginal. The indirect power exercised – either intentionally or as

a by-product – by Framework programmes, comparative or EU wide studies, Council recommendations, policy events and other similar initiatives, should not be underestimated. In many cases over the course of EPAAC, we found that simply asking Member States to participate was enough to spark new action on a pending challenge. This singular power resides in the peculiar combination of competition and cooperation found in nearly all European projects, resulting in a clear added value. The fact that cancer is high on the European agenda bolsters its place on Member State agendas, meaning that even relatively modest investments can bring significant returns.

Health Promotion and Prevention

Cancer prevention has the potential to reduce incidence by at least 33%, making it one of the most cost-effective, long-term strategies for cancer control. Yet, the challenge in realising the potential for prevention – especially among key risk groups – is one that has plagued health systems for years. The team charged with leading the Partnership's work on Health Promotion and Prevention engaged European, national and local policymakers as well as cancer leagues and other dedicated partners in the joint effort to raise cancer prevention awareness and to reduce exposure to cancer risk factors. The centrepiece of this area of work was to relaunch the European Week Against Cancer and to convey the health promotion messages from the European Code Against Cancer (see Chapter 2 for a full description of activities). The Association of European Cancer Leagues (ECL) took the lead role, enlisting the help of partners such as the MEPs Against Cancer (MAC) to maximise resource use and reach as many Europeans as possible.

Scheduled to coincide with World No Tobacco Day on 31 May, the European Week Against Cancer has been reenergised as a vehicle to carry health promotion messages to the public. In the previous edition of the European Week Against Cancer, each year was dedicated to a specific theme. It was decided that for this new edition no theme or set of themes would be assigned, since leagues and other Advisory Council members had perceived this as an imposition, and the countries and leagues preferred to set their own themes in line with their strategies and goals.

Revitalising this successful initiative, which has enhanced name recognition and collaborative partnerships, has created positive momentum once again, most particularly among the ECL member leagues, which are expected to include the European Week Against Cancer as a permanent part of their annual workplans.

Objective 1

Raise awareness on EPAAC's cancer prevention activities and enlist support from cancer societies, policymakers and pan-European partners.

An Advisory Council (Box 1.1) discussed potential methods of measuring prevention awareness and behavioural changes at a population level and decided

Box 1.1 Associated and Collaborating Partners of the Health Promotion and Prevention Advisory Council

Associated Partners

Italian Ministry of Health	Irish Cancer Society
Italian Cancer League (LILT)	Pharmaceutical Group of the European Union (PGEU)

Collaborating Partners

American Cancer Society
 Belgian Cancer Centre
 European Union Committee of the Regions (NAT)
 ECL Executive Board and other Member Leagues
 Eurocare
 Euromelanoma
 European Cancer Patient Coalition (ECPC)
 European Cervical Cancer Association (ECCA)
 European Institute for Women's Health (EIWH)
 European Network for Smoking Prevention (ENSP)
 European Liver Patients Association (ELPA)
 European Public Health Alliance (EPHA)
 Garnier International
 International Agency for Research on Cancer (IARC)
 International Association of Mutual Benefit Societies (AIM)
 Lynn's Bowel Cancer Campaign
 MEPs Against Cancer (MAC)
 National Centre of Public Health Protection, Bulgaria
 Novartis
 Organisation of European Cancer Institutes (OECI)
 Pfizer
 Smokefree Partnership (SFP)
 The Health Promotion Foundation, Poland
 Union for International Cancer Control (UICC)
 United European Gastroenterology Federation (UEGF)
 VitalOptions
 WHO Regional Office for Europe
 World Cancer Research Fund International

on themes related to the European Code Against Cancer to promote during the European Week Against Cancer.

These discussions were followed by activities directly related to formulating a communication strategy: a literature review and web search were carried out in February 2011 to identify existing campaign materials related to the European Code Against Cancer and the European Week Against Cancer, and a survey was created to gather information and expertise from cancer leagues and organisations with similar missions. The survey collected feedback on what areas of prevention require the most awareness-building efforts and recommended providing a baseline measurement of cancer prevention awareness on organisational websites.

Objective 2

Relaunch the European Week Against Cancer, to take place in May of each year to coincide with World No Tobacco Day, and to promote prevention-related themes, engaging policymakers at the European, national and sub-national levels.

A two-day conference opened the European Week Against Cancer, bringing in policymakers, experts and health advocates as well as patients and citizens, to discuss the best ways to disseminate prevention messages to different target populations.

Objective 3

Provide adaptable media templates and toolkits for use in Member States, using optimised versions of existing instruments such as the European Code Against Cancer

Members of the Advisory Council provided information and sources for a Cancer Prevention Toolkit, made available online towards the end of the Partnership.

Objective 4

Target vulnerable population groups, such as women, young people and Roma populations

Among the Advisory Council's tasks was the consideration of how to reach vulnerable groups. Strategies developed included the use of digital platforms (internet and social media) to reach young people and a focus on issues especially relevant to women, such as tobacco use and lung cancer. The social

media campaign *I'm a Fan of Life* was developed and launched to reach out to young people with cancer prevention messages.

Objective 5

Engage ECL leagues, partners and other networks to widely disseminate tools and other deliverables

The activities were based on a collaborative and inclusive approach, with regular communication regarding the development and dissemination of toolkits and other related products.

Three editions of the European Week Against Cancer will inform a final report on perception and self-reported behaviour change of Europeans. The report will also include recommendations on the future of the European Week Against Cancer and/or other cancer prevention campaign activities. The Cancer Prevention Toolkit will constitute the other main deliverable; both the report and the Toolkit will be disseminated through traditional and social media as well as cancer league websites.

Dissemination of the Joint Action

A Virtual Partnership (VP) is the hub of all dissemination efforts in the Joint Action. Flexible and interactive, the website dedicated to this end includes different layers of access and sections dedicated to specific target groups. The web-based communication strategy has allowed printed materials to be kept to a minimum, effectively enhancing their importance and impact. Moreover, the website has acted as a natural complement to other dissemination channels, including social media outlets, events and conferences, which are promoted via the EPAAC page.

Organisational structure of the Virtual Partnership

The VP was conceived with two purposes in mind: first, to facilitate synergies and communication among the hundreds of professionals working within EPAAC itself, and secondly, to engage patients and the public in its activities.

The inner level of the VP, accessible only to members of the EPAAC Joint Action consortium, is pivotal for all internal communications. It provides a platform to share and edit administrative, financial and technical documents and update other EPAAC participants on project activities. Members can access the agendas, reports and presentations for Open Forum meetings as well as other conferences and events, and use the site tools to create a dedicated and

password-protected space to manage each project individually. All in all, the VP has been a vehicle for transparency and communication within the Joint Action.

The outer level, on the other hand, is concerned with all other stakeholders, including the general public and the media. It provides overviews of all project goals and activities, as well as a platform to disseminate important documents and milestones. The interactive format invites questions and comments, and includes links to social media connected to the Joint Action, including Facebook, Twitter and YouTube. Furthermore, the website has specific sections for selected groups with targeted material and information:

- *Stakeholders (policymakers, cancer experts, academia, civil society, health care professionals, industry/patient/international health organisations)*: The stakeholder section includes recommendations arising from Open Forums, with specific implications and guidelines for policy and legislation. Health care professionals can see guidelines on diagnoses, screening and other cancer-related information.
- *Citizens*: The public can access information and statistics on cancer in Europe as compared to the rest of the world, see EU actions in the field of cancer health care and follow links to portals with related content. It also has general information on prevention, screening and symptoms of specific cancers, and is enabled to share content on social media sites.
- *Media*: Media training materials linked to Open Forum workshops and press releases are available online, while online media events such as webinars can be hosted as well.

The website is administered by the Partnership Communications Team, consisting of the project leader and three operational staff members (two communications officers and one information technology manager). These professionals work with project leaders to create and post content, interface with the press and other interested parties, and monitor web operations and comments before publication. In addition, the Editorial Board (made up of project leaders, health care and communications professionals and representatives of the European Commission) oversees activities, approving important decisions related to communication before dissemination via the web.

Other dissemination channels

Alongside the VP portal, engagement with the general public has been actively pursued online using social media and offline through traditional media outlets

and events. Social media strategies, described in full in Chapter 3, have included the development of an online game for social media, with prizes and celebrity endorsements, while more conventional products include official reports and conferences as well as engagement with broadcast and print media, including in anticipation of and following the EPAAC Open Forums.

Dissemination results

Throughout the course of the Joint Action, online dissemination efforts were monitored to judge impact by way of regular partner dissemination activity reports. Partner evaluations of the VP (both internal and open section) have been used to improve dissemination (i.e., organising VP educational activities, improving open VP organisation, etc.).

The online social media campaign *I'm a fan of life* was developed and executed as part of the Joint Action, putting into practice some of the latest concepts in promotion of health content and combining online social media, serious gaming and celebrity endorsement. This campaign created significant visibility for EPAAC and the European Code Against Cancer in online social media.

Screening and early diagnosis

Calling for the alleviation of key barriers to screening, the improvement of quality, and the extension of programmes to all populations that could potentially benefit, the Council Recommendation on Cancer Screening put cancer high on the political agenda and was a strong impulse to European action in this area. This Council recommendation aimed to reduce differences in screening in order to achieve a similar reduction of cancer-specific mortality in all Member States by establishing general principles of best practice for cancer screening as recommended by the Advisory Committee on Cancer Prevention.

To take advantage of this momentum, European and national partners in screening activities (including the International Agency for Research on Cancer (IARC), the European Science Advisory Network for Health, European Network for Health Technology Assessment, and with the European Cancer Network (ECN) for screening and prevention) initiated several actions to build capacity, increase quality and expand access to cancer screening programmes. A network of European Schools of Screening Management (ESSM), with the unprecedented mission of delivering an intensive, comprehensive course based on a common European curriculum for screening, was initiated as a pilot programme. A study on screening compliance and inequalities was also performed, drawing from scientific literature but also surveys that gathered

primary data from national and regional screening managers; this led to an exchange of experiences with the object of improving implementation across different populations. Experience from the Netherlands in developing quality criteria in routine health checks was also used, providing the basis for collaborative work with other Member States in establishing pan-European criteria.

Objective 1

To establish an intensive comprehensive training course in management of cancer screening programmes

Work began with an audit carried out by experts from the European Cancer Network on a recently established population-based cervical screening programme in Kielce, Poland. Auditors assessed implementation of the EU guidelines for quality assurance in cervical cancer screening, identifying areas in need of strengthening. Their findings helped to inform the subsequent development of the pilot course on implementation of such programmes, including a common curriculum that covers the entire screening process, from invitation to follow-up and diagnosis. The curriculum, formulated by ECN experts and the EPAAC project leaders, drew from both formal education courses, such as university post-graduate training on screening evaluation and international courses on cancer epidemiology and cancer registration organised by IARC, as well as experience in the implementation of population-based cancer screening programmes (see Chapter 4 for an in-depth look at the ESSM activities).

Objective 2

To identify inequalities in cancer screening programmes

The Centre for Public Health Research (CSISP) in Valencia, Spain, took the lead role in designing a short, open-ended survey on inequalities in cancer screening. Drawing from an initial literature review and report to identify the most important factors associated with these inequalities, the survey then gathered input from one or two national or regional screening managers from each European country, identified by ECN and the European Regional and Local Health Authorities (EUREGHA). Results were discussed with EPAAC leaders in screening and NCCPs with the object of formulating recommendations on reducing screening inequalities.

Objective 3

To facilitate expert advice to regions seeking to implement or improve cancer screening programmes

EUREGHA, and more specifically the Northwest England Health Office, the Flemish Agency for Health and Care (VAZG) and the Veneto Region of Italy, organised three successive workshops on screening programme implementation and quality improvement. Experts from national and regional population-based cancer programmes and ECN experts met to exchange best practices and discuss methods of raising awareness and overcoming obstacles to implementation, integrating CSISP work into the proceedings. Work was cumulative, building on previous findings within the Partnership and establishing a clear pathway for progress. Likewise, a EUREGHA working group, originally created to support the Joint Action, will also constitute a vehicle to take work into the future, meeting once a year in part of an effort to broaden the cooperation with and among the members.

Objective 4

To develop a pan-European consensus on quality criteria for health checks

EPAAC aimed to combine national expertise with European instruments to reach consensus on an initial set of quality criteria for health checks, aimed mainly at providers of the health checks and policymakers, in order to learn what defines a responsible health check service and to improve services accordingly. Quality criteria for health checks will also help consumers to make informed choices. The project did not aim to discuss or replace the criteria used to guide the health checks that are already regulated nor population-based screening programmes in the EU.

Ongoing work by the Netherlands Standardisation Institute (NEN) provided a solid basis for further improvements by the EPAAC project team, which was led by NEN and the Dutch Ministry of Health but included experts from several other Member States, including the United Kingdom, Ireland, Belgium and Germany. These representatives prepared a European Committee for Standardisation Workshop and drafted a Workshop Agreement, a flexible, efficient alternative to the traditional European Standard. The result was a consensus document on basic quality criteria that should be met by any health check, agreed on by all participating Member States.

Health care

Inequality in cancer care remains a persistent challenge in all countries, both

Box 1.2 Priorities for improving cancer care, Lisbon round table for better cancer care

Rapid access to diagnostics

Multidisciplinary care

Coordination of cancer care throughout the process from diagnosis to therapy, including palliative care

Provision of psychosocial care services

Consideration of patient preferences and use of evidence-based clinical guidelines

Concentration of diagnostic and therapeutic procedures of low frequency or high complexity in units with adequate caseload and audited results

Evaluation of outcomes

those with poor overall outcomes as well as the countries with highly developed cancer programmes, which struggle to extend access to the best available treatment to all populations. The Lisbon Round Table for better cancer care identified the pillars of quality cancer services (Box 1.2), and there are examples of good practices aligned with these elements at different levels of EU health services. However, the basic challenge faced by health systems is how to replicate or adapt successful programmes in new settings, often with fewer resources or greater geographic dispersion than in the original context. A Joint Action was seen as the best way to capture European innovation, extending the best practices to underserved populations.

The Partnership's aims in the area of health care included producing a comprehensive picture of the cancer care landscape in Europe, with particular attention to areas that could benefit from European added value. These included innovative organisational perspectives (regional networks), rare cancers, paediatric oncology, development and implementation of clinical guidelines, and psychosocial communication and support. Only the areas of regional networks and rare cancers are featured in detail in this book (see Chapter 5). The rest of the activities and their objectives are summarised below.

Objective 1

To identify best practices in European health services, promoting innovative network approaches to exchange experiences

The first objective was achieved by means of several activities. First of all, innovative network approaches were explored, first through a literature review and a mapping exercise of existing regional networks and then through the

celebration of a workshop, where 30 published experts and representatives of scientific societies assessed which organisational models constituted the most practical and effective approaches to cancer care.

The first specific objective focused on multidisciplinary care, a recognised approach to organising cancer care in a way that consistently brings together all medical specialists involved in cancer diagnosis and treatment (1), in addition to coping with coordination and communication issues associated with the implementation of the European reference networks for rare diseases, as acknowledged by the EU Parliament and the Council (2).

The project team initiated a process based on research and discussion among European stakeholders. First, it carried out a systematic review of the evidence, which showed how multidisciplinary teams resulted in better clinical and process outcomes for cancer patients in terms of survival, reduction of waiting times and quality of life, among other indicators. Secondly, to address the policy approach to multidisciplinary care, a working group comprising key European stakeholders was organised to discuss a background document with a list of 26 core issues drawn from the review. Finally, after wide circulation for consultation and amendments, the working group formulated a unanimous *Policy statement on multidisciplinary cancer care* to define the core elements that all tumour-based multidisciplinary teams should include. The other specific objective – on cancer networks – is dealt with in chapter 5.

The work aiming at improving treatment, symptom assessment and follow-up of palliative care, led by the European Association for Palliative Care Research Network (EAPC RN) and the European Palliative Care Research Centre (PRC) have recently focused on two key symptoms: cancer pain and cancer cachexia (loss of body mass that cannot be reversed nutritionally). Through literature studies, clinical studies and experts meetings, an evidence base and several expert agreements were reached on various aspects regarding classification and assessment of the symptoms, and the development of guidelines for treatment.

Symptom management of pain and cachexia

Regarding classification of cancer pain, four main domains were identified: (a) average pain intensity, (b) neuropathic pain, (c) breakthrough pain and (d) psychological distress. Additionally, it is important to assess pain localisation. Assessment of cancer pain must include an assessment of pain intensity on a 0–10 numerical rating scale, with ‘no pain’ and ‘pain as bad as you can imagine’ as anchor words. Patients are asked to characterise the average intensity of their pain during the last 24 hours or the last week (3), and pain localisation is assessed on a pain body map. At present, usability tests of a digital pain body

map are being conducted. Two Delphi processes are ongoing to reach consensus on how to classify and assess neuropathic pain and breakthrough pain.

Guidelines for treatment of cancer pain were published in *Lancet Oncology* in 2012 (4) and will be updated by 2015. In the updated version, the scope is broadened into 'pain management in patients with cancer'. The process of the update will be performed taking this substantial modification into consideration.

Regarding classification of cancer cachexia, the consensus definition was published in 2011 (5), including the description of cachexia as an ongoing continuum with the following stages: pre-cachexia, cachexia and refractory cachexia (6). Cancer cachexia could be assessed by means of weight loss, body mass index (BMI), and anorexia (reduced food intake).

Guidelines for treatment of cancer cachexia were developed by the European Palliative Care Research Collaboration (www.epcrc.org). These guidelines concern the stage refractory cachexia only. A new version of guidelines is under development, aiming to cover all three stages.

Eir: computer-based symptom management and decision support

Eir is a computerised tool developed by EAPC RN and PRC, which combines the evidence-based strand of knowledge about symptom assessment and classification, evidence-based guidelines and treatment decision support in a standardised system for symptom management within palliative care. The overall aim of Eir is to improve management of patients and symptoms through development of a web-based communication platform for implementation in routine clinical practice. Using Eir in symptom management within palliative care can lead to better symptom management for patients due to the potential for

- enhancing the communication between patient and physician, and between different professional levels in the health care system
- increasing and standardising the use of evidence-based guidelines in daily clinical work
- storing patient data in a safe manner that enables information to follow the patients

Paediatric cancer care guidelines

Other work dealt with disseminating and assessing paediatric cancer care recommendations and standards. Approximately 70 participants, mainly representatives from European paediatric and haematology units, Ministries of Health and parents' organisations, took part in a multi-stakeholder conference in Poland to increase policy awareness on standards of care for paediatric oncology. Discussions, led in conjunction with the European Society for Paediatric Oncology (SIOP), covered a host of issues having to do with improving paediatric oncology, including experiences in EU Member States on available services; organisational issues; national and regional cancer registries; staffing challenges and educational opportunities; core elements for adequate paediatric cancer treatment; social care aspects (including continuous education during treatment); the role of parent and patient organisations in creating European Standards of Care for Children with Cancer; and methods and tools for integrating standards into national guidelines. The Partnership engaged expert stakeholders to forge a consensus on health service standards for paediatric oncology and disseminated these to Member States. In the third year of EPAAC, a survey to Member States was carried out to evaluate implementation of these new standards, using the results of a similar 2008 study by SIOP as a baseline measurement. The results of this comparison are expected in 2013.

Complementary and alternative medicine

Finally, evidence and use of complementary and alternative medicine in cancer was assessed, and criteria for the dissemination of appropriate information were proposed. Experts from a small number of centres with published experience in this field held two meetings on the topic: one to review evidence and design a survey mapping relevant activities in Member States, and another to discuss the implications of the ensuing report. The review of the literature is ongoing, focusing on the following therapies: acupuncture, herbal medicine, homeopathy, homotoxicology and antroposophic medicine. Special attention has been given to the adverse effects and pharmacological interactions with conventional treatment of cancer.

A survey of the European structures and centres providing complementary and alternative medicine within the framework of integrative oncology is ongoing. A questionnaire has been sent to those centres identified using several approaches (web searches, Medline, etc.), with questions about the type of complementary medicine, visits and number of patients, use of therapeutic protocols and evaluation of outcomes (if available). At the time of going to press in July 2013,

30.6% of the 196 centres we contacted had responded. One out of every five centres provides these treatments for cancer patients in countries such as Italy, the United Kingdom, Germany, Switzerland, Austria and France. Preliminary results show that the most frequent therapies are homeopathy (43.7% of responding centres), herbal medicine (43.6%), homotoxicology (15.4%), anthroposophic medicine (15.4%) and acupuncture (6.5%). Other techniques, including meditation, yoga and nutritional advice, are offered in 53.8% of the responding centres. In 59% of the centres surveyed, protocols are used, and in 67%, a system for evaluation of outcomes is in place. The most frequent reason for consultation is to combat pain, nausea, vomiting and other adverse effects of chemotherapy. Quality of life support, psychological support and palliative care were also cited as reasons to seek complementary and alternative medicine.

Objective 2

To develop, review and harmonise the content and implementation of clinical guidelines

European partners focused on two areas in their work on developing clinical guidelines for cancer care: nutrition and rare cancers.

In the field of nutrition, expert panels and a literature review constituted the basis for the first draft of evidence-based nutritional guidelines; the Delphi procedure was used to refine this draft, under the leadership of the European Society for Clinical Nutrition and Metabolism (ESPEN). The guidelines arising from the work will be disseminated to European cancer centres.

In the field of rare cancers, a survey was performed to map existing networks of rare tumours and patient groups, and a workshop was held to review current clinical practice and gauge the existing consensus among practitioners. Clinical leaders from leading European cancer organisations (the European Society for Medical Oncology (ESMO), the European CanCer Organisation (ECCO) and the French Institut National du Cancer (INCa), as well as representatives from the European Cancer Patient Coalition (ECPC), discussed opportunities to collaborate on a regular basis, creating web-based tools to guarantee the sustainability of future cooperative links. The underlying goal was to explore the feasibility of the progressive harmonisation of clinical guidelines for rare cancers, an area of considerable potential for Member States given the difficulties in achieving a critical mass for research and clinical practice in tumours that appear very infrequently among the population (see Chapter 5 for more details on this work).

The implementation of clinical guidelines for cancer care was also examined, with a special focus on inequalities. Following a comprehensive literature review

of clinical guideline implementation, evidence was collated and presented at a workshop, where the European Oncology Nursing Society (EONS) and the European Health Management Association (EHMA) met with EPAAC project leaders to discuss the results and their implications. Their findings were published in a report on implementing clinical guidelines in cancer care with a focus on addressing health inequalities.

This report informed the next stage of EPAAC work on the subject: the development of a guide for effective implementation of clinical guidelines and self-assessment tool for organisations, based on the US model of guidelines for cancer symptom management for nurses. In partnership with the American team, EONS developed guidelines and assessment toolkits for better implementation of clinical guidelines in European settings. The tools were piloted in three countries and refined based on the experiences and challenges encountered, resulting in an evidence-based guide on the effective implementation of clinical guidelines in cancer care.

Objective 3

To implement a training strategy to improve psychosocial and communication skills among health care providers

A number of partner organisations, including the International Psycho-Oncology Society (IPOS), the Catalonian Institute of Oncology (ICO), and ECPC, contributed to a mapping exercise (carried out by means of a web-based survey to national health ministries' representatives in EPAAC) on health system resources in psychosocial oncology care, communication skills among health care professionals and psycho-oncology training activities, as well as the existing gaps in need versus capacity. The results indicate that in 20 of the 26 countries that answered the survey, psychosocial oncology care is included in the NCCP, but only 10 have a budget for it; it is mainly provided under a hospital budget (15 out of 26 respondents) or through charities/NGOs (15 out of 26 respondents), and mainly delivered in general or university hospitals and cancer centres by psychologists (n=26), social workers (n=21), pastors (n=21) and psychiatrists (n=19).

Twenty-one countries refer to having training resources for communication skills, but this training is only included in medical education in 17 countries, and only 5 countries have an official certification for psychosocial oncology care. Specific training needs in that area were identified by 18 countries, while 17 reported communication skills training needs. We conclude that although many countries seem to have integrated psychosocial oncology care in their NCCP, there is still much to do in terms of allocating resources and delivering

the care equitably. Also, there is a need for improving communication skills for health care professionals, as well as integrating psychosocial oncology care into health care policies, including through the establishment of certification and the use of existing clinical guidelines.

Based on these findings, EPAAC and IPOS experts designed a pilot educational programme, to be tested and delivered as a training workshop for health care professionals in a low-resource, high-needs context. Romania was selected as a setting for this pilot training. Tools were developed to optimise communication skills and psychosocial care among caretakers, and a report on the outcomes was produced by the main partners involved (IPOS and ICO).

Information and Data

In cancer control, information and data are invaluable resources for researchers, health professionals and policymakers. Although these collectives can generally see the potential advantages in the cross-border exchange of cancer data, achieving this goal is by no means a straightforward enterprise. Cancer registries, the main repository of data, vary widely in terms of geographical coverage and data quality. European initiatives, such as EUROCARE and EUROCOURSE, have insufficient links to each other and to national databases. Moreover, data holders may be reluctant to release data due to privacy concerns, intellectual property rights or other reasons. The road towards an integrated and comprehensive European Cancer Information System (ECIS) seems to be quite long and vulnerable to certain setbacks. Yet, the potential benefit to Member States, cancer patients and cancer research makes the endeavour a clear and pressing necessity.

To address this need, EPAAC brought together national and regional governmental institutions, cancer registries, research institutes, international institutes, European networks, patient associations, media and citizen representatives to review data collection and analysis as well as information dissemination. Work prioritised areas with the most critical deficiencies, and the project team mapped the cancer information panorama and formulated a strategy to take work forward until 2020.

See Chapter 6 for a full description of EPAAC activities on cancer data and information.

Objective 1

To map the main sources of cancer data in Europe and to identify the priority topics to be supported by the Partnership

Cancer registries are the cornerstone of cancer data in Europe, and they have been coordinated since 1989 within the European Network of Cancer Registries (ENCR). However, while extremely valuable, registries do not comprehensively include all relevant population data. Thus, in addition to optimising the use of cancer registry data for pursuing the other Partnership objectives, the team dealing with cancer information mapped other data sources using the indicators from the European Cancer Health Indicator Project (EUROCHIP), including health care infrastructure and services, demographic and socioeconomic data, integrating them with cancer registry data with other sources of information.

Objective 2

To unify cancer burden indicators (incidence, mortality, survival and prevalence) provided by existing European activities on a common platform

Currently, incidence rates from population-based cancer registries data are centralised and regularly published by IARC; survival rates and prevalence data are currently provided by the EUROCARE network, also through connected projects, such as HAEMACARE and RARECARE; and mortality data are available from official death certificates. Little coordination exists in terms of definitions, periods of reference, pace of updating, data sources and methods of analysis, making the cancer data panorama very heterogeneous and difficult to understand at a comprehensive level.

Thus, EPAAC brought together the major pan-European actors (Box 1.3) to standardise data, making it available on the EU web portal and the Partnership website. At the same time, the Istituto Nazionale dei Tumori collaborated with ISS, ENCR, clinical networks, oncological institutes and others to coordinate and compare high-resolution studies between countries.

Objective 3

To create a task force on population-based cancer cost research in Europe

Despite its crucial importance to research and policy, standardised and

Box 1.3 Pan-European actors in cancer information

IARC International Agency for Research on Cancer

ENCR European Network of Cancer Registries

JRC Joint Research Centre - Ispra

INT Fondazione IRCCS 'Istituto Nazionale dei Tumori' – INT

ISS Istituto Superiore di Sanità

comparable data on cancer costs are scarce. Therefore, the Joint Action organised a European level task force to reach a consensus on comparability of available data and on common methodology to collect data on costs associated with cancer. The task force included cancer experts, epidemiologists, health planners and economists from a range of organisations including INT, the Organisation of European Cancer Institutes (OECI), IARC, the French Institute of Health and Medical Research (ERI 3 INSERM), the Italian National Institute for Research on Cancer (INRC), the VEC Foundation and the Organisation for Economic Cooperation and Development (OECD). The group reviewed existing data on cancer costs and formulated methodology to collect comparable data across Europe, paying special attention to analysing the correlation between socioeconomic indicators and cancer outcomes. To this end, they performed a regression analysis and discussed the best deprivation index to estimate cancer survival by social class.

Objective 4

To initiate development of a standardised approach to collection of survivorship data using population-based cancer registries

Focusing on the health and life of cancer survivors beyond the acute diagnosis and treatment phase, survivorship research addresses quality of life of patients, families and caregivers, including health care, social, familial, sexual and emotional aspects. With INT as the focal point, professionals from international and national networks¹ worked together to produce a report on how to make the collection of this data a standard and routine part of follow-up care.

Objective 5

To develop an inventory of statistical methods to analyse population-based cancer data

The establishment of a European network on data analysis would increase European capacity for statistical analysis and pave the way for pan-European datasets, facilitating scientific projections and forecasting for epidemiological cancer indicators. While this work is well established in some Member States, other countries have little experience. Thus, ISS collaborates with ENCR, IARC, INT, the French Network of Cancer Registries (FRANCIM), and the Dutch Comprehensive Cancer Centre (IKNL) in order to formulate an inventory of statistical methods to analyse population-based cancer data.

¹ Including OECI, Alliance Against Cancer (ACC) and representatives from patient organisations (Italian Federation of Volunteer-based Cancer Organisations, or FAVO) and ECPC

Research coordination

Despite the impressive pace of cancer research, translating basic discoveries into new and more effective prevention tools, treatments and diagnostics remains a complex and difficult enterprise, requiring effective organisation, communication and cooperation among all stakeholders. Scientists, clinicians and other health care professionals, health and science policymakers, industry, funding bodies, patients, and society often compete at cross-purposes to advance priorities which should align, resulting in heterogeneous research approaches and confusing financial arrangements among national and local research bodies. Lack of coordination translates into duplication of research efforts, wasting time and resources, and severely limiting European progress in the fight against cancer.

The 2007 Eurocan+Plus project pointed to the challenges endemic to the European cancer research arena, making recommendations to optimise innovation and impact through multidisciplinary and multi-stakeholder collaboration across borders. EPAAC took up the gauntlet, bringing together Member States, Associated Countries, patient organisations, health care professionals, industry and other stakeholders in the cancer research continuum, with the aim of developing a concerted approach to achieve coordination of one third of research from all funding sources by 2013 within selected areas of cancer research.

Objective

To identify and prioritise areas for research coordination and subsequent practical implementation

Like the other project teams in EPAAC, the research project team carried out a variety of activities to achieve several distinct but related goals, but the scope of its work was large enough to cover (or at least attempt to cover) the entirety of the European cancer research continuum. Enormous efforts were expended to simply involve all relevant stakeholders; ECCO took the lead role in the work, but sought increased participation through collaboration among its Associated Partners: INCa, the Istituto Superiore di Sanità (ISS), the Spanish Institute of Health Carlos III (ISCIII), and the Spanish Centre for Public Health Research (CSISP). These partners worked closely together in developing questionnaires, gathering responses, analysing the results, and drawing in a wider network of stakeholders in order to devise methodologies for future coordination with the legitimacy and consensus to truly bear a European stamp.

The first step in the process was obtaining input from the scientific community on areas of cancer research that would benefit from coordination. Feedback

was sought through two questionnaires, which were answered by around 250 experts in total. In parallel, information was requested from cancer research funding organisations on the mechanisms for prioritising, funding and executing cancer research at a national level, as well as on perceived obstacles to coordination, willingness to coordinate with other countries and on current and future priorities in cancer research.

After analysing and consolidating the results, a research forum was held to identify common priorities and propose areas that could benefit from cross-border coordination. This work rested on two main principles: first, rigorous and practical analysis to identify opportunities for synergies; and second, pro-active engagement of as many Member States, Associated Countries and funders as possible in order to secure the best follow-up and sustainability of pilot projects.

Research bodies and EPAAC leaders then spent the next several months developing a roadmap for the implementation of research coordination, planning pilot projects in selected areas in order to apply their previous findings to real contexts and try to overcome the challenges – including funding challenges – identified. After broad consultation with the widest possible array of stakeholders, the final report was presented, detailing the priorities for future research coordination in Europe and next steps on how to make that coordination a reality.

For a full description of the methodology followed and the results obtained, see Chapter 7.

National Cancer Control Programmes

NCCPs are designed to optimise resource use in order to reduce the number of cancer cases and deaths and improve patient quality of life through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research. These programmes, which are considered the pre-eminent policy strategy to address the rising cancer burden, have been fiercely promoted by international public health organisations, including WHO and IARC, and their development in all EU Member States constitutes the central objective of the Joint Action.

While this goal was deemed ambitious and even unrealistic at the start of the Partnership, by 2013, all but 5 of the 29 countries studied (the 27 Member States in 2009, plus Iceland and Norway) had already adopted their NCCPs. The team specifically dealing with NCCPs gathered information on the basic components of the existing NCCPs, common challenges, design issues and

difficulties in implementation, working to analyse NCCPs in Member States and drawing up common indicators and guidelines to use in their future development and execution. In addition, it provided centralised access to the text of the plans for the first time, including links to the original texts and, in many cases, English translations or an English executive summary, on the EPAAC website.

Objective

To develop European guidelines and common indicators for the development of NCCPs

Work began by circulating a questionnaire on the characteristics of NCCPs in EU Member States, Norway and Iceland. Programmes were analysed based on their adherence to the WHO guidelines for NCCPs, inclusion of structural and process indicators and the self-assessment carried out by Member States. The structure and content of programmes were analysed comparatively, resulting in a consensus report – subjected to multiple rounds of revisions by the Joint Action’s Working Group, Steering Committee and Member State representatives – describing the state of play of these programmes in the EU.

After the conclusion of the Partnership, work on NCCPs will continue. The linchpin of the best NCCPs (those boasting measurable improvements in cancer indicators or with the most complete development), will be extrapolated to create a template detailing the core elements needed in all NCCPs, regardless of how these are adapted at a national level. The resulting guidelines will include approaches to all key areas of cancer management, as well as the modes of introducing the different interventions and the indicators needed to measure progress.

Work was carried out in close collaboration with all relevant partners, including Member States, and organised on three levels. The first dealt with the preparation of the background documents, questionnaires and analyses and was carried out by partners from Belgium, Ireland, Italy, Malta, the Netherlands and Slovenia. The Working Group on NCCPs, including representatives from Member States, Iceland and Norway as well as from the WHO Regional Office for Europe, EUREGHA, and the European Observatory on Health Systems and Policies, took up the work from there, reviewing and completing the information at an organisational level. Finally, the Steering Committee, which was made up of representatives from the European Commission, the Working Group, the EPAAC Steering Committee, IARC, the Observatory, ECPC and industry, as well as independent experts, reviewed all work and adopted the final decisions by consensus.

Synergies between project areas

The different projects, activities and actions that have been co-financed by the European Commission over the past several years cover a very wide range of objectives, scopes and deliverables. Likewise, they are managed in a very different manner, from small, straightforward projects focusing on specific issues to broad joint actions, which involve a diverse group of stakeholders and are designed to support an entire area of public health. While the small projects are characterised by a high degree of connectivity, the bigger projects and actions are very often challenged by their structure and the broad spectrum of objectives, requiring strong expert leadership, clear objectives and an established structure for communication to foster cooperation among participants.

The EPAAC Joint Action, with over 100 collaborating partners and 36 associated partners, clearly pertains to the latter group. From the beginning of EPAAC, the Management Team and the Advisory Board internally supported interconnections and synergies between areas of action that could add value to the initiative. In some cases, these synergies occurred naturally as a result of close linkages between specific actions, while in others they were the result of the enthusiastic involvement of project leaders and partners, or stemmed from the intense collaboration between the Partnership Secretariat, Project Management Team and Advisory Board.

Throughout the course of the Partnership, several synergies were identified between EPAAC sub-projects, including the following:

- *The use of the European Code Against Cancer for promotional strategies, in Dissemination and Health Promotion*
- *Updates to the European Code Against Cancer, by the teams in Health Promotion and Screening*
- *Use of data on cancer trends to help evaluate screening programmes, in the areas of Screening and Information*
- *Collaboration on rare and paediatric cancers, between the Health Care and Information project teams*
- *Joint definition of emerging collaborative research topics, their research base and their methodologies, between the Research and Information teams*
- *Joint definition of cancer outcome indicators for assessing quality of cancer care, between the Research, Information and Health Care teams*
- *Analysis of the relevance of cancer registries in the framework of multidisciplinary cancer care, between the Information and Health Care teams*

In addition, the group dedicated to National Cancer Control Programmes sought the input of all other project leaders in order to formulate comprehensive recommendations on these plans from every area of cancer control.

Other synergies generated over the course of the Partnership are less tangible, though no less important. The administration of EPAAC activities through the Advisory Committee provided a common forum for project leaders and partners to come together. There were opportunities to network, exchange ideas and discuss future projects, as well as to take into account the lessons gained from one area of work in others. These types of exchanges exemplify the advantage that Joint Actions have in comparison to more isolated projects; although the sub-projects can stand alone, their value – and their potential impact – increase when they are organised under a unified framework of action.

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Chapter 2

Rejuvenating the European Week Against Cancer: Working together to spread the word, ‘Cancer is preventable!’

Wendy Yared,^a Kevin O’Hagan,^b Sabrina Paladini,^c Pavel Poc,^d Alojz Peterle,^{d,e} Matic Meglič,^f Tina Lipušček^f, Ana Šinkovec^f

Main messages

- The Association of European Cancer Leagues, in collaboration with many different stakeholders including policymakers and the private sector, relaunched the European Week Against Cancer and renewed dissemination of the European Code Against Cancer.
- Engaging policymakers has been important to give visibility to cancer prevention activities. This was done at the European level via the Members of the European Parliament roundtables and at the national level with European Week Against Cancer official conferences.
- Using social media and offering attractive prizes as incentives have been effective ways to encourage young people to reflect on cancer prevention.
- The implementation of these health promotion and prevention activities was possible thanks to the coordinated support and resources of partner leagues and organisations. Only through continued investments in health promotion and cancer prevention research can governments and society curb the rising costs associated with preventable cancers.

^a Association of European Cancer Leagues; Brussels, Belgium; ^b Irish Cancer Society; Dublin, Ireland; ^c Italian Cancer League; Rome, Italy; ^d Member of the European Parliament (MEP); Brussels, Belgium; ^e MEPs Against Cancer (MAC); Brussels, Belgium; ^f National Institute of Public Health of the Republic of Slovenia; Ljubljana, Slovenia

The panorama of cancer prevention in Europe

The opportunities for cancer prevention at a European level hold much promise, with great potential to make a positive impact on individuals and communities across the continent, as illustrated in the past by the success of the Europe Against Cancer Programme in the 1980s and 90s. One of the goals of EPAAC has been to revive that energy, creating the momentum to continue this important public health mission long after the formal conclusion of this Joint Action. To do so, the Association of European Cancer Leagues (ECL) was charged with leading EPAAC's work on Health Promotion and Prevention, offering a fresh look at the challenges and the possibilities to raise awareness and change behaviours so that collectively, we can prevent cancer in our populations.

Current challenges for cancer prevention and health promotion

Despite the existing evidence and knowledge available to help prevent cancer, a number of challenges hinder effective action, including lack of information and awareness among the general public, inadequate funding for public health programmes, limited evidence to inform policymaking, interference from private industry, and insufficient collaboration among stakeholders.

The first challenge is the misinformation surrounding cancer, evident by the quantity of misleading or erroneous sources found on the internet. Studies conducted by the European Society for Medical Oncology (ESMO) presented in 2012 indicate a need to tackle these kinds of myths, such as the belief that more than 50% of cancers are genetic and unavoidable (1). Some cancer control organisations have taken steps to tackle this problem by alerting the public of misconceptions, with organisational web pages devoted specifically to exposing the myths about cancer (2,3). The Union for International Cancer Control (UICC) dedicated the 2013 World Cancer Day theme to dispelling misconceptions about cancer under the tagline, 'Cancer – did you know?' (4) However, getting the right information to the public is still a challenge.

Funding is also a major issue. Although the European Commission's Citizens' Summary for EPAAC highlighted that 'prevention is the most cost-effective, long-term cancer strategy' (5), and the World Health Organization holds that preventing chronic diseases is 'a vital investment' (6), prevention is still grossly underfunded, constituting only 2–9% of total funding for cancer research (7). Correcting this problem is not as straightforward as simply allocating more resources. European cancer societies, key funders of cancer research, have ascribed the lack of funding in this area to the lack of proposals submitted (personal communications with cancer society CEOs 2011–2014). This gap

may be partly due to the tradition of cancer research, which tends to have a short-term focus, with research grants extending less than five years. This perspective does not accommodate prevention efforts, which may take decades to yield results (8).

Another challenge to the development of effective health promotion policy is the limited evidence available in some areas, for example in the use of taxation or bans to curb obesity. France has imposed a tax on sugary drinks (9), with some early evidence to support the measure's effectiveness (10), but aggressive lobbying stalled similar efforts in New York City (11). In Denmark (the first country to implement a tax on foods with saturated fat), taxes were abolished after just one year. Strong opposition from the food industry cited the loss of Danish business and a negative impact on manufacturing jobs, and these claims could only be countered with preliminary evidence from the field of public health to defend the measures (12,13). By extrapolating conclusions from the long public health fight against tobacco, we can surmise that tax levers will eventually prove an effective contribution to a larger and more comprehensive effort to curb obesity (14), but until then, powerful pressure by vested interests will continue to cloud the debate.

Even when evidence strongly supports public health policy, there is a risk of interference by industry, for example in the areas of tobacco control and – to a lesser degree – sunbed standardisation. In Europe, the tobacco industry has most recently been directing its efforts to derail the revision of the EU Tobacco Products Directive, lobbying strongly against larger warnings, standardised packaging, and other measures. In an attempt to delay the process of this Directive, the tobacco industry flooded the EU with 85,000 responses to the consultation round (15), the highest number of responses for any Directive in EU history. On a lower scale, the indoor tanning industry actively influenced the previous EU Joint Action on Sunbeds led by the Product Safety Enforcement Forum of Europe (Prosafe) (16), while an industry representative also holds the Chair of the technical committee of the European Committee for Standardisation for sunbeds (CEN/TC 412 'Indoor sun exposure services') (17).

However, it should be noted that although industry interference in public health matters is a fact in some cases, this is by no means universally true. There are countless examples of responsible corporate actions to promote health (in EPAAC¹ and elsewhere), which are above reproach in practice and in intent. Even as health advocates try to remove the influence of commercial interests in health policy, we must not exclude industry as a partner in the long term.

¹ Three industry partners have participated in EPAAC's actions on health promotion and prevention, donating unrestricted financial support to help offset the implementation cost of being in the Partnership; see ECL website for details.

Finally, it is worth noting the need for increased collaboration. In general, cancer organisations work on their own rather than in collaboration with others. Even the UICC, a network of cancer control organisations and individuals, provides themes for World Cancer Day to guide members but usually does not collaborate with them jointly on actions. Rather, the Union makes templates and other downloadable resources available on their site for use, and members then provide information back to UICC on how the event was acknowledged in their countries (4).

The EPAAC approach, then, which pivots on collaboration with a wide range of partners across the EU, represents real innovation. Collaborating to achieve common goals eliminates duplication of efforts and costs, and bolsters complementary aims pursued by partners. In this Partnership, ECL has helped to disseminate research and policy findings by OECD and World Cancer Research Fund (WCRF) during its European Week Against Cancer conferences by organising scientific seminars alongside its Official Conferences; by inviting speakers from WCRF and OECD to present at its Official Conferences; and by sharing links and information from these organisations before, during and after the European Week Against Cancer via social media. Involving a range of diverse stakeholders has also allowed us to tap into the broad well of expertise and knowledge available in Europe. Having partners from different organisations, areas of interest, and geographic locations, we believe, increases the likelihood that our actions and information will be accepted and disseminated.

Protecting our future generations through cancer prevention

Studies have concluded that between 33% and 50% of cancers are preventable through behavioural changes alone (18–19). Children and young people are at special risk. Despite advances in medical technology, children today may have a lower life expectancy than their parents due to the obesity epidemic and its associated health risks (20). In part, this is due to the so-called ‘obesogenic environments’ in which they are raised and the contagious nature of social choices such as eating or exercise (21). The National Cancer Institute (USA) attributes as many as 30% of major cancers in the United States to behavioural factors aside from tobacco use, specifically poor diet, physical inactivity and their manifestation in the form of obesity (22).

Since 2007, the European Commission has promoted actions to enhance physical activity levels and promote healthier diets, as set out in the *Strategy for Europe on nutrition, overweight and obesity-related health issues* (23). Children are among the priority groups. In line with this strategy, one of our major focuses within EPAAC has been to reach out to future generations as part of our strategy to empower individuals to take action to prevent cancer.

Spreading the message of cancer prevention: EPAAC activities

The European Week Against Cancer

The original European Week Against Cancer was an annual health promotion campaign widely celebrated in the second week of October. Organised under the Europe Against Cancer programme's first Action Plan 1987–1989, the Week was managed and partly funded by the Commission in collaboration with European cancer control organisations. Cyprus, the Czech Republic, Slovakia and Slovenia were especially active in planning and implementing the first edition, having organised the Week in their own countries even before funding was made available by the European Commission.

In 1999, ECL was charged with planning and organising the Week through its member leagues because they had been coordinating it at a national level since its inception in 1989. Each year, the Week centred around a specific theme, such as tobacco, nutrition, occupational safety and screening. However, celebration of the Week stopped in 2002, as national leagues lost interest in supporting a mandated theme, specific funding from the Commission ceased, and the ECL Secretariat was transformed, moving from Patagonia to Belgium and hiring new staff, resulting in a loss of continuity.

Reviving the Week through EPAAC

On numerous occasions, discussions between the European Commission and European cancer leagues have discussed the idea of reviving the European Week Against Cancer. The Commission also felt that one of main fruits of the previous Europe Against Cancer programme, the European Code Against Cancer had not been given enough visibility and use. Much effort, collaboration between esteemed cancer experts, and funding had led to the development and revision of the Code, yet it was no longer being disseminated at the European level. Thus, as the ECL Board and partners discussed the revitalisation of the Week during EPAAC, communicating the European Code Against Cancer emerged as an important aim. Based on feedback from cancer leagues, it was agreed that no specific theme should be aligned with the Week in order to avoid interfering with the actions of the national leagues.

Engaging partner organisations

The European Partnership Action Against Cancer, as the name implies, hinges on actions carried out in partnership with others. This is especially important

for prevention, since resources are more limited than in other areas, and specific challenges exist which cannot be overcome by isolated measures. At the start of EPAAC, a handful of organisations, mostly regular collaborators of ECL, were approached to join the project. ECL was active from the start in disseminating information related to EPAAC via its monthly newsletter, website, and briefs to other organisations at international meetings. As the word spread, new organisations approached ECL to join its cancer prevention efforts.

European Week Against Cancer 2011 to 2013

In order to relaunch the European Week Against Cancer, the European Cancer Leagues organised Official Conferences for the Week within EPAAC from 2011 to 2013, encouraging countries and other organisations to plan events during 25–31 May each year around cancer prevention messages from the European Code Against Cancer.

The 2011 Official Conference for the revived European Week Against Cancer took place in the EU institutions in Brussels, a location chosen to give international visibility to EPAAC and to the relaunch of the Week. The President of the European Council, Mr Herman Van Rompuy, opened the ceremonies. The themes for the first day of the Conference were those in the European Code Against Cancer, targeting policymakers and the NGO community. The conference on the second day focused on the scientific evidence on the messages of the Code, targeting a more academic audience. The organisation of the 2011 European Week Against Cancer Conference was only possible due to positive cooperation with EPAAC Collaborating Partners, specifically with EUREGHA (European Regional and Local Health Authorities), and with guidance from the Belgian Cancer Centre.

Rome was chosen for the Official Conference in 2012 to coincide with the EPAAC Open Forum. Jointly organised and funded by the Italian Ministry of Health and the Italian Cancer League, the event provided a good opportunity to convene stakeholders from the Italian national health system to work together on the programme of the Week. The League focused its efforts on Healthy Lifestyles to show support for the prevention activities in its regional chapters, while the Ministry of Health provided the venue for the Official Conference, as well as for the EPAAC Open Forum a few weeks later. While the 2011 Official Conference drew media attention due mainly to the participation of President Van Rompuy, the 2012 Official Conference in Rome had wide media coverage (24,25) due to keynotes from Italian celebrities, including the Vice President of the International Olympic Committee Mario Pescante, volleyball star and cancer survivor Giacomo Sintini, and fashion designers Carla Fendi

and Lavinia Biagiotti. Actress Sophia Loren also sent a letter of support, which was presented in the Welcome Session.

In recognition of its EU Presidency and the 50th anniversary of the Irish Cancer Society, Ireland was chosen as the site of the 2013 Official Conference, with themes around Healthy Lifestyles and Tobacco Control. The Irish Cancer Society organised the event, which also served as an important platform in advancing the work and announcing the intention of the Irish Cancer Society to develop its activities in the area of health promotion as part of the Irish Cancer Society's new Strategy Statement 2013–2017, *Towards a future without cancer* (26). Reducing the risk of cancer is one of four goals in the strategy, which commits the society to developing policies and programmes to make people aware that they can reduce their risk of developing some forms of cancer through healthy lifestyles choices.

In order to reach out and engage policymakers and practitioners, it was essential that the conference address current relevant issues. Therefore particular consideration was given to the public health policy context and the advocacy work going on in Ireland and Europe. The Dublin Conference gained much media attention thanks to the Minister for Health James Reilly, a consistent advocate for tobacco control measures. He made the key announcement that Ireland would introduce standard packaging on the eve of the Conference kick-off and ahead of World No Tobacco Day. The announcement generated considerable international media interest, since this measure would make Ireland the first European country to introduce standard packaging.

Smart flash mobs for prevention awareness

Combining elements from the popular 'flash mob' and 'smart mob' phenomena² crystallised during the first Advisory Council meeting of partners as an innovative idea which could engage children and young adults on the subject of cancer prevention. The result was a choreographed, pre-rehearsed dance meant to gain the attention of the general public and inform them of cancer prevention activities during the European Week Against Cancer. Printed information on the European Code Against Cancer was disseminated after the performance, while videos were posted onto YouTube for dissemination through social media outlets.

The first flash mob for the European Week Against Cancer was made up of dancers from the European School of Brussels and took place in 2011 at a public

² The online Oxford dictionary defines a flash mob as 'a public gathering of complete strangers, organised via the Internet or mobile phone, who perform a pointless act and then disperse again' (oxforddictionaries.com). 'Smart mobs' are a closely related concept, defined as a gathering of people with specific similarities for a reason all consider as important, but which does not necessarily involve dancing (27).

Box 2.1 Steps to planning a smart flash mob

1. Find a group of enthusiastic young people committed to helping you with your message. It is helpful but not necessary that they can dance – they will learn!
2. Recruit a choreographer to put the dance movements together and to choose music for the dance.
3. Upload videos of the choreography with music, and disseminate the link for dancers to practise before the event day.
4. Get permission from the authorities to use the space for your event. A flash mob should appear spontaneous, but you don't want the dancers dragged away by the police before it starts. If you will be using copyrighted music, permission may need to be obtained.
5. Remind the flash/smartmobbers why they are doing this – cancer is preventable! Heed the 11 simple messages in the European Code Against Cancer.
6. Have a large banner so that the public knows that the performance is for the European Week Against Cancer on 25–31 May! You can prevent cancer! www.cancercode.eu
7. Post via social media beforehand that there will be a rehearsal one hour prior, at a park or spacious area nearby. Use this opportunity to recruit onlookers to join in.
8. Make sure that the performance is filmed for dissemination via social media.

square in Brussels (Place de l'Albertine). The second flash mob, coordinated by the same school, took place on the Spanish Steps in Rome, the venue of the Official 2012 Conference at the Italian Ministry of Health. The second flash mob was much more successful in reaching our goals of engaging youth and the general public, taking place in a very densely populated part of the city and drawing from the lessons learned in 2011 (Box 2.1). There were also more views and distribution of the 2012 flash mob video on social media; this may have been due to the momentum set in place by actions of the previous year.

Youth Competition

The idea of organising a youth competition came in the second year of the project. The view was that the limited involvement by schools and countries in the flash mob activity of the first year could be improved dramatically. It was unclear whether the flash mob of the first year achieved its goal to reach young people, so partners were consulted to improve youth outreach. The most accepted suggestions included the organisation of contests for young people and the production of content for social media with catchy videos and photos on YouTube and Facebook. Combining these two ideas by organising a competition for young people to create prevention materials in the form of

posters or online videos was adopted as the best potential approach to engage this hard-to-reach population.

Focus group

Planning began with a mini-focus group of eight young people (aged 12–15), who provided feedback and ideas for a youth competition around the themes in the European Code Against Cancer. The ECL staff member hosting the group asked their opinions about incentives to foster participation, possible formats for entries (poster vs. video), ways to achieve viral dissemination via social media, and potential prizes.

With regard to incentives, students agreed that the best way to foster participation was to frame the contest within a school assignment and allow students to submit joint entries with their friends; this would encourage them to research and discuss the issues around cancer. In deciding the best format for competition entries, a long discussion took place on the advantages and disadvantages of posters versus videos, with no clear consensus on which would encourage a wider participation. Finally, prizes considered for the 2012 Youth Competition were iPhones, iPads, iPods, netbooks and digital cameras. The students loved the idea of iPads and other Apple products as prizes (though iPhones were not as appealing), while digital cameras were considered a good prize for a runner-up.

Call for Submissions

Due to the unavailability of partners for a consultation on the final rules, voting procedures and prizes, these were only established in February 2012, delaying the formal call for submissions until the end of that month (extra time was needed for translation into French, Dutch and Italian).

Partners agreed that both posters and videos would be accepted to attract a wider range of ages among contest participants, and they took the advice of the Youth Focus Group, suggesting Apple products as main prizes for teams of up to five members. Information on the competition was announced to all ECL leagues and EPAAC partners via email and on the ECL website and social media platforms. Emails inviting young people, classes and students to participate were sent to dozens of headmasters of international schools across Europe, Scoutmasters and umbrella NGOs involving youth.

Schools and youth groups learned of the competition in late March or later. The original deadline of mid-April had to be extended to mid-May, with most submissions arriving after the end of April, suggesting that it took 1–2 months for news of the competition to roll out to participating schools. Some countries translated the poster announcements into their own languages, which also took extra time.

Entries

Entries were received by post and email, mostly from Slovenia and Italy. The quality of posters received in the ECL post ranged from primary-school quality to sophisticated, computer-generated images printed on paper. It was delightful to see that the bulk of submissions were artwork produced with traditional media of paints, pencils and ink, mostly from Slovenian classrooms (Box 2.2). Entries received via email were digitally-produced posters and videos, which made up 25% of the total submissions (Figure 2.1). When the competition took place again in 2013, announcements were made earlier than in the previous year, with a dedicated Facebook page (which was not the case in 2012), two factors that contributed to the triplication of the number of entries.

Social media

Unlike traditional media, which broadcasts or prints messages to the masses, social media is interactive, online and mobile. It is also dominated by the presence of young people. A European Commission-funded survey reported that 59% of all 9–16 year olds across Europe have a profile on a social networking site, with little difference between the sexes or socioeconomic status. Older teens tend to use social networking sites more than younger ones, with 77% of 13–16 year olds having a profile on a social networking site, compared to 38% among 9–12 year olds (28).

Cancer leagues, especially those in countries with high internet access rates and social networking connectivity, have been using social media to target youth for years. An especially successful campaign was implemented by the Danish Cancer Society in response to statistics that Denmark was among the countries with the highest skin cancer rates. In the first year of a 10-year sun smart campaign, they targeted sunbed use among young people by launching the campaign ‘Turn Off the Sunbed’, including a video featuring a Danish celebrity with a surprise ending. The video went viral, leading to widespread mass media coverage on TV, radio and newspapers (29). In the first month and a half after the launch, the video appeared on 300 global websites, had 1 million views in Denmark and close to 5 million views in other countries. The Danish Cancer Society saw that users of social media started to share information with their network on the dangers of using sunbeds, and lively debates took place.

Given the growing number of young people connecting to social networking sites and the positive experience of cancer leagues and partner organisations with those media, our team decided that the Youth Competition could be an effective way to engage in social media, generating interest for the Competition and raising the visibility of cancer prevention by sharing submissions created by young people after the competition ended (30).

Box 2.2 Case Study: Promotion of the European Code Against Cancer Poster Competition in Slovenia

Colleagues at the National Institute of Public Health of Slovenia used the Slovene Network of Healthy Schools to promote the poster competition. The Slovene Network is part of the Schools for Health in Europe (SHE), an initiative of WHO, EU and the European Commission whose main aim is to positively influence the health and health-related behaviour of school-aged children through holistic approaches. The Network involves 43 countries.

The Slovene Network of Healthy Schools (SNHS) is well connected and well organised. Founded in 1993 with 12 pilot schools, it has since grown to 324 schools throughout Slovenia: 58% of all Slovene primary schools are included, as well 45% of all high schools and 16% of high school dormitories. The Slovene network has dedicated teams at each school, systematic planning, evaluation of tasks, regular meetings with team leaders, theme-driven activities, national meetings of the Slovene Network, and training for teachers and health workers.

While it was important to have a good network in place, the following contributed to the large number of students entering the competition:

Motivation of Regional Coordinators and Team Leaders of individual schools

Quick preparation of letter for Network of Healthy Schools, since there was a short length of time for the acceptance of submissions

Fast response of EPAAC Communications Team and Secretariat to all enquiries from teachers and schools

Appealing prizes to the students (iPads, iPods, digital cameras)

Steps to engage students successfully through the SNHS:

1. Prepare a letter for the Network of Healthy Schools;
2. Have the regional health institutes (or other recognised authority) forward the letter to regional coordinators;
3. Have that level (the regional coordinators) forward information on the competition to team leaders at individual schools in their region;
4. Team leaders at schools should then pass on information to their fellow teachers; and finally . . .
5. Students receive the information!



Figure 2.1 Winning entry from the 2012 youth poster competition, by Claudio Pavione of Italy

Courtesy of: Association of European Cancer Leagues

The Youth Competition had a slow start, but picked up momentum and eventually helped increase site visits to the ECL and EPAAC websites with information on the Code. In the spirit of collaboration, lessons learned from

activities related to the European Week Against Cancer have also been shared and applied to the design of the *I'm a Fan of Life* online social gaming campaign organised by the EPAAC Dissemination team (see chapter 3); they benefited from ECL's feedback on a variety of elements related to the design of the campaign (whose main target group was also young people).

Raising Awareness on the European Code Against Cancer through the European Week Against Cancer

One reason for reviving the European Week Against Cancer was to create a vehicle to give more visibility to the European Code Against Cancer, a set of 11 straightforward messages to help individuals prevent cancer through simple behavioural changes. Last revised in 2003 (Third Revision), the Code seemed to have been forgotten or misinterpreted over the past decade, and its website looked outdated and neglected in late 2011 (Figure 2.2), with the 'Europe Against Cancer' logo and a 'last updated' year of 2003 for the page. A consultation on the WhoIs internet database³ shows that the original URL was taken over by a new administrator on 31 January 2012 following the relaunch of the Week. The private party who purchased this domain name specialises in spamming (teleworm.us, listed as a 'fake email generator'), and they are using the original Code URL to commercially market products claiming health benefits.

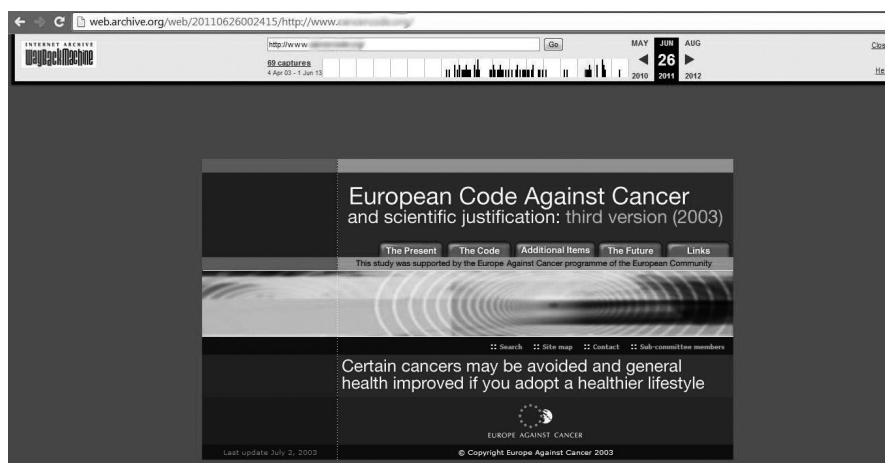


Figure 2.2 Homepage of the CancerCode website as it appeared on 9 October 2011, in its original unchanged form, created during the previous EU-funded Europe Against Cancer programme 'Last update July 2, 2003'.

Source: www.webarchive.org

³ www.whois.net is a database of domain names and provides information on website creation date, buyer, etc.

The owners of the original URL for the Code (an Italian consultancy company) sold the domain name to a private party months after the relaunch of the European Week Against Cancer. The fact that the site had an interested buyer shortly after ECL started communicating the Code is indicative of the new traffic it was picking up, which started after the creation of the Partnership. Our actions generated enough traffic to the Code's website that these marketers found it worthwhile to take over from the original webmasters.

Fortunately, our activities under EPAAC have also had positive repercussions, and coordination to produce an updated Code (fourth revision) is ongoing by IARC. We hope that this new iteration builds onto the momentum enabled by the EPAAC project, engaging an even greater number of health professionals in the dissemination of the Code.

Involving policymakers

Our activities were also supported by the MEPs (Members of the European Parliament) Against Cancer (MAC). The MAC group agreed during one of its planning meetings in 2010 to give priority to prevention issues by aligning itself with the work of ECL within EPAAC. Subsequently, roundtable meetings were held on prevention topics such as alcohol and cancer (December 2010), colorectal cancer screening guidelines (March 2011), introducing EPAAC to the MEPs (November 2011), cancer prevention and complementary and alternative medicine (March 2012), and sunbeds and cancer (December 2012). MAC MEPs were invited to EPAAC meetings, and the President of MAC, Mr Alojz Peterle (former Prime Minister of Slovenia), was invited to be a keynote at the 2011 Open Forum in Madrid and at the 2013 last Open Forum in Ljubljana.

Mr Peterle continuously provided his support to cancer prevention and EPAAC by giving prevention issues and the European Week Against Cancer visibility through several articles for *The Parliament Magazine*. For the 2013 European Week Against Cancer, he encouraged the EPAAC partnership model, stating, 'Cancer needs a comprehensive and holistic approach integrating a diverse list of stakeholders such as insurance companies, unions, educational institutions, family associations, patient associations and pension systems, among others' (31). While Mr Peterle promoted cancer prevention at the European level, others helped raise awareness at the national level (Box 2.3).

Box 2.3 Case study: Raising prevention awareness at the National Level in the Czech Republic

Mr Pavel Poc, Czech MEP, is committed to improving the colorectal cancer screening situation in his country. Mr Poc led the European Colorectal Cancer Days in May 2012 and April 2013 in Brno, Czech Republic, with the aim of disseminating up-to-date knowledge among politicians, experts, patient organisations, national representatives and other stakeholders and discussing the establishment of effective systems for colorectal cancer screening and early detection. In the spirit of EPAAC, these events were organised in partnership with a professional organisation and various international, European and Czech expert societies, patient organisations and civic associations.



1st Conference of the European Colorectal Cancer Days, Brno, 2012

The European Colorectal Cancer Days in 2012 were instrumental in bringing about significant changes in the Czech National Colorectal Screening Programme, leading to the introduction of personal invitations and changes in methodology of diagnostic tests in 2013. The event is becoming a traditional annual open forum for all involved institutions, subjects, experts, decision-makers, patients and individuals from the general public dedicated to raising awareness of colorectal cancer. Organisers are convinced that meetings such as these lead to positive changes in the implementation of CRC screening programme in different countries, driven by cooperation and exchange of experiences.

Gauging the impact of the new European Week Against Cancer on cancer prevention awareness

Although data is not yet available on how this new edition of the European Week Against Cancer has impacted leagues, other organisations and individuals by disseminating prevention information, a number of signs suggest that our actions through the Partnership have brought the visibility of the European Code Against Cancer back to health professionals, policymakers and the general public.

Web traffic is one indicator. As of 2012, the page featuring the Code was the second most visited link on ECL's website, second only to the homepage. Moreover, the European Week Against Cancer was widely covered in traditional and online media (links gathered after the 2012 edition in Rome on the European Week Against Cancer and the European Code Against Cancer filled up 20 pages), a sign of the many citizens that EPAAC was able to reach through those outlets. As hosts of the 2012 and 2013 Official Conferences and organisers of smart flash mobs, national cancer leagues and Member State governments have also collaborated in cancer prevention efforts.

It is also worth noting the special efforts that EPAAC made to reach difficult target populations, particularly young people. With the organisation of the Youth Competition to communicate the Code, we involved schools and youth organisations, key settings for the dissemination of health promotion messages at the local level. By using social networking channels prior to and following the competition, we were able to utilise a form of media frequently used by our target audience.

Lessons to take forward

An important lesson learned is that patience and perseverance are required, since actions take time to pick up momentum. The Second Youth Competition in 2013 had three times as many entries as the Competition in 2012, while hits on the Code's page on the ECL website made it the second-most visited page during the second year of EPAAC. Although these preliminary results are not ironclad evidence of the effectiveness of our work at EPAAC, they do create a forward impetus, hinting at the promise that can be realised if European cooperation in cancer prevention efforts continues.

That said, our work was not without challenges. Having partners with different foci complicated the arrival at any consensus among the Advisory Council. Indeed, the first meeting among all the partners was occupied by long discussions on when the Week should take place. The week coinciding with World Cancer Day (4 February) was rejected since it would interfere

with the themes previously set for that day. October, when many countries celebrate Breast Cancer month, and January, which coincides with Cervical Cancer Prevention Week, were discarded as possibilities for the same reason. Busy months such as September and dormant months over the summer were also excluded. In the end, a consensus finally formed around the end of May, coinciding with World No Tobacco Day. Agreement on the contents of the European Week Against Cancer Toolkit was difficult to reach as well, since some organisations had been using materials whose effectiveness had never been evaluated, while others felt that only information backed up by peer-reviewed evidence should be included. The final compromise consisted of providing links to partner websites, where information for specific areas could be downloaded and used for health promotion activities.

EPAAC also provided a unique testing ground for youth outreach, a relatively untouched area of cancer prevention efforts and one which still needs considerable development. For the competition and flash mob participation, we contacted schools and youth movements (Scouts, Guides, etc.) directly, and we sought the help of member cancer leagues and partner organisations.

Contacting international schools directly did not work well. Dozens of emails were sent and calls made, and personal visits were made to the Headmasters of two of the largest international schools in Belgium and the French Lycée. The lack of action among the schools might have been due to administrative blocks and lack of time to promote these activities. The French Lycée explained that a general assembly of the teachers would have to grant administrative approval, and the Scouts and Guides explained that the second half of the school year was very busy for them with camp and other activities. We learned that schools and youth movements need to be contacted well in advance to allow for administrative processes as well as teacher and scout planning.

Reaching out to young people via our cancer leagues and partner organisations was more successful. Leagues and partner organisations assisted by emailing announcements to their networks and by placing information on their websites regarding the competition and the flash mob. One result of these collaborative efforts by partner organisations included receiving videos of two flash mobs conducted by two Spanish organisations, neither of which was involved in EPAAC nor with ECL. Another result was the greater number of youth competition submissions from Slovenia, Italy, and Portugal, where partner organisations in these countries had well-connected networks with schools and put them to use.

Using YouTube and Facebook to reach young people saw only limited success in 2011. Young people were more engaged in 2012, when the number of

submissions doubled that of the previous year. This may be due to an increased effort to use social media to inform students as well as help from partner organisations in sharing the information within their networks. Building on the momentum started the previous year also played a role.

Since little work of this kind has been done, especially at a European level, we had much to learn. However, our experience will inform future work in health promotion campaigns targeting young people, laying a solid foundation on which to build future programmes.

Looking ahead

Since 2010, ECL has seen a dramatic increase in queries about the Week and interest in becoming a partner in associated activities. In 2010, we had just nine collaborating partners, a number which had tripled by mid-2013, constituting a clear asset in terms of engagement, ideas and enthusiasm. In the three months after the 2012 Official Conference for the Week Against Cancer, there was on average one request per week to join ECL's work.

Moreover, we began to see real engagement at the highest levels of European government during the period of the Partnership 2011–2013, in the form of invitations to important cancer control meetings at the European level, including roundtables at the European Parliament, a meeting of the Consumer Network in standardisation for Member States organised by the European Commission, and non-EU meetings such as the 2012 World Cancer Congress in Montreal, Canada. Prior to the Partnership, ECL mainly received requests to present on its organisation and how it collaborates with cancer societies and other organisations, or on its advocacy activities, but not to talk about prevention. Thus, our coordination of the health promotion and prevention work within EPAAC has reaped clear benefits for us, our members and our partner organisations across Europe.

Conclusions

EPAAC has provided a platform of cooperation for organisations committed to curbing the cancer burden by raising awareness on primary prevention and facilitating a network of experts working towards common goals. The collaboration among stakeholders highlighted the fact that cancer prevention holds relevance for all organisations working in chronic disease prevention, especially for those who aim to raise awareness of the main behavioural risk factors that can lead to cancer (tobacco use, alcohol intake, poor diet and physical inactivity).

Our actions have also demonstrated that there are advantages to working together with others, including increased visibility not only for the coordinating body, but for the work and efforts of all collaborating partners. All partner organisations were consulted in the organisation of Official Conferences for the European Week Against Cancer (as well as for the 2012 EPAAC Open Forum, where one of the two main themes was Health Promotion and Prevention), and all were invited to provide suggestions for topics and speakers; these often came from the partner organisations themselves.

We hope that these activities, implemented under advice and in collaboration with other organisations, may serve as a model of best practice, encouraging other organisations in Europe and elsewhere in the world to work together to identify common resources and minimise duplication of efforts in enhancing cancer control. The engagement of so many partner organisations has certainly increased the visibility of EPAAC, as well as bolstering the strength and authority of organisations whose mission is to spread the message of cancer prevention.

The Association of European Cancer Leagues hopes that the European Commission will remain committed to supporting the European Week Against Cancer as well as other vital public health initiatives, and we look forward to continuing to contribute to better health for all Europeans by securing ample support for health promotion in current and future EU initiatives.

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Chapter 3

Online social media as a tool to improve cancer prevention and health promotion

Matic Meglič,^a Aleš Lamut,^a Ana Šinkovec,^a Wendy Yared^b

Main messages

- Online social media are an important channel to engage target populations in health promotion. Innovative content presentation is, however, required for prevention messages to be noticed by the online population.
- The EPAAC Dissemination team added elements of gaming and celebrity branding components to improve the reach of cancer prevention messages as compared to a generic social media approach. Engagement level and sharing also improved.
- The online social gaming campaign described in this chapter is reusable and transferable to other prevention- and promotion- focused public health interventions.

Introduction

Social media¹ are an increasingly important and widely used channel for sharing health-related information, constituting an innovative way to increase the general public's awareness and understanding of cancer prevention messages. One of the objectives laid out by the European Commission at the launch of EPAAC was to assure the Partnership's presence and visibility in the online

^a National Institute of Public Health of the Republic of Slovenia; Ljubljana, Slovenia; ^b Association of European Cancer Leagues; Brussels, Belgium

¹ Safko, L & Brake, D.K. (2009) write that the term 'social media' refers to activities among people gathered online who share information using conversational media that make it easy to create and share content in the form of words, pictures, videos, and audios (cited by 1).

environment, specifically through the use of online social media such as Facebook, Twitter, YouTube, and LinkedIn. This chapter describes the background, rationale, execution and preliminary results of the activities carried out by the Dissemination team in pursuit of this goal. A full description of all our work – including our support of the EPAAC Health Promotion and Prevention activities – is included in Chapter 1.

The EPAAC dissemination team

Our team was based in the National Institute of Public Health of the Republic of Slovenia and consisted of the team leader, tasked with formulating the overall communication strategy and managing all its activities, two communications experts and one information technology (IT) manager. The communication experts engaged in dissemination on a daily basis and periodically produced deliverables² in support of the Partnership. They also worked closely with the EPAAC project management officer to make sure all relevant information was shared with partners and stakeholders in a timely way. For the online social gaming campaign (see below), the design and implementation were outsourced to a digital marketing company. The IT manager provided support on technical issues related to the website construction and maintenance, infrastructure and specific issues related to the set-up and maintenance of EPAAC online social media channels.

In the spirit of EPAAC, one of the keys to our work has been cooperation with all other teams collaborating in the partnership to collect information, produce bimonthly reports and carry out other dissemination activities to share important news or documents. In the context of online social gaming, we cooperated mainly with the Health Promotion and Prevention team, as its focus was closest to ours.

The visibility of the Partnership was improved by several published journal articles describing the ongoing efforts to tackle cancer. Jelenc and colleagues wrote an article entitled ‘Joint action European partnership for action against cancer’ (2), which describes the objectives and organisational structure of the Partnership. Radoš Krnel and Jelenc, authors of ‘A team fight’ write about the European level cooperation in cancer control (3). Albreht and Jelenc published an article entitled, ‘The current state of national cancer plan policies in the EU countries’ (4), discussing the background and current state of national cancer plan policies based on preliminary survey results. In the article entitled, ‘A woman’s world’ (5), Jelenc and colleagues discuss the impact of women’s cancers in the EU and the European Commission efforts to reduce the burden among European women.

² For example, Gantt chart for project deliverables and milestones overview, dissemination activities chart, etc.

Expanding health promotion efforts through online media: challenges and opportunities for public health

'By understanding how social networks can be used to improve learning, performance, and organisational outcomes, we can use the power of human interaction to improve the human condition.'(6)

Social interaction has been greatly affected by the 'rise of network society' (7)³, increased urbanisation and individualism. Particularly, younger generations in the developed world are facing (and often driving) the transformation of interpersonal communication. Rural villages and urban neighbourhoods, where group interactions generated a community identity (hence a feeling of belonging and peer support) are increasingly being replaced by virtual communication. Online social media channels, supported by ubiquitous wireless and mobile technology, are 'creating new spaces for social cohesion and opening up the potential for youth to access health information wherever they are and whenever they need it' (8). This heavy use of mobile technology and social media tools has led to novel communication platforms that allow users to engage and express themselves from a non-physical location, and 'mixed reality' social experiences have emerged, 'where information and virtual narratives can be superimposed on the real world and real people, blurring the boundaries between the physical and virtual world' (9).

Introduction to social media

'Social media' is an umbrella term for online applications that help people stay constantly connected, mainly through portable internet-enabled devices (e.g., smartphones, tablets and laptops). Indeed, the wider adoption of online social media has been accelerated by rapid improvements in citizens' internet access (10) and mobile technology, leading to the corresponding social networking applications – including health apps (11) – for smart phones. The term 'web 2.0' has been used to label the shift seen in the online environment 'from unidirectional and read-only . . . to multidirectional communication characterized by participation, collaboration, and openness' (12). In online social media – particularly gaming – several factors intersect that favour the involvement of users: (a) the online social network, driving involvement via peer pressure and peer norms; (b) the visual attractiveness and game design of online games; (c) contemporary Western culture of individualism, with increased online presence of youth; and (d) the interpersonal communication shift to the sphere of online media in contrast to physical meeting places.

³ Meaning the influence of the information technology revolution especially from the 1980s on, on changes in the international economy and interpersonal communication.

Today, many private or public enterprises use social media to gain access to a very wide public, with information exchange in almost real time and an enhanced interactive experience. The most widely used platforms include Facebook (social networking), Twitter (micro-blogging), YouTube (video sharing) and LinkedIn (professional use)⁴:

- Facebook, which had nearly a billion users in January 2012 (13), draws in users for an average of 5 hours a month (this figure rises to 8.4 among 15–24 year olds) (14). They can follow their friends' posts and share a large variety of online content. Despite privacy concerns (15), the website has been able to capitalise on its popularity through targeted content sharing and advertising ('promoted content'), which is tailored to user tastes. In the process, it has become a leading worldwide communication channel not just for individual users, but also for companies, public institutions, politicians, and traditional print and broadcast media.
- Twitter created its own online niche by offering a different kind of social networking service, called micro-blogging. Users send and read short messages of up to 140 characters, known as tweets. Multimedia and links can be also added to the message. Reaching the threshold of 500 million users in 2012 (16), Twitter has become a popular way to 'follow' any user virtually, from a friend to a celebrity, in real time, and to disseminate content that traditional media do not or cannot pick up (together with Facebook, Twitter was credited with an instrumental role in advancing the Arab Spring) (17). The use of mechanisms such as the hashtag (#keyphrase) and the 'at' sign (@epaac_ja) help messages get to the interested party more effectively, while 'opinion leaders' and 're-tweets' foster network connectivity through cut-points and reciprocity.
- YouTube is a website for viewing, uploading and sharing videos. Founded in February 2005, YouTube is now available in 56 countries and 61 languages and boasts that '100 hours of video are uploaded to YouTube every minute' (18). A study in early 2013 showed that YouTube is the second 'most popular social media site for teens' after Facebook (19). Most of the content is provided by individuals.
- Finally, LinkedIn is the world's largest online professional network. Launched in 2003, it had reached 200 million users worldwide by January 2013. Connecting professionals with colleagues and companies (as well as second- and third-degree relationships) on the basis of existing or potential professional links, the platform allows users to seek jobs, business

⁴ There are many other online social media channels within different categories of online social media (e.g. Blogs, Micro-Blogs, Social Networks, Video Sharing, Social Bookmarks, Image Sharing, Podcasts). To mention some of them: Flickr, DeviantART, XING, Google+ and tumblr.

opportunities and collaborations with minimal effort and based on existing relationships.

Gamification

What does the term ‘gamification’ mean? The authors of *Gamification by Design*, Zichermann and Cunningham, provide both short and long definitions (20): ‘The process of game-thinking and game mechanics to engage users and solve problems.’ (pg. xiv) and ‘Gamification brings together all the disparate threads that have been advanced in games for non-gaming contexts. In this way, we unite concepts such as serious games, advergaming, and games-for-change into a cohesive worldview that’s informed by the latest research into behavioural psychology and the success of social games’ (pg. xiv). When playing and engaging with different game features, players are expected to be involved and focused on success. Playing the game therefore creates an opportunity to influence the user with the content introduced during the game. This in turn may contribute to changing attitudes, for example regarding particular health-related issues resulting in a potential for behaviour change.

Can social media influence health?

The web 2.0 communication revolution has important implications for public health institutions, which can now deliver customised health-related information to millions of people. In the USA, Thackeray and colleagues (2011, cited by 20) recently found that 60% of state health departments were using at least one social media application. Social media are also being increasingly used by physicians to ‘attend’ their patients online, as well as to create or share medical content (Hughes 2010, cited by 1).

When discussing the impact of social media on behaviour change, however, it is best to be cautious. Physical involvement in community action is probably more influential on individuals than online interaction, and the use of social media for health promotion is a relatively new field that lacks tools to evaluate outcome. Turner and Bruner have shown that people who don’t have a live, physical experience of an event are limited in their capacity to remember it, leading to reduced capacity to change attitudes, values and behaviour (21). Thus, ‘social media should not be viewed as a solution to the complexities of behaviour change and improved health outcomes, though there are certainly applications that can support the change process. Rather, the use of social media in health promotion should be valued for its potential to engage with

audiences for enhanced communication and improved capacity to promote programmes, products, and services' (1).

Online networks have the potential to educate the population on health matters in new ways. The reasons lie in their capacity to disseminate content virally⁵ while simultaneously facilitating social motivation and support, modifying norms (23) and possibly influencing behaviour change. In this aspect, social media offer something unprecedented: direct access to an individual's social network, in real time, and without the need for tedious network enumeration by participants (24). In theory, this kind of access could support an optimal network intervention model where dissemination and social support are linked and synergetic. In fact, recent work has uncovered the 'communicable nature' of behaviours within social networks (25), regardless of physical distance, raising the possibility of creating interventions that could set off a chain reaction that spreads from the 'target' users to their friends, for example by inducing smoking cessation while simultaneously strengthening the social support network needed to create external motivation and reinforce abstinence.

Online public health content generally has a rather conservative, scientific character, and it does not typically motivate people to engage in sharing it, still less to internalising its messages. Most often it is just not as interesting as other topics. Consequently there exists a clear need to reframe the presentation of these messages and make them more appealing. One promising approach is to empower citizens to generate their own content and to create social and celebrity-driven motivation (as in the EU-led *Quit smoking with Barça* (26)).

Gamification may also motivate behavioural changes, a concept which is progressively being introduced in more serious spheres, including health. Together with online social networks, this so-called 'serious gaming' may be one of the approaches with the greatest potential to transform public health, both in prevention and health promotion and in the management of chronic disease, because of its ability to engage patients, and improve compliance with treatments and reduce the rate of attrition. An interesting example of serious gaming is *Azmo the Dragon*, a computer game tied to a meter for forced expiratory flow rate, which is designed to help children with asthma improve their peak flow measurements and perform breathing exercises (27). In recent years, a number of online healthy lifestyle management services have been introduced, focusing on companies offering services to their employees with the aim of improving productivity and claiming reductions in health insurance

⁵ 'By definition, viral comes from the word "virus", which is a medical term used to describe a small infectious agent that can attack all types of organisms. In terms of the Internet, a piece of content can spread just like a virus if people become "infected" when they see it. This result usually comes from evoked emotions that spur the viewer to share it, so they can relate with other people and discuss how they feel' (22). Facebook deems content to be viral based on the following: 'The percentage of people who have created a story from our Page post out of the total number of unique people who have seen it'.

fees. An explanation of combining online social networks and serious gaming for motivating people to stay healthy is available in a short TEDx lecture video online (28).

In short, the opportunities to use social media to improve population awareness of health-related issues – and potentially to change behaviours – appear to comprise a promising area that merits active consideration by public health advocates and health-related organisations.

Bringing cancer prevention to online media through the European Partnership

There is also potential for more effective communication about cancer prevention through online channels. Innovative examples include Cancer Research UK's *Skindividual* (29), an initiative that challenges young United Kingdom citizens to devise the best way to throw a party with skin cancer prevention messages, and *Made In The Shade* (30), which used a well-known photo-sharing site (www.tumblr.com) to support simple online content creation for a sun protection campaign. A YouTube skin cancer awareness campaign posted by the David Cornfield Melanoma Fund of Canada, 'Dear 16-year-old me' (31), achieved viral success almost immediately after it was posted, prompting comments such as 'Wish I saw this years ago. Diagnosed three weeks ago with Melanoma', 'PLEASE don't use a suntan bed – it's dangerous' and 'Let's fight cancer together.' Another example is the Breast Cancer Awareness Facebook page (32), with almost 4 million 'likes'. Gamification has also been tried: Re-mission (33) is one example of a game created to educate and motivate youngsters with cancer.

However, progress by the cancer community in using social media is still modest, and new initiatives are required. In creating the EPAAC strategy for dissemination and communication, we considered various methods to share content and cancer-related information with the population and other stakeholders. With a tight budget and a competitive media landscape, social media emerged as a promising and relatively inexpensive communication channel that could allow the creation of something original that would appeal to different audiences from those reached by traditional media. While much of our work focused on raising the visibility of the EPAAC initiative, we believe the most important contribution we have made was to spread awareness of general cancer-related information. We aimed to demonstrate how social media can be used for this particular purpose, and to explore the limitations of the approach.

EPAAC, online

Online social media and cancer prevention

Our initial activities focused on establishing online social media accounts to expand the flow of information about cancer and EPAAC and to reach additional segments of the professional and general public. Our main objective was to create and disseminate content through online social media profiles (Facebook, Twitter, LinkedIn, YouTube) and to increase the online involvement of the target population.

The campaign was designed to share cancer prevention messages with the target population in a way that might influence lifestyle changes, ultimately helping to decrease the number new cancer cases, as part of the broad EPAAC mission to reduce the burden of cancer. We also coordinated our work with the European Cancer Leagues (ECL), which launched a youth competition and used the most popular social media outlets for this age group – Facebook and YouTube (see chapter 2). We hoped that interactive involvement in prevention information could improve knowledge of cancer prevention among the general public, and that the exchange and acceptance of this information might eventually change attitudes and behaviour. In developing the content of cancer prevention messages, we relied on European Code Against Cancer (34), a source that was already aligned with the EU.

To establish our online identity, we first created new profiles, which we populated with basic information (who we are and what our purpose is; what online resources we follow, etc.). Next we started inviting peers (Facebook), following others (Twitter) and inviting professional peers as connections (LinkedIn) to our profile. We made sure to connect with especially relevant organisations, including ECL, which had pages for the European Week Against Cancer and Youth Competition as part of their EPAAC actions. We set all profiles to be publicly viewable. In Facebook, it is instrumental to have as many friends as possible to allow for a broad base of first-level connections, thus exposing more people to whatever posts are made. This also increases exposure to second-level connections; friends of first-level friends can see all their activity, further broadening the dissemination of those posts.

To facilitate our work, we employed several social media management and analytics tools (Hootsuite, Sharedby and Google Analytics) to manage and automate the process of information distribution in a systematic and time-efficient manner, and to monitor and evaluate our dissemination achievements (e.g., number of ‘likes’, assessment of shared content, etc.). A number of these applications exist with slight differences in functionality; their main purpose is to streamline the processes of publication and content sharing and to provide

oversight of the sources of messages and the channels used to share them. If we needed to post information on an important project issue, we could do so by writing a single message, eliminating the need to copy the message to each of the different profiles individually. Hootsuite (35) was one tool we chose, in part because its dashboard allows several profiles to be open at the same time. This management application allowed us to automate and schedule the posting of messages in different profiles and different media. When searching for cancer-related news feeds, we could structure the order of appearance of messages for the whole day in advance. This saved time and generated an updated and content-rich profile.

Once the online social media profiles were established and the first friends and followers successfully invited, communication officers could start to post and share content. The officer usually began the day by checking daily media and other relevant sources for new cancer-related information. During the course of the project, we built up a comprehensive list of trustworthy health- and cancer-related web sources. We used RSS⁶ feeds extensively, which provided an aggregated stream of new posts from the web pages that we followed within a single application. Based on the short descriptions of new posts on these dedicated web pages, we were able to identify relevant content, review it and post it on EPAAC profiles. Web content needed to be published with caution, balancing message types (e.g., scientific or news articles), narratives (positive vs. negative health outcomes) and sources (e.g. governmental, non-governmental, news magazines and professional cancer associations). This enabled us to provide more diverse cancer-related content and to attract more web traffic.

Some information required different text-editing interventions prior to publication on social media channels. Public web content (magazines, scientific news, etc.) was usually copied and pasted directly into our posts. Sometimes we applied minor changes to the narrative of accompanying text to make it more attractive for the reader. When disseminating project information, the accompanying text (usually a short description of the news) had to be written by the project manager and communication officer. Project news could then be posted together with accompanying text on the EPAAC website and social media profiles.

Besides social media management, regular online community maintenance was also required. This is specifically relevant on LinkedIn and Facebook. For the latter, the management of friendship requests, responses to invitations, friends'

⁶ 'RSS is the acronym used to describe the de facto standard for the syndication of web content. RSS is an XML-based format and while it can be used in different ways for content distribution, its most widespread usage is in distributing news headlines on the web. A web site that wants to allow other sites to publish some of its content creates an RSS document and registers the document with an RSS publisher. A user that can read RSS-distributed content can use the content on a different site. Syndicated content can include data such as news feeds, events listings, news stories, headlines, project updates, excerpts from discussion forums or even corporate information.' (36)

birthday greetings, ‘liking’ other pages, posts, etc., all contributes to an active status and helps to cultivate a broader online social network of followers.

One step further: construction of the I’m a Fan of Life App

Based on experience from previous communication campaigns, we were concerned that the social media approach would not be sufficient to reach the very wide public that we hoped to attract. We judged that the ‘expert’ character and health policy orientation of the EPAAC programme would not be of intrinsic interest to young people. By adding cancer-related content in the format of a game, we aimed to improve the reach of EPAAC in online environments and to bring EPAAC and cancer awareness to a wider circle of internet users. In this effort, we redefined the value chain of our intervention and added a number of elements to improve it: an online game to make the content more interesting, EU celebrity-branded gifts to incentivise citizens to engage and win rewards, and celebrity branding to improve the visibility of our messages and induce online message virality (Figure 3.1).



Figure 3.1 Value chain for online social media campaign

This was achieved by implementing the EPAAC Facebook application *I’m a fan of Life*. Its basic operating principle was that user engagement and information sharing (cross-posting) is action-based, requiring users to share content and accomplishments in the game, thereby exposing our campaign to their peers and supporting the viral spread of messages. By playing the game, the users have also educated themselves about cancer prevention. Motivation was ensured by using basic gamification principles such as fun (game, competition), good cause (health), and prizes (a celebrity-branded, limited edition T-shirt). To provide continuous assessment of the effectiveness and efficiency of our approach, we monitored several parameters, including the simplest indicator of our reach and engagement: the number of people ‘liking’ the EPAAC Facebook page.

Our idea of online social gaming was based on individuals’ action, borrowing its principle from EU-funded Joint Actions that aim to improve relevant population health outcomes on a large scale. With the support of the EPAAC Editorial Board, our team decided to draw the content for the game from the European Code Against Cancer, because they provide a reliable, evidence-based source on cancer prevention.

We discussed several game design ideas to attract young adults, but because of constraints on resources and technology and our limited knowledge of marketing, we outsourced the final design and implementation of the online social gaming application to a digital marketing company, Sonce.net. Our team worked closely with them on two main issues: (a) the design and content of the game and (b) the recruitment of European celebrities to attract young people's participation. Several meetings led to proposals about game dynamics, cancer-related content, giveaways and a list of European celebrities to invite. After incorporating inputs from other project partners (particularly Health Promotion and Prevention team), a final version of the EPAAC Facebook strategy was approved by EPAAC's coordinator and Editorial Board.

We then proceeded to develop the application. Our subcontractor focused on the technical issues for the application's 11 games, while our team prepared cancer-related messages and facts in line with the 11 Cancer Code commandments. We drew cancer-related information from the websites of reliable organisations such as the World Health Organization and the European Commission, and adapted them to make them as positive and affirmative as possible (for example, changing 'When you smoke you have a x % probability of dying from lung cancer' to 'If you stop smoking now, your body will fully recover from tobacco-related consequences in approximately y years.'). The final versions of the accompanying messages and facts to be used in the application were submitted for review to EPAAC team members and medical doctors from the National Public Health Institute of Slovenia (EPAAC lead partner) before final review by the EPAAC Editorial Board.

In order to secure celebrity endorsement and branding, we worked intensely with the Sonce.net team on the first round of contacts. We decided to proceed step by step and to focus on a limited number of celebrities among the 60 initially proposed from different areas (sports, arts, film, music, etc.). The decision about which celebrities to approach first was mainly based on three criteria: first, the extent to which the celebrity is known among young European citizens; second, the degree to which their lifestyle reflects a healthy attitude; and last, the ease with which we could establish initial contact. We contacted the first celebrities via organisations or people who had worked with them previously⁷. Among the first who agreed to cooperate were Alpine ski champion Tina Maze and renowned film director Pedro Almodóvar.

To test our gamification strategy, we decided to start with Tina Maze; she had had considerable media exposure in the 2012/2013 winter season, and sport itself promotes a healthy lifestyle. Additionally, Maze had just released her first

⁷ For example, to reach Tina Maze we contacted the music record company that launched Maze's first music single, 'My Way Is My Decision'.

music single and video, which had achieved over one million views on YouTube in about a month.

Before launching the game on Facebook, we asked the European Commission officer supervising EPAAC to approve the celebrities' names in order to avoid possible conflicts with EU health-related positions. We also had to establish the IT infrastructure, test the functioning of the application, and define the legal terms of use.

What's in the app?

The main goal of the campaign was to promote preventive actions and healthy habits to reduce the risk of acquiring common forms of cancer. Increasing the number of people 'liking' the EPAAC Facebook page was a simple measure to assess the reach of our campaign. Our target group on Facebook consisted of the general population aged 13–65. In particular, we hoped that our campaign would reach young people, cancer survivors and their friends and relatives, who may be more receptive to the campaign messages, as well as health-conscious citizens in general.

The entry point for design of the application was users' point of view and experience. Emphasizing the *action* concept included in the name of the project (EPAAC Joint Action), we aimed to empower Facebook users to be activists who educate themselves on matters of health and encourage their family and friends to do the same. This concept was captured in our slogan, 'You, the voice of health'. In addition, we aimed to create a title for the app that was simple, strong and attractive. The draft version, 'Be the voice of cancer prevention' was discarded by our extended team, which settled on 'I'm a fan of life' as a way to capture the essence of our campaign's message in an original and engaging way (Figure 3.2).

The campaign was designed to last four months, long enough for users to participate not just once but several times. The 'activist' user was faced with a new challenge every week (11 in total) based on the Cancer Code commandments, each in the form of a game. We chose game designs, for example Rebus⁸ (Figure 3.3), that were well known to most people, easy to play but at the same time interesting enough to keep users motivated to continue. Once the player had successfully completed the challenge, he or she would be presented with the full Cancer Code commandment, a short explanation and a positively communicated fact. The players had also the opportunity to click on the internet links which led them to external web sites with trustworthy and attractive health and cancer prevention content.

⁸ A representation of words or syllables by pictures of objects or by symbols whose names resemble the intended words or syllables in sound (www.merriam-webster.com/dictionary/)

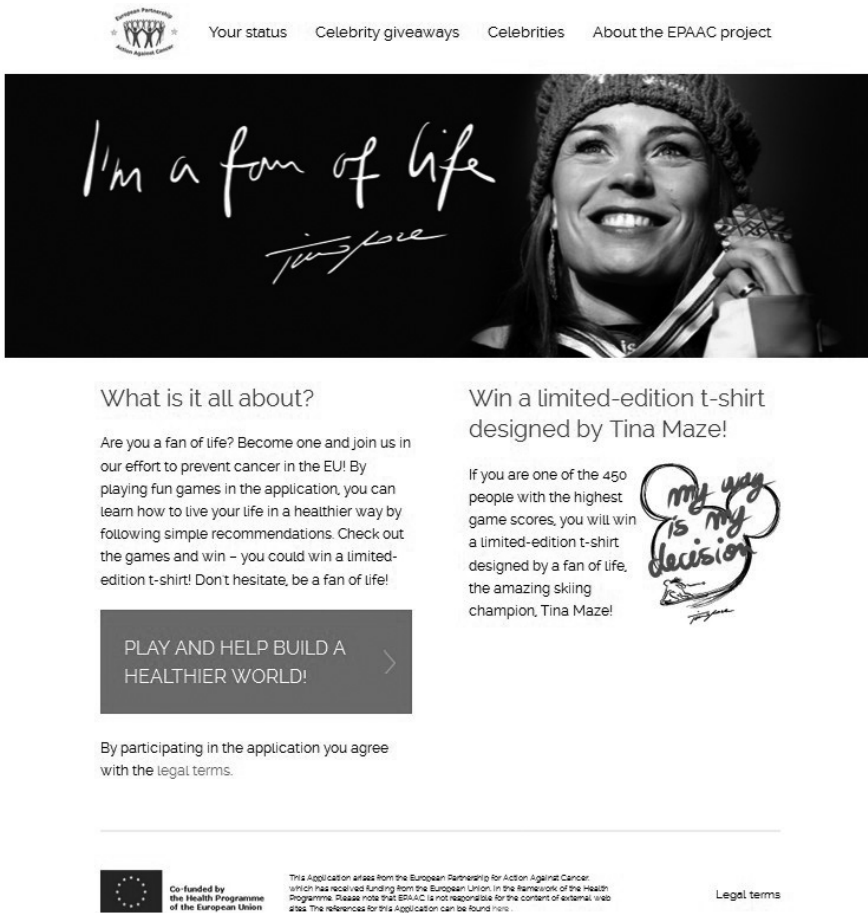


Figure 3.2 *I'm a Fan of Life* Facebook landing page

Source: <https://apps.facebook.com/im-a-fan-of-life/>

In order to increase involvement and promote content sharing, a points system was devised, with incentives in the form of prizes. Solving each of the 11 challenges earned the user 20 points; sharing the game level on their personal Facebook page (their ‘timeline’) gave them another 10, and inviting friends to play brought one additional point per friend. Users finishing all the levels were awarded with 500 extra points. The application had leader-boards with total points across challenges and the player’s current ranking. ‘Liking’ EPAAC’s Facebook page was a prerequisite to enter the application, providing an objective measure of new users as well as ensuring future visibility of EPAAC content on users’ timelines.

After 12 weeks of challenges, prizes were awarded to the winners. Some of our project partners suggested offering technical gadgets such as iPads or iPods

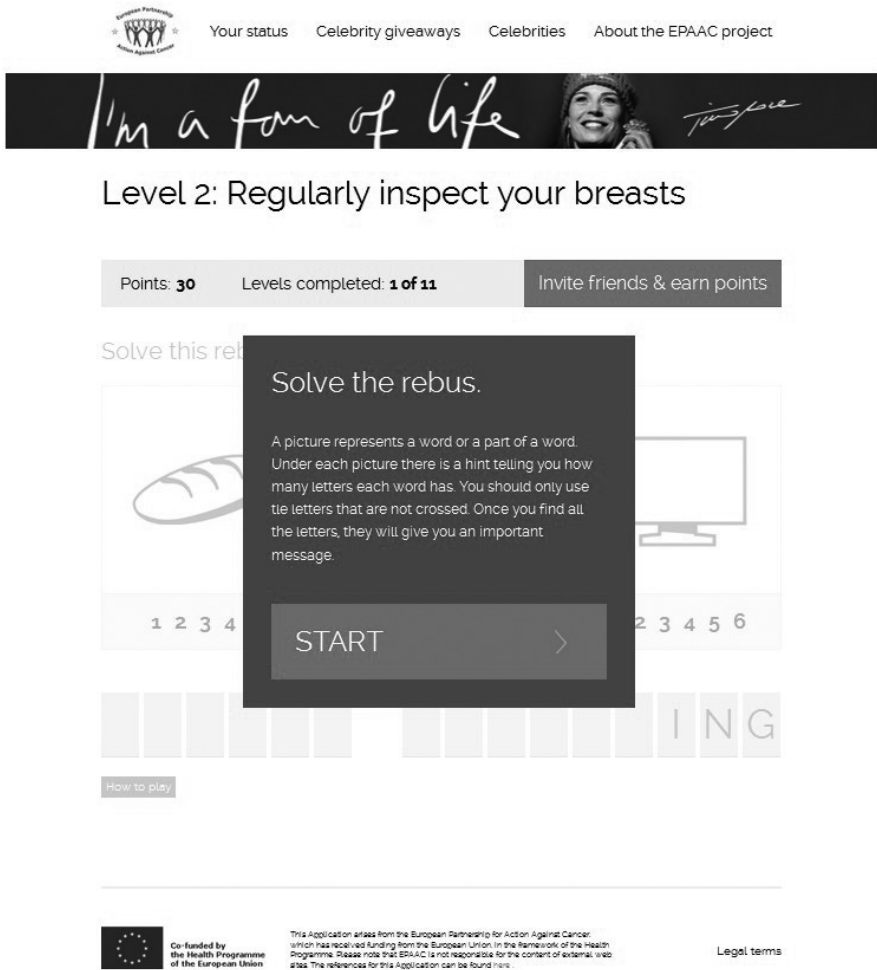


Figure 3.3 Example of a game: Solve the rebus

as prizes, since these had been used to motivate young people during the European Week Against Cancer Youth Poster Competitions in 2012 and 2013⁹ (see chapter 2). However, budget limitations constrained us to only one kind of prize: a limited edition T-shirt, made from high-quality natural fibres, bought through fair trade and sent in a box that could be converted into a cardboard hanger. Tina Maze designed the T-shirt, which included a hand-written slogan and her personal autograph, and the T-shirts were produced and marked with a number from 1 to 500. In all, 449 T-shirts were sent to the final winners, and another 50 were sent to winners selected in draws for the giveaway.

⁹ These campaigns were organised by EPAAC partner working on Health Promotion and Prevention: <http://bit.ly/100EsRb> and <http://bit.ly/11TkgUu>, 13.4.2013.

As part of the celebrity involvement in our campaign, we personally handed over the T-shirt with the number 1/500 to Tina Maze at the International Ski Federation (FIS) Alpine Ski World Championship in Schladming, Austria, in February 2013, a moment that was captured in a promotional video for the campaign. Given the impact of visual imagery on social media campaigns, the video was of paramount importance; to identify Maze's brand with EPAAC more closely, we bought the rights to use her music video 'My way is my decision' and additional skiing pictures from Schladming¹⁰ to use in our campaign.

Dissemination of the campaign

In line with our full dissemination strategy, the Facebook campaign activities were promoted through a variety of other communication channels. We announced the launch of the application via the EPAAC web page (37) as well as on EPAAC Twitter and LinkedIn accounts, and on EPAAC's Facebook page. We regularly posted updates on the Facebook pages of professionals, politicians, and organisations connected to the cancer community. Other social media channels dealing with cancer-related topics were also targeted. The communication officer devoted time every week to identifying appropriate profiles and channels, commenting on their actions and informing them of our campaign.

Because the messages posted on their timeline/page were often hidden or deleted, we changed tactics. The communication officer prepared a short request and promotional text about the campaign and sent it as a private message to administrators of cancer- and health-related organisations with the hope that they would publish it on their Facebook timeline. Additionally, we asked project partners to share the news within their personal and professional networks, as well as with their national media. We also reached out to the European community through web pages related to EU Health (e.g., a web magazine about health published by the European Union) and the EU Health newsletter. Other important updates and activities were carried out on EPAAC's LinkedIn profile to generate connections with potential partners and target groups. Within Facebook, we used targeted advertisements to promote the campaign, a decision that was made based on indications of increased company spending on paid social media ads (38). Implicit in this choice was the acknowledgement of the transformation of social media advertising channels from experimental to mature. Indeed, after running Facebook ads, we noticed a substantial increase of new users of the app all over Europe.

¹⁰ The video is available at: <http://www.youtube.com/watch?v=m1ubcAj36OM>

The impact of effective public health communication

Health promotion and primary disease prevention are cornerstones of public health, and interventions in these areas are designed to produce positive, long-term impacts on the health of citizens. This goal is shared by the EPAAC initiative, which aims to establish public health policies and good practices applicable in Member States and at the EU level. With this in mind, the dissemination activities performed in EPAAC served a number of purposes:

- Application of novel approaches and tools (online social media, gamification) to health promotion and cancer prevention in an EU-wide context;
- Production of an example of good practice that can be reused, adapted and expanded in individual Member States and at the EU level; and
- Evaluation of a practical example of an online communication campaign to discover what works and what doesn't for public health messages in online social media, so that stakeholders and Member States can learn from the experience and tailor their own approaches accordingly.

The EPAAC social media and gaming campaign was designed to have both direct and indirect benefits for citizens, stakeholders, Member States and the EU as a whole. Citizens could benefit directly from improved access to up-to-date health information on cancer prevention and health promotion from a trustworthy source (the European Code against Cancer) that had strong consensus from EU policymakers and experts and was provided through active participation in social media. The EPAAC gaming approach also offered target groups a relatively new experience of receiving – and processing – health information. Indirect benefits for citizens included improved awareness of cancer prevention among the target group. For a more quantitative assessment of the impact of online social gaming on EPAAC, see the analysis and discussion section below.

Member States also had much to gain from this experience. The dissemination campaign gave them the opportunity to learn from an innovative approach, providing all the ingredients necessary to put together a practical toolkit for these kinds of interventions in the future. Direct lessons for Member States include the following:

- How to disseminate public health content online and to engage targeted populations in cancer prevention;
- How to establish online communication and dissemination channels;
- How to improve targeting of particular populations online; and

- How to create additional motivation for engagement of citizens by adding gaming and celebrity elements into the value chain of intervention.

Indirect benefits for Member States will spring from the application of these lessons in the dissemination of other health-related content to European populations.

Our experience can also inform other stakeholders' efforts to advance a variety of health interventions. Health care professionals and institutions, professional organisations, NGOs, and other public health advocates can benefit directly from this practical example of networking and collaboration with different stakeholders in the public and private sectors to build added value for a common goal.

Analysis and discussion

Presence on social media has allowed us to reach additional population segments with cancer information that might not be accessible through web pages and print media. Most social media users tend to be young or middle-aged, whereas website visitors and print media readers tend to be somewhat older. When a project aims to inform, discuss or educate, it must engage younger generations – whether professionals or the public; these individuals are often the main generators of new ideas and social pressure for change, including in the field of cancer policy.

Content on Facebook usually supports more relaxed, casual communication. In that sense, news about cancer or cancer-related Joint Action activities might not be as tempting for the average user as other media news or personal stories. Although we can always try to post information that is itself attractive (e.g., new research breakthroughs or advice on how to lead a healthy lifestyle), the number of people engaging with the content remains low if no additional methods such as gamification or co-branding are applied. As observed in EPAAC, not all project partners and professionals are necessarily social media users. This limits the potential for network growth.

Today, the internet is an important source for health information, but citizens are increasingly confronted with an avalanche of misleading and market-driven health information, from promotions of food supplements, alcohol and fast food to dubious medication and treatment methods. Thus, the visibility of messages about prevention in a fiercely competitive social media space is an important challenge. We need to continue developing expertise in social media and gamification to move to the forefront in this field and to develop higher visibility in these channels. In this regard, the concept of sharing cancer

prevention messages using gamification strategies is one that can probably be generalised to other fields of public health.

In this section, we present preliminary data on the impact that our online social gaming campaign has had on EPAAC’s visibility and engagement with the public and a strengths, weaknesses, opportunities and threats (SWOT) analysis of the EPAAC online social gaming campaign.

Preliminary results of the online social gaming campaign

In order to assess the impact of our gaming campaign on the online visibility of EPAAC and cancer prevention messages, we conducted a preliminary analysis on the use of our EPAAC Facebook page, comparing basic Facebook-derived indicators (‘likes’, reach, talking about this) before and after the launch of the campaign (on 22 March 2013). Before the launch of the game, the page had accumulated 166 ‘likes’; by 22 June this figure had increased to 16,828 ‘likes’ and remained the same till 29 July 2013, when it was last checked.

There was no substantial gender change in the demographic profile of people who ‘liked’ our page before and after the launch of the gaming application (Figures 3.4 and 3.5). Before and after the launch of the campaign, females predominantly liked our Facebook page (around 57%) with males following (around 42%). There are some indications that young, well-educated women are more likely to spend time seeking health-related information, including online or through social media (39–41), and this could explain the higher proportion of females who ‘liked’ our page in both time periods. Research revealed that in recent years, women have begun to play online social games more than men (42,43).

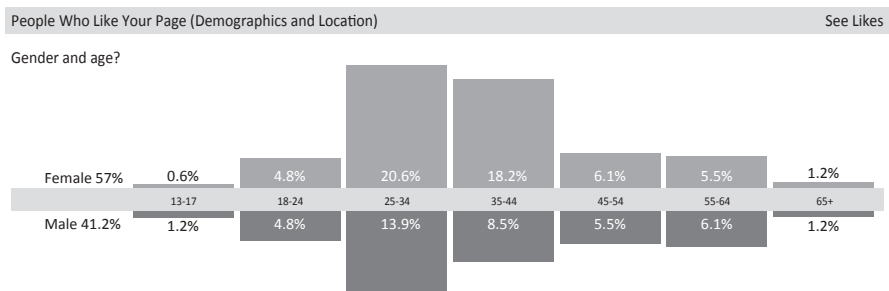


Figure 3.4 Diachronic evolution of Facebook ‘likes’ from 1 Jan 2013 to 21 March 2013 (N=166 ‘likes’)

Note: The percentages of people who ‘liked’ our page for each age and gender bracket is based on the data people enter in their Timeline. Percentages may not add up to 100 because not all Facebook users specify their gender or age.

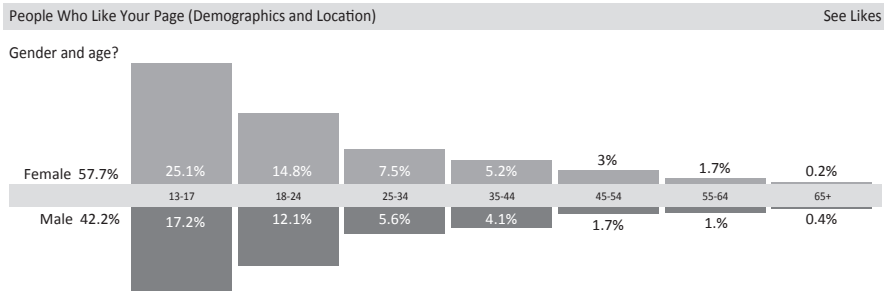


Figure 3.5 Diachronic evolution of Facebook ‘likes’ from 22 March 2013 to 22 June 2013 (N=16,828 ‘likes’)

The age structure of users ‘liking’ our page changed substantially after the launch (Figure 3.5), attributable also to the targeting of Facebook ads described below. Before, middle-aged users (25–34 and 35–44 years old) were the most frequent users ‘liking’ our page. After the launch, the younger age groups (13–17 and 18–24 years old) gained more prominence. Roughly 70% of all ‘likes’ in this period came from these two age groups. This is in line also with the above-mentioned gaming factor, which attracts more young people. Our results show clear potential to use gamification strategies to reach young people with health-related messages.

Accessing the cumulative data on the geographic distribution of our page ‘likes’, we also noted a shift after the the launch of the application. Before, there were 32 users living in Slovenia, 17 in Belgium, 13 in Italy, 7 in the US, 6 in both Portugal and Spain and 5 in the Netherlands. Afterwards, the vast majority of ‘likes’ came from users living in Romania (n=7,420), Italy (n=2,479), followed by Portugal (n=1,815), Bulgaria (n=1,555), Slovenia (n=709), Poland (n=569), Hungary (n=401), Lithuania (n=256), Spain (n=182), the United Kingdom (n=171), Slovakia (n=161), France (n=151) and Germany (n=128). Based on these figures, we assume that the gaming campaign contributed to a more heterogeneous geographical distribution of European users who ‘liked’ our page.

The relatively strong representation of Slovenian users could stem from the fact that our team was based in Slovenia, and we promoted the app extensively via our own online social networks; also, Tina Maze is Slovenian with a huge Slovenian fan base. Likewise, the huge discrepancy between the number of ‘likes’ coming from Romania and Italy as compared to other countries may be explained by the promotional procedures of Facebook ads. With a tight budget for these kinds of promotions (approximately 6000 Euros), we positioned the ads in the Facebook environment of countries that we speculated would

have the most interest in the campaign. For example, ads were extensively placed on Facebook in Italy after informal sources suggested that Italians were traditionally quite motivated to play games and join campaigns in return for giveaways. Possibly there are some cultural similarities with Romanian users driving their motivation to join the campaign.

The online channels where the ‘likes’ came from¹¹ reveal the importance of Facebook ads. The scant amount of ‘likes’ in the period before the launch came mainly from 10 visitors clicking on the ‘like’ button on EPAAC’s Facebook page, 9 people accessing it from their own or someone else’s Facebook timeline, and another 9 people connecting from an external site with a Facebook social plugin (Like Box and Like Button). Afterwards, ads and sponsored posts (n=14,044), mobile devices (n=1,473) and friend referrals (n=401) were the most common channels to drive new ‘likes’ (Figure 3.6).

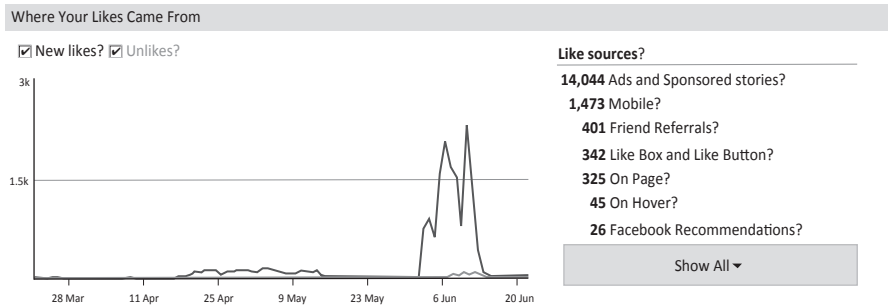


Figure 3.6 Sources of Facebook ‘likes’ in the period from 22 March 2013 to 22 June 2013

With regard to data on the reach¹² of our Facebook page, we noticed some major changes after the launch of the EPAAC campaign. In the first period (1 January 2013 to 21 March 2013), roughly 55% of those who accessed our content (33.5% of females and 21.7% of males) belonged to the 25–34 age group. Most came from Slovenia (n=130); Belgium (n=16); Romania (n=10); Germany, Spain, Italy (n=9 each) and the Netherlands (n=6). In the second period (22 March 2013 to 22 June 2013), our content also reached more females than males (55.3 % vs. 44.0 %) (Figure 3.7). When looking at the reach indicator, the 25–34 age group remained well represented. In the second period we also noted a substantial shift of the reach indicator towards younger age groups (13–17 and 18–24 years of age). Users from the 13–17 and 18–24 age groups comprised 51.2% of all users who saw any content on our page in

11 The number of times our page was liked, broken down by where the like happened.

12 The number of people who saw any content about our page in the given time period, broken down by country. This is based on the person’s estimated home location.

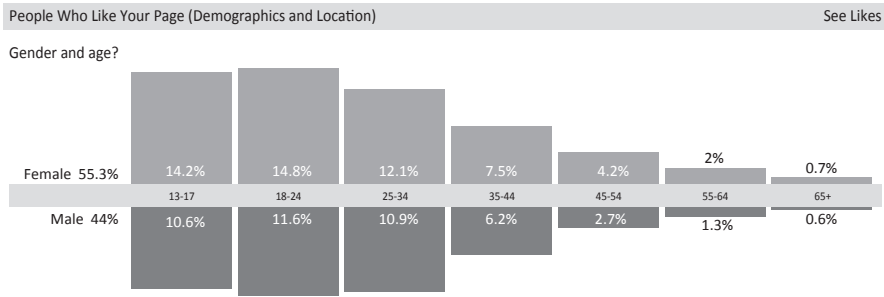


Figure 3.7 Demographics of EPAAC Facebook reach, 22 March 2013 to 22 June 2013

this period, a fact which can be attributed to the Facebook ads targeting young people. We also observed lower proportions of users who saw any content on our page among older age groups (Figure 3.7).

Most users whom we reached with our content lived in the following countries: Romania (n=1,414), Slovenia (n=374), Portugal (n=348), Bulgaria (n=340), Italy (n=274) and other European countries.

With regard to content, we examined data on the type of content on our Facebook page that reached the most users or was most likely to be viewed and shared. We analysed data on the title and type of the post, reach¹³, engaged users¹⁴, ‘talking about this’¹⁵ and virality¹⁶. The different posts related to the *I’m a Fan of Life* campaign reached more unique users and had the most engaged users (i.e., people ‘liking’ it, commenting on it or sharing it), people talking about it and positive virality compared to all other EPAAC posts since the opening of our Facebook account. This fact highlights not just the impact of Facebook ads but also the importance of constructing the posts with a ‘personal touch’ or narrative and the importance of adding visual elements, like pictures copied from the app.

Facebook ads had a significant impact on the ‘talking about this’ indicator and the viral reach indicator (Figure 3.8). These ads spurred a significant increase in the number of unique users who created a story from our page post (stories are created when someone ‘likes’, comments on or shares our post; answers a question we posted; or responds to our event). The percentage of users who created a story from our page post also increased significantly. Both trends were reversed after the Facebook ads were discontinued, highlighting the importance of this kind of promotions for active user engagement with the campaign.

¹³ The number of unique people who have seen our post.

¹⁴ The number of unique people who have clicked on our post.

¹⁵ The number of unique people who have created a story from our Page post. Stories are created when someone ‘likes’, comments on or shares our post; answers a question we posted; or responds to our event.

¹⁶ The percentage of people who have created a story from our Page post out of the total number of unique people who have seen it.

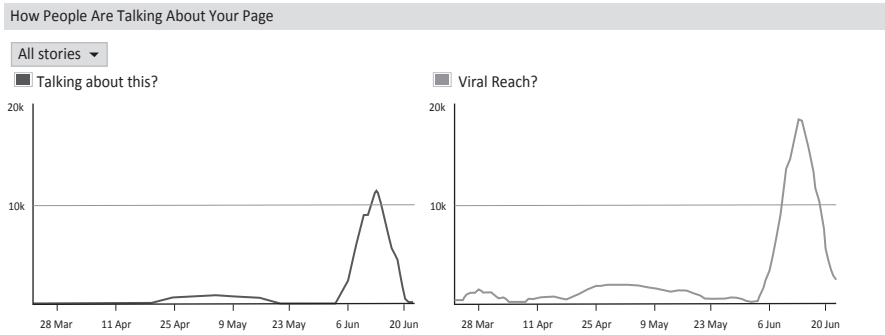


Figure 3.8 Facebook indicators on engagement and viral reach, 22 March 2013 to 22 June 2013

At the end of the campaign, we noticed a discrepancy between the number of ‘likes’ ($n=16,828$) and the number of active game players ($n=5,481$). The reasons for this discrepancy need to be further studied.

The number of visits to the epaac.eu page increased steadily throughout the whole operational period of the site. A total of 21,239 visits (by 11,999 unique visitors) were made to our site between its launch in 2011 and 22 June 2013. We documented 62,319 page views, with an average visit duration of almost three minutes, and an average of three page views per visit. We could not attribute any significant increase in the number of visits to EPAAC web page to users of the *I'm a fan of life* campaign, suggesting that visits to that web page were determined mainly by factors other than our Facebook page activities, such as information about important project deliverables and events. Users of this site are mainly professionals, while the EPAAC Facebook page targets the general public.

SWOT analysis of EPAAC Online Social Gaming

Online social gaming emerges as a potentially powerful tool in public health communication, but this field is still undeveloped at a practical level, presenting challenges in campaign implementation (Table 3.1). Online social gaming holds great opportunity to engage the recipients of messages in social media. If used well, it can provide a cost-effective means to communicate public health messages. Our work within EPAAC serves as an example for other public health interventions. It is also a contribution to rationalising costs and reducing the duplication of efforts in the context of EU joint action policy. As Guy Dargent captured it, ‘High added value demonstrates the “return on investment” for Member States and ensures sustainability ... the objective is to save money,

Table 3.1 SWOT overview of EPAAC Online Social Gaming

Strengths	Potential to reach young audiences and to influence behaviour change EPAAC specific: example for other public health dissemination campaigns to learn from
Weaknesses	Weak theoretical base
Opportunities	Use of online social gaming in other public health fields
Threats	Lack of skills in public health use of online social gaming

and to provide better service to citizens’ (44). With this campaign, we were successful in reaching our preferred target group: young people.

In marketing, branding is crucial for successful promotion of any company or service. Health promotion programmes often struggle with this (1), but our campaign, *I’m a fan of life*, established an understandable, simple and strongly expressive brand capable of accommodating a variety of lifestyle-related messages.

Available financial resources substantially influence the functionalities and the overall user experience of the application. Budget restrictions influence not only the game but also the prizes and giveaways for game players. In EPAAC, time and resource limitations influenced our decision to launch the game with only one celebrity in the beginning and to use a stepwise approach. The limited scientific data available on the applicability and impact of online social gaming on attitudes and behaviour change were another factor in this decision.

Other sectors show that gamification is an important concept, improving reach and impact. For certain demographic profiles, online games promoting health may generate far better results than traditional approaches. Gamification in public health provides an excellent opportunity to increase the reach of health messages while containing costs. We hope that the information about the development, implementation and evaluation of our online social gaming activities sheds new light on this approach and motivates other professionals to think about alternative approaches in their health promotion efforts, especially when they aim at reaching young people.

A key challenge to the development of online social games for public health is the fact that we are still at the start of the learning curve. Time will be needed until the field of public health gathers sufficient collective expertise to use online social games in an efficient manner.

Conclusion: the added value of social media and the potential of online social media in public health

The use of online social media for public health purposes is a promising area, ripe for further exploration and evaluation. Our journey with the EPAAC cancer prevention campaign enabled us to demonstrate two key points: the difficulty in reaching a large public using an ‘off-the-shelf’ social media approach, and the positive effect of online gaming on engagement and reach of the campaign. We have also uncovered a number of uncertainties in how to handle these novel concepts for public health purposes.

We were able to successfully test a number of concepts and practical approaches from the social media and online social gaming domain, such as the use of rewards to motivate people to engage in the campaign, gamification to keep users engaged and to drive content sharing, and the use of celebrities to increase exposure. We have also shown that improving the visibility of cancer prevention messages and reaching a young target audience are possible with this approach. Young people are more active users of Facebook, and they are also one of the key target groups for public health communicators disseminating cancer prevention messages. The adolescent and primary school period is not just the time when young people are most susceptible to developing unhealthy habits like smoking, physical inactivity and poor diet (45). There is also evidence that it is the most important period in building the knowledge base for lifestyle decision-making later in life (46).

There were other benefits of the EU-wide approach to this campaign, including establishing collaboration between Member States and creating a network to disseminate information, provide content and adapt it to fit the unique needs of particular Member States.

Practical examples and experiences presented in this chapter are aimed at motivating stakeholders in public health to consider the potential of online social games in their future prevention activities – not just to reach different target audiences, but also to add an ‘entertainment touch’ to improve their communication methods and consequently public receptivity to health prevention messages.

The online social gaming campaign we describe is easily reusable and transferable to other prevention- and promotion-focused public health efforts, confirming the sound investment of time and resources to design and test the online social gaming concept.

The future seems very promising for advanced piloting and research of online social gaming, adding more value by developing an improved user experience, connecting promotion and prevention online social gaming to existing e-Health

services (i.e., personal health care records, electronic health records), local community actions and coordinated care approaches, as well as embracing new and emerging technologies such as geo-tagging to connect gaming dynamics to actual physical activities. However, we will need to remain active in measuring impact, defining appropriate business models and ensuring that online social media, gaming and related technologies also find their place in informing the development of health policy.

The EU could play a pivotal role in developing the use of social media and gaming concepts in improving public health by embracing the integral role of these technologies in current and future public health campaigns. We urge the EU to promote and financially support the development of online social media and gaming campaigns and to share good practices across the EU.

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Chapter 4

Building European capacity and expertise in secondary cancer prevention: towards a common core curriculum for cancer screening

Ahti Anttila,^a Stephen P. Halloran,^{b,c} Florian A. Nicula,^d Alban Ylli,^e Nereo Segnan,^f David Ritchie,^g Dolores Salas Trejo,^{h,j} Ana Molina-Barceló,^b Marlou Bijlsma,^k Lawrence von Karsa^l

Main messages

- Many years of coordinated effort are needed to implement high-quality screening programmes. International collaboration to exchange experience and share capacities in training and programme management can avoid common pitfalls and improve the pace of nationwide implementation.
- The intensive training course of the European Schools of Screening Management has demonstrated that a key barrier to effective collaboration between countries and programmes in implementing cancer screening can be overcome.
- To enable all EU citizens to benefit, the ESSM network should expand its collaborative activities at an academic level, where translational research to improve knowledge of implementation of cancer screening programmes can thrive.

^a Mass Screening Registry/Finnish Cancer Registry; Helsinki, Finland; ^b Bowel Cancer Screening Hub; South of England; ^c Royal Surrey County Hospital and University of Surrey; Guildford, United Kingdom; ^d Oncological Institute 'I. Chiricuta'; Cluj-Napoca, Romania; ^e Institute of Public Health; Tirana, Albania; ^f CPO Piemonte and AO 'City of Health and Science'; Turin, Italy; ^g North of England EU Health Partnership; Brussels, Belgium; ^h Centre for Public Health Research (CSISP), FISABIO; Valencia, Spain; ⁱ General Directorate of Public Health; Valencia, Spain; ^k Netherlands Standardisation Institute; Delft, Netherlands; ^l International Agency for Research on Cancer; Lyon, France

Introduction

Cooperation for innovative, population-based screening

Despite the proven capacity of population-based screening to reduce the burden of breast, cervical and colorectal cancer in the population, early detection of these cancers in most countries around the world still relies on less effective approaches such as opportunistic testing and, all too frequently, on the diagnosis and treatment of people who already have symptoms (1). Concerted efforts to widely establish a better approach to early detection of cancer began in the Europe Against Cancer Programme in the late 1980s. Since then, dedicated professionals, decision-makers and other stakeholders across the EU have repeatedly joined forces to extend the benefits of population-based cancer screening to increasing numbers of European citizens. Pan-European networks were created and co-funded by the European Commission, enabling Member States to share experiences in piloting population-based screening programmes (2–6). This stimulated further international exchange of experience in implementation of cancer screening programmes (7) and led to wide cooperation within and beyond the borders of the EU in the development of the multidisciplinary European guidelines for quality assurance in breast, cervical and, most recently, colorectal cancer screening (6,8–12). The guidelines are widely recognised within and beyond the borders of the EU as the ‘gold standard’ of best practice in cancer screening (13–16), facilitating the commissioning of regional and national screening programmes recommended by the Council of the European Union since 2003 (13,14,17). Today, Europe leads the world in the implementation of population-based screening as a tool of cancer control. Over the next decade, well over 500 million screening tests will be performed in the EU in population-based screening programmes for breast, cervical and colorectal cancer (14).

Continued improvement needed in Europe

Though significant progress has been achieved to date, there is no room for complacency in efforts to make high-quality cancer screening available to all EU citizens. Population-based programmes to effectively bolster health equity, along with an organisational infrastructure for effective quality assurance, have not yet been fully implemented in all Member States; indeed, in some countries or regions, no such programmes exist (14). Considerable challenges remain, including wide variation in the performance of programmes across the EU compared to selected standards in the European guidelines (3) and in the large volume of diagnostic examinations still being performed as part of opportunistic programmes, particularly in cervical screening (2,14). This

situation points to the generally lower access to screening for less advantaged sub-groups of the target population (18,19) and illustrates one of the persistent dichotomies of European health care: even as Europe consecrates its global lead in implementing secondary prevention of cancer, significant deficiencies remain in the availability and uptake of population-based programmes (14,18–22). In a community that recognises the importance of promoting and protecting the health of all its citizens, it is crucial to address this contradiction.

The European Partnership's work on screening and early detection included several projects aimed at the heart of this matter, designed to generate new knowledge, skills and tools that enable more citizens of the EU to benefit from early detection and treatment of cancer.

Improving cancer screening in the EU through an innovative pilot course

Our primary aim was to address the stark deficits in access to and quality of cancer screening. Our work aimed to show the way forward in wider implementation and improvement of population-based cancer screening programmes in the EU.

We focused on developing and piloting an intensive training course for decision-makers, coordinators and other staff engaged in the planning, implementation or evaluation of cancer screening programmes. This chapter includes a discussion of our work. We provide examples from Albania, Romania and the United Kingdom to illustrate how cooperation and innovation in an intensive, state-of-the-art training course can help professionals to confront the complex issues that are crucial to successful implementation of population-based cancer screening. Recent efforts in these countries to implement screening programmes reflect wide variations in the nature and scale of the problems that must be overcome, but they also point to the existing potential in European screening programmes, which are vital to improving cancer control in Europe.

Considerable interest in intensive training

The decision to conduct the first training exercise of this type in Europe was not simply motivated by the appeal of cooperating and innovating to improve cancer screening within the framework of the EPAAC. Indeed, previous exchanges in the European Cancer Network (ECN) for screening and prevention (in which the former European cancer screening networks were consolidated) and bilateral contacts between the International Agency for Research on Cancer (IARC) and countries neighbouring EU Member States, revealed considerable interest among potential candidates to participate in an intensive training



Figure 4.1 ESSM course Module 1 participants

course. However, the EPAAC banner, which entailed financial support as well as a certain degree of political and social legitimacy, turned out to be crucial to the success of the pilot course, and it was welcomed warmly by participating delegates and faculty (Figure 4.1).

Methods

For expert support in designing and piloting the intensive training course, a network of European Schools of Screening Management (ESSM) was initiated. The ESSM is coordinated jointly by the leader of EPAAC work on screening, Dr Ahti Anttila, and the leader of the project secretariat at IARC in Lyon, Dr Larry von Karsa. A team of experts, highly experienced in coordination and evaluation of the population-based cancer screening programmes in Italy, Sweden, Slovenia, the Netherlands and the United Kingdom, was also recruited to work closely with us in the design and preparation of the course. Together, we formed a senior management team to oversee course implementation during EPAAC (Box 4.1). At one of our initial meetings, responsibilities for drafting the agenda and plans for the course were designated, as were roles for reviewers, chairs, coaches or leaders of various sessions or exercises during the course.

In selecting participants, we were conscious of the unique opportunity as well as the challenge that the course presented; the delegates would be participating in compact, intensive training sessions, including peer discussions and self-directed

Box 4.1 European Schools of Screening Management (ESSM) network, senior management team

Dr Ahti Anttila (coordinator), Mass Screening Registry, Finnish Cancer Registry, Helsinki, Finland.

Dr Lawrence von Karsa (coordinator), Quality Assurance Group, Section of Early Detection and Prevention, IARC.

Professor Harry J. de Koning, Department of Public Health, Erasmus MC, The Netherlands.

Professor Julietta Patnick, Directorate of Health and Wellbeing, Public Health England, United Kingdom.

Dr Maja Primic-Zakelj, Epidemiology and Cancer Registries, Institute of Oncology, Slovenia.

Dr Nereo Segnan, CPO Piemonte and AO 'City of Health and Science', Turin, Italy.

Dr Sven Törnberg, Department of Cancer Screening, Regional Cancer Centre, Karolinska University Hospital, Sweden.

group work to provide deeper insights into the knowledge and skills essential to implementation of population-based cancer screening programmes in accordance with European standards. Therefore, a competitive selection process was used to assure that the participants would be able to actively participate in the training and thereby take full advantage of the opportunity to teach and to learn from their peers. To enhance the quality of the interaction between faculty and delegates, the number of delegates was limited to approximately one per faculty member. To promote the impact of the training on implementation of cancer screening in the EU, selection criteria included the likelihood that a candidate would work on implementation or improvement of cancer screening programmes in the near future. Furthermore, applications were only accepted if approved in writing by the applicant's head of unit. Finally, the potential influence of the unit on screening policymaking and programme management in the country of origin was also taken into account.

For similar reasons, we asked the faculty recruited for the course to go further than giving lectures or leading exercises during the intensive training. Of equal, if not greater, importance was their participation during open discussions on the conditions under which screening programmes are currently being planned and implemented, the progress achieved thus far, the problems encountered and the applied solutions. These practical discussions, along with our team's continuous internal assessment of the pilot course, enabled us to identify the key issues to be covered as the course unfolded and to maximise the benefit for the participating delegates.

Complexity and variability of the screening process, target cancers, and protocols

In addition to the selection of the delegates and the recruitment of the faculty for state-of-the-art training, many additional challenges had to be dealt with in developing and piloting the intensive training course. One of the most complex tasks was the development of the core curriculum. We aimed to cover all of the issues essential to successful implementation of population-based cancer screening programmes, including the full scope of the multidisciplinary and multi-step process involved in population-based screening (Figure 4.2), from identification and invitation of each eligible person in the target population to performing the screening test, and (if warranted) diagnostic follow-up of abnormalities detected, as well as diagnosis and treatment.

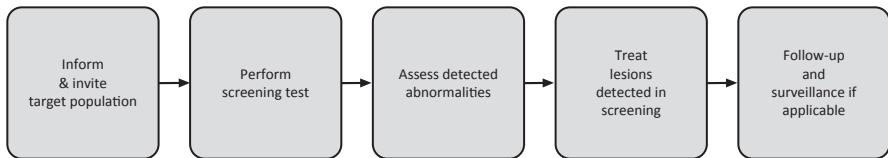


Figure 4.2 Process of cancer screening

Source: adapted from (23) with permission of Deutscher Ärzte-Verlag

Overarching themes that are crucial to ensuring the outcome and maintaining an appropriate balance between benefit and harm at each step in the screening process also had to be dealt with in a manner that explained the issues and provided the tools essential to effective programme implementation and service management. Topics included, for example, the concept of screening as a public health endeavour as well as key methods and approaches in quality assurance, information and communication about screening methods, planning, organisation, training, and monitoring and evaluation of programme impact. During the curriculum planning it was therefore necessary to identify the most important elements in achieving and maintaining the quality and performance of any screening programme and to take into account differences between programmes that can have significant impacts on the quality and performance of such programmes.

Scope and depth of curriculum

Determining the appropriate scope and depth of the curriculum was also challenging due to the complexity of the screening process (Figure 4.2 is a highly simplified schematic). For example, in a quality-assured colorectal cancer screening programme, administering a faecal occult blood test and communicating the result involves at least five different activities, carried out by many different people (distributing the test by mail or making it available for pick-up in designated

places; taking the test at home, generally over a 3-day period; returning the test to a laboratory for reading; processing the test at the laboratory; and informing the person screened of the test result). Diagnostic work-up and clinical management of the lesions detected in screening requires multidisciplinary teamwork and efficient coordination of these activities. Adherence to comprehensive quality assurance guidelines, with up-to-date, evidence-based standards, procedures and protocols of best practice, is crucial in guiding the process (14,24).

Due consideration also had to be given to the different choice of cancers targeted for screening in each participating country. Even programmes screening for the same cancer varied in terms of methods, devices and equipment, and eligible age ranges and screening intervals. Many of the discussions during the course were driven by delegates' interest in learning from both faculty and peers in order to formulate operative strategies to address diverse problems arising from the wide variation in screening protocols and settings in which they are applied.

Establishing a population-based screening programme

The challenges in developing the curriculum piloted in the intensive training course went beyond the complexity of the screening process itself. Indeed, experience in Europe shows that establishing a population-based screening programme is also complex (14,15,24,25), and it requires decades to be successfully rolled out and for the full impact to be observed. Crucial issues of programme management come into play during the different phases of implementation, including sustainability, coordination, communication, evaluation, continuous quality improvement, and the need to motivate and focus very large numbers of stakeholders on common goals and actions (15,24,26,27). Moreover, for many years after start-up, individual programmes are unlikely to be in the same phase of implementation as programmes in other countries. This makes it difficult to identify timely cross-cutting issues that are relevant to all participants. Finally, programme management must deal with the different tasks under the circumstances that are specific to their country or region, as shown below in the examples for the United Kingdom, Romania and Albania.

The curriculum therefore had to take into account a diverse set of circumstances, including the disparate phases of implementation of each programme represented at the course, the variability in available resources, the heterogeneous approaches to organisation and financing, and the diagnostic and treatment capacity of the health care systems. It was therefore important to include elements in the curriculum that enabled the faculty and the delegates to cooperate in identifying and addressing the key implementation issues currently confronting each programme, and those that would be likely to be important in the future.

Interactive course design

Given this complexity, we built interactive components into the curriculum that enabled faculty and delegates to cooperate in modifying the curriculum as the course unfolded. The aim was to identify and focus on the needs of the programmes and countries represented at the course, while also covering the issues relevant to any population-based screening programme.

This was accomplished by dividing the originally planned two-week, full-time training course into two one-week, full-time modules, separated by a four-month period. In this interim period, the delegates continued their regular professional duties in their home countries. At the same time, they cooperated in small working groups to perform a practical task assigned to their group. Each working group was coached by one or two faculty members.

The composition and assignments of these working groups, and their coaches, were determined during the first course module through an interactive process involving all delegates in small groups, with one or two coaches from the faculty in each group. One delegate in each group served as a *rapporteur* who summarised the results of the group session at a plenary discussion with all course delegates and faculty. The faculty and delegates then decided the membership of each working group for the interim period, the final tasks and the respective coaches. A few delegates chose to participate in two working groups because the practical tasks of both were particularly relevant to their country or programme. To finalise the course curriculum, the agenda of the second module was revised and agreed with the senior management team during the interim period. The final curriculum took into account the suggestions received from delegates and faculty members.

Results

Key components of pilot course

A total of 26 decision-makers, coordinators and other professionals employed in the planning, implementation, or evaluation of cancer screening programmes in 11 EU Member States or acceding countries (Bulgaria, Croatia¹, Czech Republic, Estonia, Latvia, Lithuania, Poland, Romania, Slovenia, Spain and Sweden), four candidate or potential candidate countries (Albania, Kosovo, Serbia and Turkey) and Georgia and Morocco took part in the first intensive comprehensive training course in implementation of population-based cancer screening programmes held in Europe (Table 4.1). Altogether 26 experts from 9 EU Member States (Belgium, Denmark, Finland, Italy, Slovenia, Spain,

¹ Acceding country at the time of going to press

Table 4.1 ESSM pilot course 19-23 November 2012 and 11-15 March 2013, delegates

Country/institution	Delegates and affiliation
Albania	Kozeta Filipi, Department of Epidemiology, Cancer Unit, Institute of Public Health
Bulgaria	Yulia Panayotova, Health Psychology Research Centre
Croatia	Melita Jelavić, Croatian National Institute of Public Health Dunja Skoko-Poljak, Ministry of Health
Czech Republic	Ondrej Majek, Institute of Biostatistics and Analyses, Masaryk University
Estonia	Piret Veerus, Department of Epidemiology and Biostatistics, National Institute for Health Development
Georgia	Levan Jugeli, National Screening Centre, UNFPA Georgia/ National Screening Centre
IARC	Kirstin Gross Frie, Screening Group, Section of Early Detection and Prevention, IARC
Kosovo	Elvis Ahmedi, Kosovo State Board on Cancer Control, Ministry of Health Mejreme Maloku, Institute of Oncology, UCC Pristina
Latvia	Daiga Santare, University of Latvia, Faculty of Medicine
Lithuania	Rugile Ivanauskiene, Department of Preventive Medicine, Lithuanian University of Health Sciences Vaida Momkuvieniė, National Health Insurance Fund, Ministry of Health
Morocco	Loubna Abousselham, Population Management, Ministry of Health
Poland	Arkadiusz Chil, Swietokrzyskie Cancer Centre Andrzej Czuba, Maria Skłodowska-Curie Memorial Cancer Centre, Tumour Pathology Department Jolanta Kotowska, Breast and Cervical Cancer Screening Programme at Lower Silesian Oncology
Romania	Florian Nicula, Oncology Institute, Romanian Northwest Regional Cervical Cancer Screening Programme Management Unit Luciana Neamtiu, Oncology Institute, Romanian Northwest Regional Cervical Cancer Screening Programme Management Unit
Serbia	Aleksandra Jaric, Institute for Oncology and Radiology, Department for Breast Imaging Snežana Žujković, Implementation of the National Cancer Screening Programme in Serbia, KBC ZEMUN, Hospital for Obstetrics and Gynaecology
Slovenia	Jozica Maučec Zakotnik, National Institute of Public Health, National Colorectal Screening Programme
Spain	Elena Pérez Sanz, Centre for Public Health Research Isabel Portillo Villares, Screening Programme in Prenatal and Colorectal Cancer
Sweden	Miriam Elfström, PREDICT FP7 project, Karolinska Institute
Turkey	Müjdegül Zayıfoğlu Karaca, Ministry of Health

Table 4.2 ESSM pilot course 19-23 November 2012 and 11-15 March 2013, faculty

Country/ institution	Faculty and affiliation
Belgium	Hilde Bosmans, Medical Physics & Quality Assessment, KU Leuven University
Denmark	Elsbeth Lyng, Institute of Public Health, University of Copenhagen
Finland	Ahti Anttila, Mass Screening Registry, Finnish Cancer Registry
Norway	Stefan Lönnberg, Cancer Screening Registry of Norway
Italy	Nereo Segnan, Paola Armaroli, Livia Giordano, Antonio Ponti, Carlo Senore, CPO Piemonte and AO 'City of Health and Science' of Turin Luigi Bisanti, Marta Dotti, Giuseppe Salamina, Department of Prevention - ASLTO1
Slovenia	Alenka Repse-Fokter, Celje General Hospital
Sweden	Sven Törnberg, Department of Cancer Screening, Regional Cancer Centre, Karolinska University Hospital Lennarth Nyström, Umea University
Netherlands	Harry de Koning, Department of Public Health, Erasmus Medical Centre
United Kingdom	Stephen Halloran, NHS Bowel Cancer Screening Southern Programme Hub Julietta Patnick, Directorate of Health and Wellbeing, Public Health England Philippa Pearmain, West Midlands Cancer Intelligence Unit, University of Birmingham
IARC	Anouk Berger, Education and Training Group Rolando Herrero, Prevention and Implementation Group, Section of Early Detection and Prevention René Lambert, Screening Group, Section of Early Detection and Prevention Rengaswamy Sankaranaryanan, Screening Group, Section of Early Detection and Prevention Isabelle Soerjomataram, Cancer Information Section Eero Suonio, Quality Assurance Group, Section of Early Detection and Prevention Lawrence von Karsa, Quality Assurance Group, Section of Early Detection and Prevention

Sweden, the Netherlands and the United Kingdom) and IARC cooperated with the ESSM faculty in conducting the intensive course (Table 4.2). For more information on the contents of the course, see the overview of the final curriculum (Table 4.3).

Course evaluation results

The success of the course is documented in the evaluation completed by the delegates during the two weeks in which they attended the full-time modules

Table 4.3 ESSM pilot course, abridged curriculum

Module 1	19–23 November 2012	Chair(s)
Section 1	Cancer burden & relevance to screening & treatment in European & Mediterranean settings	A Anttila
Section 2	Principles of Screening	A Anttila
Section 3	Screening organisation	S Törnberg, J Patnick
Section 4	Screening evaluation	N Segnan
Section 5	Communication	L Giordano, N Segnan
Section 6	Introduction to quality assurance guidelines for cancer screening, the European experience	L von Karsa
Section 7	Quality assurance systems and training	L von Karsa
Section 8	Planning module 2	A Anttila, N Segnan, L von Karsa
Interim group work (Section 9)		
Group 1	Formalising the protocol of quality assurance system for a cancer screening programme	
Group 2	Screening for cancer in Mediterranean countries	
Group 3	Drafting a report that provides rationale for data linkages	
Group 4	Planning a feasibility phase intervention to improve attendance and adherence	
Group 5	Reconsidering programme strategy or reorganising the programme organisation/policy	
Group 6	Defining the management team and the responsibilities of the cancer screening programme	
Module 2 11–15 March 2013		
Section 10	Health Economics Evaluation	H de Koning
Section 11	Research on efficacy of new screenings & relative effectiveness of new technologies in cancer screening	A Anttila
Section 12	Screening programmes & research	N Segnan
Section 13	Key issues in quality assurance and programme management	L von Karsa
Section 14	How to continue the training/future activities	A Anttila, L von Karsa, N Segnan

at IARC in Lyon. At least 75% of the attending delegates evaluated each item in the curriculum. Every component in both modules received high approval (highest or second highest rating on a seven-point scale; results for module 2 shown in Figure 4.3). All the topics covered were deemed by most delegates to be highly relevant to their work. Nevertheless, not all topics of special interest to the delegates were covered during the first module. After the first week of training, the respondents recommended inclusion of additional topics:

- costs of planning and implementing screening programmes
- epidemiologic evaluation
- role of management units
- multidisciplinary teams
- different models of screening in different countries with quality assurance system and associated costs

By the end of the second module, the evaluation showed that all perceived gaps had been addressed. The respondents indicated that no additional topics were needed. Evaluation of the second module also covered the group work during the interim period between the two modules. Respondents chose the highest approval categories to express that the course group work was very strongly (90%) or strongly (10%) relevant to their work and that it had very strongly (85%) or strongly (15%) helped them to link the course content to practical activities.

Examples of implementation and planning for cancer screening in different European settings

The decision-makers, coordinators and other responsible screening staff attending the course stressed the benefit of learning from the wide variation in the strengths and weaknesses and the conditions under which planning and implementation of population-based screening is conducted in Europe. Three brief examples are presented here to illustrate the scope of the issues that were addressed in the course and the need for further collaboration to overcome key barriers. The narrative style in the accounts provided by faculty and delegates has been maintained as much as possible to convey the enthusiasm expressed during the course.

Perspectives on colorectal cancer screening in England

In England, we embarked on the road to colorectal cancer screening in the late 1990s, convinced by the evidence of a 16% reduction in mortality following four international, population-based randomised clinical trials (RCTs) using guaiac-based faecal occult blood testing. While the medical science was convincing – particularly with one of the trials in Nottingham, translation into successful screening of a population of 55 million needed much more. The National Screening Committee, the Department of Health and the government backed a pilot programme to explore logistics, identify resources, develop quality measures, evaluate clinical outcome and enable more accurate economic modelling.

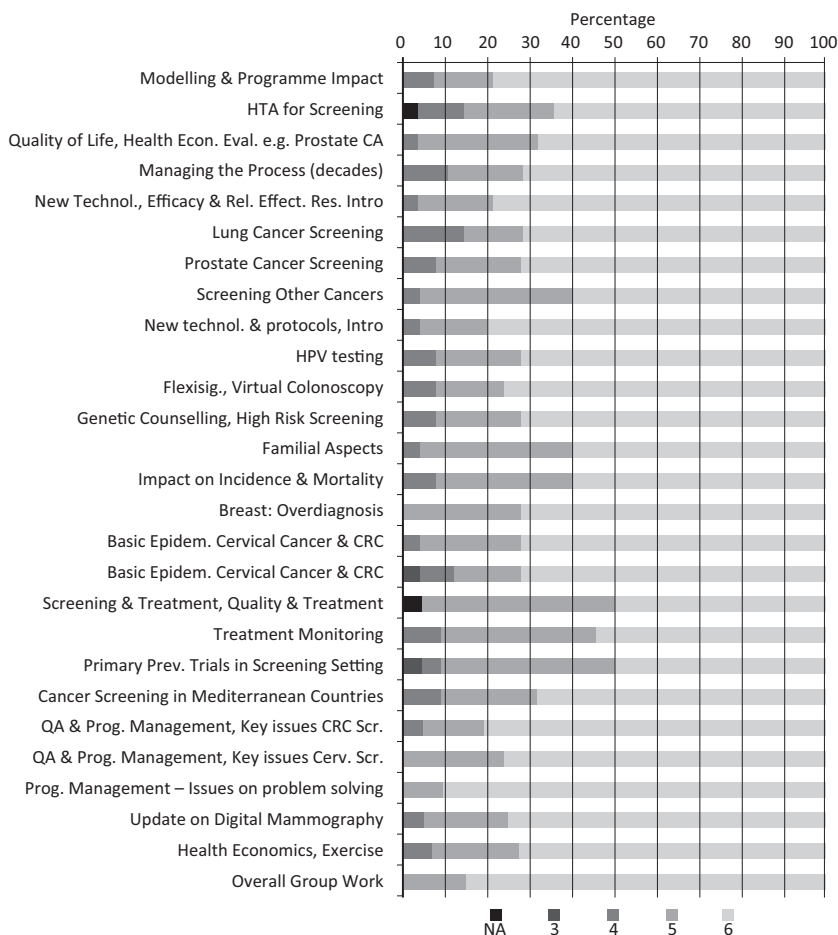


Figure 4.3 Evaluation of Module 2 of ESSM course by participating delegates

Note: Proportion of responding delegates and respective rating on a scale of 0 to 6, where 6 indicates the highest level of approval, broken down by individual lecture, exercise or group work. NA: not applicable.

One of the early steps in the planning phase of the programme was the need to identify the most suitable test technology. Two types of faecal occult blood testing were available: the long established guaiac test (gFOBt) and the relatively new faecal immunochemical test (FIT). RCT evidence of clinical effectiveness was only available for gFOBt, so this method was adopted. A laboratory-based, six-month evaluation of the merits of six devices was commissioned for early 2000, and in the meantime, bids for pilot clinical evaluation sites in England and in Scotland were sought and identified. The chosen centres demonstrated enthusiasm, had the necessary facilities, and could reach a socioeconomically and ethnically diverse population of approximately one million. The stage was set for three rounds of biennial screening pilots that would provide the

knowledge, experience and confidence upon which the national programme could be launched in the summer of 2006.

Success in population-based screening needs good practice based on firm evidence. Although the latter can be obtained by means of a scholarly review of published papers, the former needs to be taught or learned from observations and experience. The bowel cancer screening programme in England was informed by the successes and mistakes of breast and cervical screening in the United Kingdom and elsewhere, which had been set up some 10 years earlier. The recommendation of the Council of the European Union (17) had pointed in the direction of population-based screening for colorectal cancer, but the European quality assurance guidelines had not yet been written; indeed, the knowledge and experience required to write them was yet to be acquired!

One can marvel at how well lessons had been learned from ‘poor experiences’ in England; systems need to be simple, and a single, comprehensive source of population information is important, as are a unique personal ID, a unique test ID and a single national database holding all screening-related data from the moment of invitation up to the pathology outcome. These resources are needed to avoid steps that might otherwise cause delay, reduce efficiency, generate unnecessary costs or weaken the quality of the screening process. The screening programme needed to scale its activities to make it efficient and economically viable, enabling the quality of processes to be monitored and enhanced.

High quality must be the trademark of screening programmes. Experiences of internal and external quality control and assessment in a laboratory are a good primer, but performing invasive tests on ostensibly healthy people is particularly demanding. The risk to individuals – and therefore to the credibility of the programme – means that proven quality systems must be in place from day one. England was actively involved in producing the first edition of the EU guidelines for quality assurance in colorectal cancer screening and diagnosis. This experience demonstrated that knowledge pooled from many different experts (authors, referees and editors) is required to learn about best practice.

By May 2013, the English bowel cancer programme had issued 17,495,065 screening invitations and identified 15,832 cancers and 47,927 advanced adenomas from among 191,780 high-quality, closely monitored colonoscopies. It has brought better endoscopic practice to parts of the health service that deal with patients who present symptoms of a colorectal neoplasm. It has also stimulated a generation of screening enthusiasts who have seen for themselves how quality and population screening can have a major impact on public health. This is only the beginning, though. Having shared our experience of systems that improve endoscopy performance, the English programme needs to learn

from the Italian and Dutch programmes about screening programmes based on the FIT, and to continue to develop population-based flexible sigmoidoscopy screening as a preventive programme for all persons aged 55–60. All of these components will contribute to the mutual learning experience enabled by the new network of European Schools of Screening Management. This will help to realise the full potential of bowel cancer screening across the 50 countries and 740 million citizens of the European region.

Romanian strategies and management resources in organised cervical cancer screening programmes

In Romania (population 21 million), cervical cancer incidence and mortality are among the highest in Europe (28), with no clear historical decrease in the burden of disease (29). The first Romanian Strategy of Cancer Control Planning was designed by the Romanian Ministry of Health based on guidance from IARC after a meeting organised in Budapest. Since the 1970s, Romania has had links with IARC and the European Network of Cancer Registries (ENCR) through two regional cancer registries in Cluj and Timis County, which provided data for several volumes of the *Cancer Incidence in Five Continents* series (30–33).

At that time, the new strategy initiated quality controls for diagnosis and treatment services, but adequate resources were not provided. Secondary prevention measures focused on improving early diagnosis in cytopathology laboratories, and opportunistic activities covered less than 2% of the population at risk. In the meantime, quality assurance guidelines for cytopathology, colposcopy and treatment were disseminated with classifications, standards of laboratory control, and protocols for treatment and follow-up; these were updated by European professional bodies. Training for cytology and colposcopy was organised in the country's main universities in order to generate human resources for future screening activities.

In 1998–2001, two feasibility studies were conducted in Cluj County and the counties of the Northwest Region. One feasibility pilot focused on resource provision and networking laboratories with gynaecology units; test quality; and response to invitations sent. The first Screening Management Unit was established. Another feasibility study focused on family doctors; it demonstrated a good learning curve in smear taking and high compliance of women to screening networks where family doctors were the point of first contact.

In 2002, the Cancer Commission of the Ministry of Health decided to pilot a regional population-based cervical cancer screening programme, first in Cluj County and four years later in the entire Northwest Region. It continued until 2008, when it was suspended to change legislation in order to prepare nationwide

roll-out (establishment of seven other regional management units). The pilot was coordinated by a screening Management Unit established in Cluj that was connected with the regional cancer registry. Quality assurance and control in implementing, monitoring and managing the pilot were based on two volumes of guidelines, adapted from the European guidelines. Management experts were trained, and the staff took part in several European working groups. The results of the 2002–2008 pilot were published in 2009 (34). The main results are summarised below:

- Screening Management Unit established with specially trained experts
- National Screening network founded and plans developed for quality assurance and control of the taking and reading of samples, diagnostic assessment and treatment
- Regional cancer registry, screening and dysplasia registries developed for performance monitoring
- Quality control guidelines disseminated, with training and protocols
- Invitation-based information strategy developed, taking into account feasibility testing with face-to-face contacts between health mediators and isolated populations of Roma, Hungarian and Ukrainian mountain peasants
- Approximately 124,000 tests performed, with over 4,000 follow-ups and treatments recorded in the screening registry of precursor lesions detected, treated and followed up within the programme
- Only approximately 20% coverage of regional target population due to lack of resources

Between 2008 and 2012, government financing did not provide for any implementation and monitoring activities. In the framework of the EPAAC and other European initiatives, however, the screening management unit in Cluj initiated and participated in training courses both in Europe and in Romania. By 2012, it had been involved in organising screening courses for 6,000 family doctors and 1,200 specialists in Romania, financed by EU structural funds. In collaboration with the Screening Quality Assurance Group at IARC and the Finnish Mass Screening Registry, the unit in Cluj also organised a Working Group on Screening Strategies in 2008 to formulate recommendations for decision-makers on how to organise screening programme management at the national level, how to plan for screening policies and organisation, and how to prioritise, pilot and decide on national roll-out of screening programmes. To date, however, only the recommendations dealing with cervical cancer screening have been adopted at the national level; at the regional level, breast

and colorectal screening feasibility studies, and population-based pilot screening programmes are included in the 2014–2018 Romanian Cancer Control Plan.

The national cervical cancer screening programme was officially launched in 2012 following an order by the Ministry of Health, and it is now organised in eight regions, each of which is managed by a separate unit. One unit in the Northwest Region has continued from the 2002–2008 pilot. Unfortunately, the number of women screened in the programme is still very small compared to the number of women in the whole target population, due to limited management resources and experience at the national level at the current stage of implementation. In the first six months of the programme in the Northwest Region, 76% of the invited 25–64 year-old women attended the programme (over 60,000 women were tested). In other regions the uptake was significantly lower but is currently increasing; this is likely to reflect limited previous experience in screening management.

The key operational elements of the programme include the following:

- Target population of 5.9 million women aged 25–64 years
- Free Pap test for eligible women every five years
- National coordination by Ministry of Health through the Cervical Cancer Screening Commission, led by a state secretary
- Implementation coordinated by eight Regional Management Screening Units
- Each region covers 4–6 of the 42 counties in the country
- Each region establishes county networks, and commissions lead hospitals with gynaecological outpatient units and cytopathology laboratories
- Samples are collected by laboratories and GPs
- Invitations sent by Regional Management Units through family doctors
- NGOs are responsible for promotional campaigns
- One-fifth of target population is invited every year using the population database from county health insurance files

The screening management unit in Cluj now has more than 10 years of experience in managing cervical cancer screening programmes. This experience can be used in developing quality assurance systems at the regional and national level for quality-assured roll-out of the cervical screening programme. Given the scale of the national screening programme, the very high burden of cervical cancer in the country and the complexity of effectively managing the quality of the screening process, adequate resources for screening management are

an important issue. New pilots need to be planned to test the feasibility of possible novel methods, such as HPV-based screening that could facilitate the implementation and improve the effectiveness of the national screening programme. Such innovation requires a European dimension in order to avoid common pitfalls and avoid unnecessary expense and delay in adopting improvements that have been proven to work elsewhere in Europe.

Current situation and prospects for breast and cervical cancer screening in Albania

Albania is a potential EU candidate country in economic transition. Only about half of its 3.6 million people are covered by health insurance, although primary care is available free of charge to the whole population through approximately 400 publicly financed health care units. Cancer diagnosis and treatment are also provided free of charge, but most services are concentrated in the only oncological centre in the country, in the capital city of Tirana. More than half of all breast and cervical cancers are diagnosed at an advanced stage (III or IV), due to insufficient access to diagnostic and cancer management services for a large proportion of the population.

Organised breast and cervical cancer screening programmes do not exist in Albania. A limited number of mammography centres (eight public facilities and six private) perform a small number of examinations (3–5 per day). Diagnostic biopsy and radiotherapy are available only in the main hospital in Tirana. Over 5,000 Pap tests are taken and read annually, and biopsy and treatment of precancerous lesions (using the loop electrosurgical excision procedure, or LEEP) are limited to a few centres in the cities of Tirana and Durres. Those centres could be used in a pilot project for cervical screening. The maternal health services network is well developed: it could serve as an organisational backbone for these screening services, provided that screening technologies suitable for the skill sets of maternal health service providers are selected.

In recent years, a number of international consultations (WHO, IARC, IAEA² and UNFPA³) have been conducted and projects have been initiated to develop policies and improve capacity for secondary cancer prevention. In the short to medium term, current plans call for early detection of breast cancer to focus on developing skills and capacity for clinical breast examination by public health care providers. Mammography is reserved for assessment of lesions detected in screening; breast screening will be undertaken using clinical breast examination (CBE) provided by primary health care providers with referral to the secondary

² International Atomic Energy Agency

³ United Nations Population Fund

care level for mammography when CBE abnormalities are detected. Primary health care providers will also train women in breast self-examination.

Capacity for multidisciplinary management of breast cancer cases currently does not fulfil needs. About 25 radiologists, mammography technicians, pathologists, surgeons, physiologists and nurses have recently trained in short-term clinical residencies at the Aviano location of the Italian National Cancer Institute, supported by IAEA and Friuli Venezia Giulia Region. The aim is to expand capacity for breast cancer screening, diagnosis and treatment in the oncology hospital in Tirana and in two regional hospitals, in Durres and Shkodra, as an initial step towards establishing a national network of breast cancer centres. In 2012, doctors at somewhat less than half [180] of the Albanian primary health centres were trained in CBE, risk evaluation, and referral for diagnostic mammography when appropriate. Meanwhile, the Institute of Health Insurance approved the inclusion of numbers and quality of CBEs performed among performance indicators for health centres (December 2012), providing a good base for programme sustainability. In 2013, training will be completed for GPs and started for nurses. Plans for the next 2–3 years focus on establishing an organised and sustainable model for comprehensive breast cancer control in three major regions of central Albania: Tirana, Durres and Elbasan. Priorities include a quality assurance system for breast imaging and reduction of waiting times for breast cancer investigation and treatment.

Short- and medium-term plans for cervical cancer screening are currently based on conventional cytology. Some pilot activities in liquid-based cytology and HPV screening for women at high risk have been conducted at Durres regional hospital and the Institute of Public Health, respectively. UNFPA support is expected to begin in 2013 for a screening coordination office with dedicated, qualified staff. The aim is to build capacity among maternal health care providers in taking samples, counselling, reading slides, and in diagnostic and therapeutic colposcopy.

In recent years, campaigns have been conducted to raise awareness for breast cancer and improve early detection of cervical cancer, but they remain mostly dependent on international support. A number of epidemiologists and prevention professionals have attended courses on cancer screening in other countries, including the ESSM pilot course on cancer screening management and a US National Cancer Institute summer course on cancer prevention. Partnerships with other regional networks such as Euromed⁴ Cancer Registries Network have been pursued.

⁴ EUROMED initiatives: see footnote 5.

Participation in two modules of ESSM during November 2012 and March 2013 was an excellent opportunity to build capacities for the planned national cancer screening office. The Albanian delegate who attended the course was exposed to best practices for breast and cervical cancer screening and early diagnosis. The course provided a good chance to focus on Albania's specific needs and priorities in cancer screening management under the supervision of European experts. In the short term, the networking opportunities offered by the course will most likely lead to collaborative grant applications and projects with neighbouring countries, at a time when these can really contribute to Albania's capacity to plan and implement effective and systematic cancer screening programmes.

Further progress in Albania to develop an effective and sustainable approach to early detection of breast and cervical cancer will require additional investment of resources and technical assistance through international collaboration, especially European networks. A major challenge will be making effective diagnostic and treatment capacity accessible to the entire population, not just the women attending screening programmes.

Developing and testing a sustainable model for population-based cervical cancer screening and international collaboration in certification of breast centres could focus attention on the most cost-effective steps that could be taken to improve diagnostic and treatment protocols. Training opportunities abroad, or assistance in establishing national training capacity, will be needed for professionals who provide services at each step in the screening process (e.g. cytology, diagnostic and therapeutic colposcopy, follow-up, screening and diagnostic mammography, other non-invasive and invasive assessment procedures, and multidisciplinary management of breast lesions).

Further evidence of the need for greater capacity to implement and improve cancer screening programmes in Europe

The above examples demonstrate the wide variation in current approaches to implementing population-based cancer screening programmes in Europe. They also illustrate the urgency of improving the situation, given the high burden of disease and the highly unfavourable distribution of the stage of disease at diagnosis in some European Member States and candidate and potential candidate countries.

Further evidence of the need for action to improve the current situation has emerged from other projects in this strand of the Partnership. For example, the Centre for Public Health Research (CSISP) in Valencia, Spain, investigated inequalities in access to population-based cancer screening. The investigation

was prompted by reports that inequalities in access to screening by sex, age and socioeconomic status had been observed even in fully implemented population-based screening programmes, and despite the fact that such programmes are intrinsically more equitable than opportunistic or partially implemented population-based programme (18,22,35). These findings are consistent with other results showing lower participation of population groups with low socioeconomic status in breast, cervical and colorectal cancer screening programmes (20,21,36). The conclusions of these studies justify more research on social inequalities in cancer screening. These studies should be specific to the health care system and programme setting, and should involve screening management and coordination units in order to promote rapid translation of the results into practice.

The motivation and readiness of decision-makers and stakeholders at the regional level to engage in efforts to implement and improve cancer screening programmes, and the need for appropriate training was also demonstrated in the project conducted by a network of 12 European Regional and Local Health Authorities (EUREGHA). The sub-national perspective is important in cancer screening programmes, because responsibility for cancer screening service delivery lies with regional authorities in a number of Member States. Nevertheless, even though cancer screening also requires more centralised national systems, the regional and local levels are crucial for effective implementation of high-quality, population-based programmes. There are still knowledge gaps between the activities and organisational solutions for the various levels of the coordinated activities within large-scale programmes. The knowledge attained by screening programme managers and leading researchers from the local and regional tiers can offer valuable insights into the barriers and potential solutions for better implementation of organised screening programmes. Thus, there is added value in the opportunity to learn from the experiences of fellow professionals, also within the same country. Of special importance is the focus on engaging the regional and local levels in order to learn from their practical insights. This includes learning from peers about innovative and successful practices (such as with innovative social marketing and tailored campaign techniques to increase uptake in organised screening programmes); understanding the barriers to implementation or weaknesses in existing programmes (such as counterproductive incentives that lead to over-screening); and discussing the contrasting opinions on common issues (such as the role of the GP and other health care personnel in the programme). Local and regional environments also provide platforms to develop good practices and solutions to cancer screening where effective evidence-based screening is not yet in place.

Another innovative project in this strand of work by the European Partnership was conducted by the Netherlands Standardisation Institute (NEN) and has shown the potential benefit of applying the knowledge available in the ESSM to other areas of prevention. In cooperation with the organisers of the intensive ESSM training course, NEN developed initial quality criteria for health checks. Such services offer single or periodic examinations to detect a condition or risk factor but are seldom organised in a publicly mandated programme with comprehensive quality assurance (37). CWA 16642 (Quality criteria for health checks) is mainly aimed at providers of health checks and policymakers. Providers might learn what defines a responsible health check service and improve their services accordingly. Policymakers might learn how to make decisions about the need for policy or regulations for health checks or providers. Quality criteria for health checks will help consumers to make informed choices. Application of the quality criteria developed in the project may help to reduce unnecessary prophylactic testing in the EU that has the potential to cause more harm than benefit. The final document is available from www.epaac.eu (38).

Discussion

Approximately 150 million people in the European Union are in the age range recommended by the Council of the EU for breast, cervical or colorectal cancer screening (17). Population-based screening programmes are complex endeavours, involving tens of thousands of professionals and staff in large Member States, depending on the size of the population and the cancers targeted for screening. The scale and the complexity of the tasks confronting decision-makers, coordinators and other professionals planning or implementing these programmes illustrate the importance of continuous training in coordination, monitoring and evaluation. Yet, these very challenges make it difficult for these individuals to take time in their daily work in order to acquire and maintain the requisite skills and to keep pace with new developments.

EPAAC has allowed us to tackle this challenge, bringing together competent, highly experienced leaders and reference centres in Europe to collaborate with decision-makers and key staff at a national level. Together, we developed and tested a comprehensive training course on implementation of population-based cancer screening programmes. The substantial variation in the conditions under which screening programmes are planned and conducted in Europe, as well as the different phases being implemented at the time, were both a challenge and an opportunity for learning. The clear success of the project in coping with these challenges is documented in the evaluation by course participants. It shows that the coordinated interaction between faculty and course participants

actively involved in the planning or implementation of screening programmes was very fruitful. The exchanges of experience during the course about concepts, problems and potential solutions enabled collaborators to identify and resolve the key issues in managing the process of programme implementation.

The benefit of international collaboration in improving the implementation of cancer screening programmes not only results from the opportunity to learn from the successes and the mistakes of other programmes. Given the limited number of screening programmes in the world, few countries have substantial experience and training capacity for programme implementation. Sharing resources for training can expand capacity and avoid delays. This approach was also crucial to the success of the present project. By joining forces with a project aiming to assist countries in the Mediterranean region in improving early detection and screening (Cancer Screening and Early Detection in Mediterranean Countries, CSiMC)⁵, we were able to provide financial support for 21 delegates, 6 more than originally planned, and the faculty was more than doubled in size, from 10 to 26. Additional faculty members were particularly beneficial in creating a critical mass for high-quality peer discussions during the course.

Outlook

Knowledge of how to conduct quality assurance for screening programmes that aim to reduce the population burden of common cancers has expanded considerably in recent years (6–12). This important component of cancer control is clearly recognised in the EU policy on cancer screening (17) and is firmly anchored in the policies of the EU Member States (14); for a recent example see (16). Likewise, it is a cornerstone of effective National Cancer Control Programmes that can effectively link improvements in the quality of the entire screening process to the continuum of symptomatic care (awareness raising, health promotion, diagnosis and subsequent treatment).

Of equal, if not greater importance in efforts to improve the health of the European population will be assuring the quality of the lengthy translational process by which population-based cancer screening programmes are established across a country or region (13,14,24). Promising methods that should be applied include the pan-European collaboration developed in the European

⁵ CSiMC is one of a number of projects in the EUROMED initiative of Italy, France, and Spain that encourage collaboration between EU Member States and non-EU countries in the Mediterranean region. The CSiMC project is financed by the Italian Ministry of Health and is supported by the governments of France, Italy and Spain as well as IARC and WHO headquarters and the WHO regional offices in Europe, the Middle East and Africa. It aims to assist EU neighbouring countries in the Mediterranean region in implementing population-based cancer screening programmes or in appropriate efforts in capacity building when population-based cancer screening is not yet a recommendable option for cancer control. The project is under the scientific responsibility of the CPO Piemonte and AO 'City of Health and Science' of Turin and is coordinated by the Department of Prevention (ASL TO1) of Turin.

Cancer Network, which permitted successful development of comprehensive, multidisciplinary quality assurance guidelines (6,8–12), organisational and behavioural aspects of collective impact highlighted in North America (26), and behavioural aspects of motivation and communication emphasised from relevant experience in Australia (27). A common element in all of these methodologies is the essential role of a sustainable organisational infrastructure focused on coordination and translation of knowledge into effective action. This will be the prime role of the ESSM in the future: providing an infrastructure to enable the existing competence and reference centres for cancer screening in Europe to expand and intensify their collaboration at an academic level and to incorporate new centres that may be created in current and future EU Member States into the network.

Sustainable support for the ESSM network to provide the requisite institutional infrastructure for cost-effective expansion of intensive training courses will enable Member States to leverage synergies with other relevant EU initiatives and activities, such as the EU Framework Programme for Research and Innovation Horizon 2020; the EU Health Strategy, Together for Health; and the initiatives of the European Commission's Joint Research Centre to develop an EU-wide quality assurance scheme in cancer health care services that addresses not only screening programmes but also the whole pathway of care.

Sustained financial support for the ESSM will permit future training to cover the full range of professional, technical and scientific expertise needed to maintain the quality of the entire screening process in evolving programmes, and it will enable countries not yet ready for screening systematically to improve their procedures for early detection of symptomatic disease (1). The latter approach has significant potential to strengthen health systems development and capacity building in countries neighbouring the EU. International collaboration in improving early detection of cancer is therefore a win-win strategy with great potential to improve the health of the population both within and beyond the borders of the EU. It also has the potential to touch the lives of millions of citizens who are invited to attend population-based screening programmes, or who are cared for by improved services for early detection and treatment of cancer. In doing so, it demonstrates to very large numbers of people the benefit of peaceful cooperation in the pursuit of common values that aim to give every person an equal chance of improving their quality of life.

Conclusions

Joint priorities and principles of health policy agreed at the level of the EU institutions have been very important for EU Member States in planning

modifications of existing cancer screening programmes, as well as in planning new programmes and pilots, such as for colorectal cancer screening. Integration of both regional and national coordination and evaluation of screening programmes has been essential in developing the widely recognised European guidelines for quality assurance in cancer screening. Effective implementation of the European recommendations and the principles of population-based cancer screening are also important for neighbouring countries, particularly European countries outside the EU. Due to insufficient resources in several of these countries, appropriate cancer diagnosis and management services are not available to a large part of the population. Hence there are particular challenges in planning and prioritising cancer screening and prevention programmes in these settings. The successful development and piloting of the first intensive training course for decision-makers, coordinators and other staff in population-based cancer screening programmes in Europe is an important achievement of the new European Partnership for Action Against Cancer, and one that will eventually benefit large numbers of people within and beyond the borders of the EU.

The core curriculum produced in the course will provide further added value in the future, when the exercise is repeated with delegates from other programmes or from the same programmes in more advanced phases of implementation. However, the curriculum itself is merely a tool; its successful application requires intelligent users. The future impact of this important instrument will therefore depend on the sustainability of the ESSM network of competence and reference centres launched in the framework of the project.

The experience we report here demonstrates the need for sustaining and strengthening the ESSM network to enable it to expand its collaborative activities at an academic level, where translational research to improve knowledge of implementation of cancer screening programmes can thrive.

This will ensure that an effective and mutually beneficial exchange of experience between screening programmes and countries in and around Europe can continue. That is essential to maximise their beneficial effect on the burden of disease in the population and minimise the risk.

Many of the current cancer screening programmes in EU Member States with the highest level of resources would not have been started, or would still be in an earlier phase of development, had it not been possible to exchange experiences and share capacity for training, monitoring, evaluation and innovation across borders. Effective promotion of the ESSM network will therefore also be crucial to the success of the European Commission's initiatives to develop an accreditation scheme for breast cancer screening and management in the EU based on updated and evidence-based quality assurance recommendations.

Due to the ongoing economic recession, there is also a particular need in many Member States to improve the cost-effectiveness of screening programmes. A number of Member States also require support from external funding to initiate and pilot these programmes effectively. Our experience with the ESSM also demonstrates the benefits of international coordination and scientific support for this cross-border collaboration, which ensures that the efforts of the EU and the WHO are consistent, particularly in promoting the population-based approach to implementation that is conducive to effective quality assurance, and in striving to achieve the high European standards.

Sustaining the European Schools of Screening Management (ESSM) as a unique new facility for international cooperation should therefore take account of the evolving needs of new, as well as more mature cancer screening programmes. It will lead to more progress in improving the early detection and treatment of cancer in Europe and in other regions that may seek to follow this European example of best practice.

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Chapter 5

More than a European sound box: capitalising on the added value of the European perspective in cancer treatment

*Josep M Borrás,^a Joan Prades,^a Jeanne-Marie Brechot,^b Sara Faithfull,^c
Annalisa Trama,^d Paolo G. Casali^d*

Main messages

- Differences in cancer outcomes among EU countries are related to differences in prevention policy, screening, access to specialised care, availability of innovative treatments and organisation of cancer care provision.
- The EPAAC sub-project on Healthcare explored networks for their innovative and efficient manner of organising the patient journey at regional, national and EU level. Networks facilitate multidisciplinary cancer care and rapid access to accurate diagnosis and treatment of cancer.
- EPAAC identified key challenges to the network approach, including the need to balance organisational innovation with continuity of care and stability, as well as the integration with primary health care and patient involvement in network management.
- Our experience shows that specialised, high-quality care of rare cancers has a European dimension, which can be explored through a network model supported by evidence-based clinical guidelines, clinical expertise, a multidisciplinary approach and evaluation of outcomes.

^a Catalanian Institute of Oncology; Barcelona, Spain; ^b Institut National du Cancer; Boulogne-Billancourt, France;

^c University of Surrey; Guildford, England; ^d Fondazione IRCCS Istituto Nazionale dei Tumori; Milan, Italy

Introduction: challenges in achieving standard quality in European cancer treatment

Perhaps one of the facts that most differentiates the European Partnership for Action Against Cancer (EPAAC) from past initiatives promoted by the European Union is the inclusion from the very beginning of specific objectives on cancer care, in addition to the more traditional areas of work on primary prevention, screening and information systems. It is well known that the organisation of health care, the provision of health services and the decisions regarding priority areas for funding are all competencies of Member States. Thus, EPAAC represents something of a departure from these standing legal arrangements, opening informal channels and mechanisms to deliberate and make decisions at the EU level, sometimes shaping a professional-based interdependence that already existed in some form.

The rationale for this new approach is based on the added value that EU-based actions bring in response to the stark differences in resources and outcomes existing across European health care services. In the area of cancer care, our mission at EPAAC was to identify and prioritise the contributions that would benefit most from a joint approach. To this end, different objectives were pursued, including the identification and assessment of best practices across European health services, the exchange of experiences regarding innovative organisational approaches, and the inclusion of patients' perspectives in health care organisation and services (see Chapter 1 for more details on EPAAC activities focused on health care). We engaged a number of diverse institutional partners (Table 5.1) in order to address these issues, and all contributed to making this Joint Action a truly participative initiative.

The assumption underlying our work was that cancer outcomes could be improved in all or most countries if the entire range of activities and services for cancer were performed at anywhere near the levels achieved by the top health systems and providers (1). In this regard, and in accordance with European treaties establishing equality as a key principle of the EU, it seems justified to expect that all Europeans should be able to access good services for cancer prevention, screening and treatment, including nursing and supportive services. In this way, we can reduce the risk of suffering cancer as well as improve survival and quality of life, independently of citizens' place of residence and socioeconomic level, and decrease mortality rates. The high level of cancer incidence across Europe makes this a crucial issue, with great potential to reduce avoidable inequalities in areas such as life expectancy, health status and access to high-quality health services.

Table 5.1 List of EPAAC associated and collaborating partners in health care

Associated partners

National Coordination for Oncological Diseases, High Commissariat of Health, Ministry of Health, Portugal

Polish Ministry of Health

Catalonian Institute of Oncology (ICO)

French National Cancer Institute (INCa)

European Health Management Association (EHMA)

European Society for Paediatric Oncology (SIOPE)

European Hospital and Healthcare Federation (HOPE)

European Society for Clinical Nutrition and Metabolism (ESPEN)

European Oncology Nursing Society (EONS)

Norwegian Directorate of Health, Norwegian University of Science and Technology

European School of Oncology

Tuscan regional government, Italy

Belgian Ministry of Health

National Institute of Public Health of the Republic of Slovenia

Collaborating partners

European Coordination Committee of the Radiological, Electromedical and Healthcare IT industry

International Agency for Research on Cancer (IARC)

European Society of Radiology

Fondazione IRCCS Istituto Nazionale dei Tumori. Surveillance of Rare Cancers in Europe, RARECARE Project

International Psycho-Oncology Society (IPOS)

European Cancer Patient Coalition (ECPC)

European CanCer Organisation (ECCO)

Europa Donna - The European Breast Cancer Coalition

European Institute of Women's Health

European Society for Medical Oncology (ESMO)

European Association for Palliative Care (EAPC)

Lombardy regional government

Cancer Policy Unit, Department of Health and Children (Ireland)

European Observatory on Health Systems and Policies

European Union of General Practitioners (UEMO)

The approaches and experiences presented here point out the feasibility of building a European perspective to exchange best practices in cancer care and of supporting the initiatives carried out at national or regional levels. Common efforts through the EPAAC Joint Action, then, constitute more than a European sound box¹: they consist of a new lever to support European cancer care policy and develop a more cohesive Europe.

Differences in outcomes

There is consistent evidence that significant European variations exist in terms of health outcomes. The best evidence we have of such differences is provided by the EUROCORE project, which compares the data on survival from most population-based cancer registries in Europe (2). Relevant differences between countries are shown for all tumour sites, including adult and paediatric tumours as well as in rare cancers. Although a trend to convergence in survival has been observed, there are still large differences among patients with frequent tumours such as breast or colorectal cancer (Figure 5.1 and 5.2).

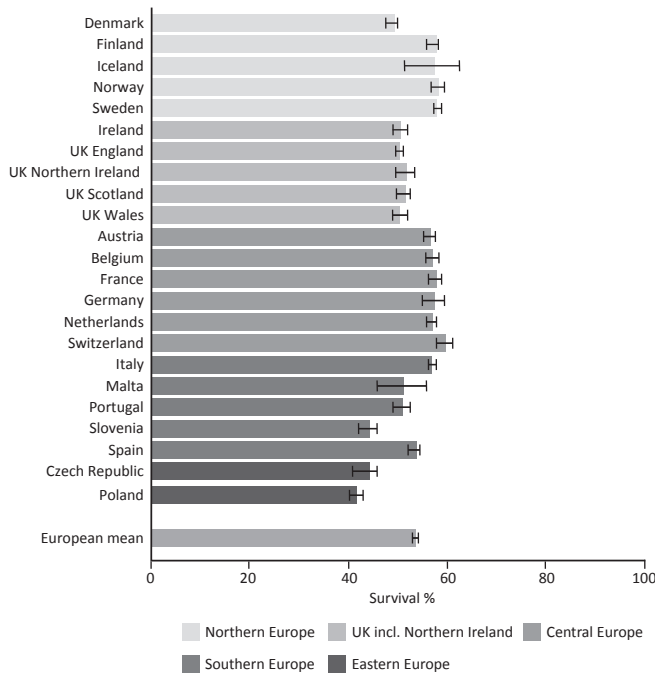


Figure 5.1 Age standardised five-year relative survival estimates for colorectal cancer in selected European countries, 1995-99

Source: (2)

¹ An open chamber in the body of a musical instrument that modifies the sound of the instrument and helps transfer that sound to the surrounding air

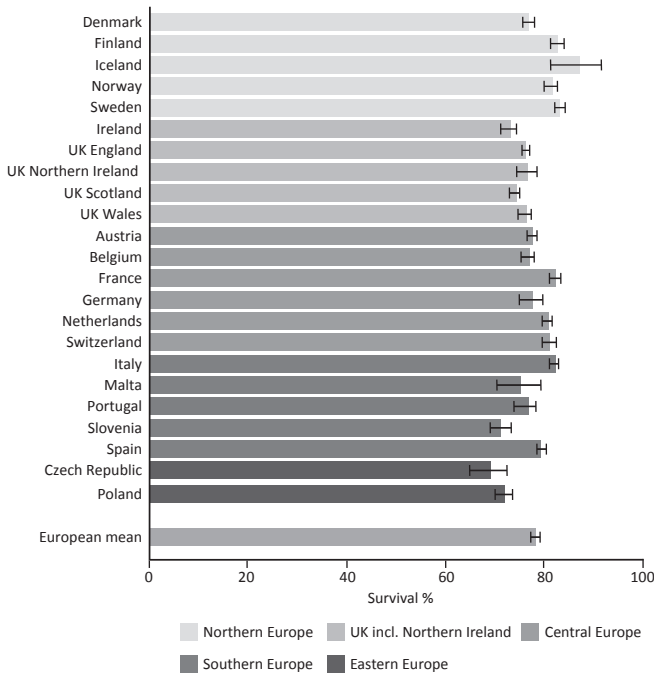


Figure 5.2 Age standardised five-year relative survival estimates for breast cancer in selected European countries, 1995–99

Source: (2)

These differences in outcomes and in health systems' provision of prevention and care may reflect past decisions on funding, policies for prevention or screening, and access to interventions for the diagnosis or treatment of cancer. In fact, health systems organisation has been associated with cancer outcomes through different mechanisms: coverage and access to care, availability of effective innovative treatments and quality assurance of care (3). Also, it should be kept in mind that the consequences of changing these decisions require time to become apparent; thus, the precise point in time that they were implemented is worth consideration in assessing the expected outcomes. On the other hand, as documented in the assessment of the objectives of different National Cancer Control Programmes (NCCPs, see Chapter 8), there are differences in the way to cope with this gap in survival between EU countries (4), for example through diverse configurations of multidisciplinary teams, which may or may not include professionals such as specialist nurses, palliative care specialists, psycho-oncologists, or others.

Important variations in service delivery remain between and within countries for different health care settings, with repercussions in the quality of care provided to individuals. Remarkably, it is increasingly feasible to assess these services for

cancer patients by using cancer registry data (5), including the effects of service delivery structures and processes on outcomes (6). Preliminary results of a study by the Organisation for Economic Cooperation and Development (OECD) (on the factors related to the variations in survival) show that differences in survival are associated with a combination of structural factors, spending and quality of care (7).

It is important to note that the role of the organisational aspects is independently related to better outcomes. Quality in the delivery of cancer services (combination of screening programme characteristics, waiting time from diagnosis to initial treatment, and reported provision of optimal treatment) can explain approximately a third of the differences in cancer survival, while a cancer-specific policy may be responsible for up to a quarter. The key elements of the latter include the full implementation of an NCCP, with specific targets and timeframes; close monitoring of progress; implementation of clinical guidelines (including the necessary professional training); and enforcement of quality control measures. EURO CARE data has also shown the importance of access to diagnostic facilities and therapeutic strategies in different high-resolution studies and in specific analyses comparing developed countries in Europe or elsewhere (8,9).

The challenge of coordinating different specialities, professionals and levels of care

Cancer requires integrated approaches that range from prevention and diagnosis to treatment, rehabilitation and palliative care. In recent years, organisational issues have been more prominent in cancer policy, as evidenced by the priority given to providing patients with prompt access to appropriate specialists for accurate diagnosis and subsequent treatment. Fast-track referral programmes for patients whose physicians suspect cancer have been implemented in different countries, with wide support from primary care physicians and patients (10–12). Likewise, consensus is growing that a multidisciplinary approach to cancer care is the best way to make decisions about each patient's diagnosis, treatment and support. However, the practical implications for clinical practice and their impact on outcomes are all a matter of debate (13,14). Indeed, knowledge transfer approaches are often limited within health care, and there is a lag between research and adoption. EPAAC objectives included holding in-depth discussions with a range of stakeholders on how to implement evidence-based guidance for multidisciplinary teams (MDTs).

Services for diagnosis and treatment are found at primary, secondary and tertiary care levels. Most cancer patients will need one or more services at each of those levels, and organising a seamless care pathway remains a challenge. Ways must

be found to ensure that all parts of the service are developed logically, that they communicate effectively, and that care for the patient is well coordinated (1). This requires combining vertical integration of the services provided at different levels of care with horizontal coordination of the different professionals and services within and between hospitals.

Other challenges should also be taken into account, such as the value attributed by patients to the relationship between quality of life, therapeutic options and expected outcomes. In addition, some issues are gaining relevance as a direct consequence of increasing survival as well as patient and societal expectations, including the needs of long-term survivors and psychosocial care (see Chapter 1 for a description of the activities in this field).

A case in point: rare malignant tumours

In the case of rare malignant tumours, several characteristics converge to make it an area of particular interest for the EU. Representing approximately a fifth of all tumours, rare cancers are both a highly pertinent concern for European cancer patients and one that cannot easily be addressed without joining forces. The 20% figure of rare cancers includes solid adult cancers (16%), malignant haematological disease (4%) and malignant paediatric tumours (less than 1%). Each of these groups is characterised by specific features and patient needs, requiring the involvement of diverse medical specialities (15). Models developed for rare cancers are also interesting in the study of frequent cancers, especially when molecular characteristics define subgroups of patients who may be responsive to targeted therapies. Subsets of rare cancers may therefore be determined within the broader category of frequent tumours according to the expression of specific biomarkers.

The differences in outcomes for rare cancers among different European countries are at least as relevant as in the more frequent tumours, and their overall survival is lower. They usually require complex interventions for diagnosis or treatment, which would ideally be handled in a single centre where all the necessary expertise is assembled efficiently and the results audited consistently. Because these so-called ‘reference centres’ are quite rare themselves, informal networks of professionals have emerged within and between countries to share information, expertise and clinical research protocols. However, evaluating the efficacy of new therapies with traditional approaches is hindered by enormous difficulties due to the low frequency of these tumours and the difficulties associated with including enough patients in clinical trials.

These challenges are recognised by Member States, patient associations, scientific societies and other relevant stakeholders, and a plethora of specific

initiatives exist to tackle them, including EUCERD, the European Committee of Experts on Rare Diseases (www.eucerd.eu), a forum where patients, industry, researchers, Member States and the Commission come together. It is also relevant to mention the project on Surveillance of Rare Cancers in Europe (www.rarecare.eu), funded by EU Framework programmes; RARECAREnet, the new project on Information network on Rare Cancers (www.rarecarenet.eu/rarecarenet/); and the multistakeholder initiative Rare Cancers Europe (www.rarecancerseurope.org). Disease-specific networks include SIOPEN-R-NET², the European MCL Network³ ProTheTs⁴, EET Pipeline⁵ and KidsCancerKinome⁶, among others. The EU directive on cross-border health care also provides a further impulse for pan-European action in this area, setting the framework to build European reference networks for rare diseases. It aims at efficiently facilitating access to the required expertise in reference centres across Europe.

EU action on health care: collective action for common challenges

EPAAC offered a remarkable opportunity to involve a wide variety of stakeholders in an innovative exploration of the European perspective in cancer care. Although the allocation of resources and health care priorities devoted to cancer care at a national level are beyond the scope of this Joint Action, we have been able to make significant progress in assessing the feasibility of exchanging best practices between EU Member States. The number of associated and collaborating partners that have participated, from scientific societies to patient groups, points to the considerable interest in this type of work. The variety of objectives (see Chapter 1) also reflects the opportunities offered by the Joint Action framework. With quite modest means, but ambitious hopes, we have been able to build a network of cancer care stakeholders with interest in forging a European perspective on the issue – in fact, the first step towards European added value.

Networks have emerged as an approach chosen by several health care providers and health systems to cope with this challenge; they are discussed below. The diversity of the problems that have been addressed, as well as the organisational initiatives based on this concept, made it a good choice for assessing the usefulness of the exchange of best practices in this project.

² International Society of Paediatric Oncology European Neuroblastoma Research Network (www.siopen-r-net.org/)

³ the European Mantle Cell Lymphoma Network (<http://www.european-mcl.net/en/>)

⁴ Prognostic and therapeutic targets in the Ewing's family of tumors (www.prothets.org/)

⁵ European Embryonal Tumor Pipeline (www.eet-pipeline.eu/)

⁶ Aiming at selecting and validating drug targets from the human kinome for high risk paediatric cancers (www.kidscancerkinome.org/)

Exchanging best practices: the network approach for more cost-effective cancer care

Clinical networks are emerging as a shared response to the challenge of coordinating cancer care. This is a complex endeavour, involving different levels of care and numerous health care providers (which are already complex organisations themselves) working sometimes across linguistic and/or cultural boundaries – all factors that complicate the implementation of good practice. There are two main objectives associated with clinical networks: first, equity of access to good quality care, achieved through coordination and improvements in cost-effectiveness; and second, knowledge exchange with a patient-centred approach to care. The network approach allows coordinating access to different types of evidence-based care, concentrating resources, and sharing best practices and knowledge – characteristics that help ensure appropriate, timely care for individual patients and clear advantages in terms of clinical benefits. Networks also represent a shift from competition to cooperation in the organisation of health care. Although some degree of competition is inherent in health systems (as different providers compete for recognition and scarce resources), there are many benefits to sharing knowledge and coordinating service delivery, both for patients and the health care organisations that serve them.

Indeed, the consideration of networks as an option to improve cancer care is justified from both health service and professional perspectives. At times, the reason to launch a network is the lack of alignment between policy, hospital and clinical views when delivering cancer care. We saw evidence of this in the United Kingdom, where networks have acted as a driver of change by bringing together the organisations that delivered services with those that planned and purchased them. Clinical leadership was a common feature of almost all experiences reviewed, while the central objectives were sharing knowledge and coordinating the care pathway in an efficient way.

Cancer has been a test case for the progressive implementation of this approach in the delivery of care. To assess how this process is taking place in different countries, our team reviewed and discussed experiences in the United Kingdom, Italy (ROL, in Lombardy), France (ONCORA Cancer Network, in Rhône-Alpes), the Netherlands (South Eindhoven), Belgium (Iridium cancer network, in Antwerp), Denmark (Danish Multidisciplinary Cancer Groups) and Spain (Catalonian Institute of Oncology (ICO) network). The development of European reference networks was also considered. Three of these networks (the Iridium network in Antwerp, the ROL network in Lombardy and the ICO network in Catalonia) were then selected for a detailed assessment, which allowed us to narrow the focus of our discussions to key issues.

Models of networks

Our review of experiences clearly underscores the varied level of integration found in different organisational models (16) (Figure 5.3).

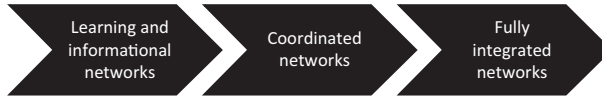


Figure 5.3 Network approaches by level of integration

Learning and informational networks

Learning networks are established to share best practice, knowledge and information. Main features include ‘soft’ networking mechanisms, flat structures and non-integrated delivery systems. Because personal and professional relationships drive network creation, their stability is linked to the benefits perceived by members. Like social networks, learning networks are not usually imposed or mandated; instead, they spring from the initiative of individuals or groups of professionals, for example, networks promoted by scientific societies to develop clinical guidelines or telemedicine.

Coordinated networks

Coordinated networks go a step further in the integration of service delivery. The model known as ‘Managed Clinical Networks’ is characterized by formal coordination among institutions, which become nodes of the network even if they retain full autonomy. The agreement involves financial and clinical responsibility.

Fully integrated networks

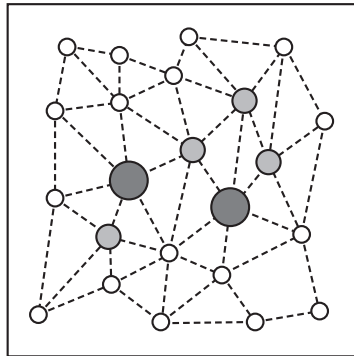
Integrated delivery systems, or managed care networks, are responsible for the entire clinical pathway. Resources are centrally managed through a hierarchical structure. Thus, this model cannot be considered a network of organisations but rather a network organisation. One example is Kaiser Permanente in California (USA).

In Europe, experiences in Catalonia (17) and Lombardy (18) are worth mentioning for their different approaches to clinical management (Boxes 5.1–5.2).

Box 5.1 The Lombardy Cancer Network (ROL)

ROL is a regionally based network in Lombardy, Italy, aiming to ensure appropriate and equitable provision of high-quality cancer services. The Istituto Nazionale dei Tumori (INT) in Milan, the leading partner of the network, is firmly supported by the Lombardy government. ROL can be considered a distributed network, as relationships are mainly based on collaborative capacity-building. In this regard, ROL pursues three main avenues of action: developing a community of clinicians and researchers in Lombardy; creating a common language by sharing and updating diagnostic and therapeutic guidelines for disease management; and using a common information system (SISS) to design and generate a structured document (a ROL-DOC) of clinical data. SISS is a linchpin of the network, permitting the interaction, assessment and monitoring of medical practice, and consolidating clinical guidelines and consensus recommendations generated at the network level.

This model is connected through an information system with embedded clinical guidelines. Additionally, clinical research in the network has been made feasible through funding by the regional government granted to support the network.

Distributed network model***Lessons learned in network organisation for cancer care in Europe***

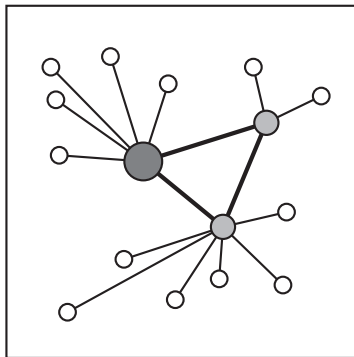
The dynamic nature of cancer care brings organisations to increasingly rely on networks for knowledge and expertise, leading to a variety of experiences and models across Europe. The exchange of best practices regarding the organisation, implementation and outcomes of cancer networks sheds light on some key issues, presented below.

Cancer networks, especially those aiming to influence clinical practice, have been identified as an appropriate instrument to help improve equity and

Box 5.2 The Catalanian Institute of Oncology Network (ICO)

The Catalanian Institute of Oncology Network is a managed clinical network based on a double-level, centralised 'hub and spoke' model. ICO is made up of three tertiary hospitals (including one cancer institute) and fourteen local hospitals. Relationships among the tertiary hospitals are based on a contractual framework, and they make strategic decisions (for example on clinical guidelines and drugs prioritisation) for subsequent adoption by local hospitals.

In turn, the local hospitals set up bilateral agreements with the area tertiary hospital. The main added value of ICO resides in its ability to increase access to high-quality cancer services by directing specialised resources to areas where those services are not typically available. Medical oncologists, radiation oncologists, haematologists and other specialists divide their time between tertiary and local hospitals, thereby streamlining services and use of evidence. ICO constitutes a centralised network of cancer services, aiming to increase accessibility to the reference hospital even as it allows local hospitals to retain control over clinical decisions regarding frequent cancers on their own tumour boards.

Hub and spoke model

quality while optimising the use of scarce expertise. However, because no single network model exists, our team analysed the different kinds currently in use. Differences related to aspects like dimension, professional and/or institutional involvement, level of integration, and diversity of stakeholders (although they were mainly hospitals). These typologies were based not only on preferences but also on perceived needs for cooperation.

In addressing the implementation of cancer networks, there is a need to balance organisational innovation with continuity of care and stability. Cancer networks in the United Kingdom have shown how the work of many professionals in teaching hospitals involves a multilevel outlook (for instance,

across levels of complexity or care) rather than simply longitudinal. Thus, professional performance was already embedded in complex systems, and changing management towards a network model was crucial in order to avoid overlapping roles and competences and to foster engagement in network principles and objectives. Also, from a provider's perspective, it is very difficult to engage clinical teams if the network covers too large an area with separate clinical pathways. Defining adequate boundaries for the networks, then, is key, mainly in terms of the goals likely to be assumed (for strategic planning, operational delivery, etc.) and stakeholders potentially involved, especially when the network is not limited to a defined geographical area.

Likewise, another area of interest is the assessment of the network's approach to cancer care. Managers often ignore evaluation of clinical and process outcomes, which is a mistake. Network organisation in cancer care service provision is a good model, but its usefulness must be demonstrated within the specific health system context. Making information on network outcomes available may well be crucial to improving adherence to network goals, especially for new or peripheral stakeholders.

In this regard, linking data to cancer registries may drive quality improvement. The assessment carried out by the Rhône-Alps Cancer Network (France) on compliance with clinical guidelines and observed improvement in clinical outcomes, describes one notable example (19). Another is found in the Eindhoven cancer registry in southern Netherlands, where use of the population-based cancer registry data was important during the centralisation/ decentralisation process of different treatments and in quality improvement for care of tumours such as those of the digestive tract (20).

The role of patients in a network context, with the exception of the United Kingdom, is not properly addressed. Indeed, the United Kingdom experience showed the difficulties in recruitment of the proper patient profiles at this level. Such patients have to be real representatives of the clinical experience in the network in order to take full advantage of their role as drivers of quality improvement. One option is to include patients' representatives at the management level of the network. Patients, families and caretakers are especially concerned about the increasing complexity of care pathways, so information on how to deal with the health system structure should be developed and provided by means of health services coordinators and mechanisms across the network's points of contact (general practitioners, nurse case managers, administrators, etc.).

Engaging primary care practitioners is relevant if the network is to cover the entire patient pathway, including prevention and detection as well as treatment

and disease management. Finally, in dealing with the issue of network sustainability within the context of the ongoing reforms in Europe (trend towards concentration of services, transnational research and care coordination, etc.), some key issues were brought into focus:

- The political sphere is always present; balancing a certain level of political involvement with technical management is needed.
- Strong network leadership should be developed; this should be open to specialities other than medical oncology.
- Current regulation and funding mechanisms in most EU health systems do not facilitate inter-organisational coordination; an accreditation system would be advisable in the medium term.
- Defining external and internal accountability in a network context is required.
- Patients should be incorporated into advisory positions within the network.
- Junior doctors and nurses should be acquainted with this model of management early on.

In brief, despite being very difficult to capture the network approach in a single model, it is clear they do bring added value to both patients and providers.

Innovation and cooperation: European added value in caring for rare cancers

Networks on rare cancers: an opportunity for Europe

‘Rare cancers are not so rare’ is the title of a well-known paper in the field (15), nicely summarising a key feature of this group of tumours, namely, that they are very infrequent individually, but considered together, they make up about 20% of all cancers, representing a highly relevant challenge to health systems. They are not so rare, indeed.

These tumours pose special burdens on patients, requiring diagnostic and treatment expertise that may not be readily available close to their residence. Patients sometimes have to travel long distances to access appropriate pathologic diagnosis and multidisciplinary treatment, and they have few options for a second opinion. In many cases, referral patterns are based on informal networks of professionals. Health and social costs (the latter due to health migration) can be higher because clinical expertise and specific diagnostic and/or therapeutic procedures are usually concentrated among just a few professionals and hospitals.

Scientific societies and patient associations (21) have repeatedly called for the development of a European approach to this issue. The EU and various Member States have also been very active, supporting research and health information projects for both adults' and children's diseases, as outlined above under 'A case in point: rare malignant tumours'. There is also a wide consensus on the need to share expertise in the diagnosis and treatment of these tumours; this knowledge is in short supply due to low numbers of patients and the consequent lack of evidence on the efficacy of different therapeutic options. These factors help explain the significant clinical variability in the diagnosis and treatment at hospital or professional level. Discrepancies in the proposed treatment for these patients are not infrequent, and the need for patients themselves to use the web to search for second opinions and additional information are common features.

Building on the evidence shared by national and international expertise

There is increasing collaboration among different professionals, centres and patient groups through informal networks that exchange good clinical practice on rare malignant tumours. Research networks, usually based on cooperative groups of clinical researchers, have also been fundamental in promoting good quality clinical research. The combination of clinical knowledge and research projects has led to a concentration of expertise in specific hospitals and professional networks, recognised by the clinical community as references for specific rare tumours.

Recently, different European countries have developed formal approaches for organising the so-called expert centres on different rare adult cancers, for example in France (22). The rationale for this network approach resides in several factors: (a) the difficulty of diagnosing these tumours, which can lead to delays or even misdiagnoses; (b) the management problem posed by limited access to highly specialised therapies, which are only available in a few institutions; (c) inadequate access to clinical trials when available; and (d) the specific needs of the patients suffering from these diseases.

The French experience has given rise to a number of innovative practices. Better use of information technology is a key feature: it is used to facilitate the systematic second reading of the tissue sample by virtual slides as well as the discussion of the patient's file by experts through web conference, without the need to transfer the patient. The networks are composed of expert regional centres spread throughout the national territory and coordinated by a national expert centre. The French 'hub and spoke' model also improves patients' access to clinical trials, facilitates their registration in dedicated databases and favours

the dissemination of information for them – all activities supported by strong collaboration with patients' organisations. Twenty-three clinical networks and four pathological networks for rare cancers have been designated. In 2011, more than 6000 patients with rare cancers benefitted from a second pathological opinion, and the final diagnosis or medical management was modified in 27% of sarcomas, 15% of malignant mesotheliomas, and 11% of rare neuroendocrine tumours. Forty-six clinical trials were initiated and 17 completed, the vast majority in sarcoma patients. In the same year, 835 patients with rare cancers were included in a clinical trial. To date, more than 8900 cases have been registered in 13 clinical databases over several years. Annual reports of the activity of these networks will continue, and a global evaluation of the organisation will be conducted in the near future.

There are interesting examples of organisation of services for rare cancers in other European countries, such as the United Kingdom, where guidelines for organising low frequency procedures and diseases are being implemented (see www.specialisedcommissioning.nhs.uk).

Also, the RARECARENet project is working on identifying criteria for centres of expertise for the whole range of rare cancers as well as on providing a list of patients' associations working in the field of rare cancers, in a collaborative project carried out with the involvement of different scientific societies and the European Coalition of Patients Associations (ECPC). Examples like this could serve as a model in the exchange of experiences that require a combination of expert input and organisational design in order to build a consensus between clinicians, managers and patients. However, it would require strong institutional and professional commitment as well as data on the design benefits.

Another aspect to be considered is the feasibility of harmonising clinical guidelines at a European level in light of the differences in practice across Member States. In the case of rare malignant tumours, the added value of such an exercise is clear, raising the potential for this approach to become the backbone of a European reference network on the most complex of these diseases. However, the challenge posed by this objective is relevant, as indicated by the recent reviews of the regulatory basis, development, implementation and evaluation of clinical guidelines in European countries, which showed the great variability in the process of guideline elaboration among EU countries and the lack of the assessment of their implementation in our health care systems (23,24).

EPAAC addressed the management of rare cancers in Europe in a three-step process. First, we mapped the existing networks devoted to rare cancers in specific populations; second, we explored the agreements and discrepancies in

current clinical practices; and third, we assessed the feasibility of harmonising clinical guidelines. In parallel, we chose one tumour (sarcoma) as the most suitable option to carry out a case study for this exercise.

Combining evidence and expertise to set recommendations

We needed two types of information before assessing the feasibility of harmonised clinical guidelines for sarcoma. First, we had to map patients' associations as well as cooperative research and care networks in the field, and second, we needed to review the clinical guidelines in different EU countries. This was achieved by means of a survey of experts and patients' organisations, a relatively straightforward exercise due to the limited number of experts in this field. Indeed, the small number of experts represented both an advantage in terms of carrying out a harmonisation exercise, as well as the best justification for its necessity.

An expert meeting was then convened to carry out the feasibility assessment. This consensus-building process, focusing on reaching clinical agreement about the best evidence-based care for these tumours, represented the first step in building European reference networks. As such, it constituted a valuable exercise in and of itself (regardless of the results of the consultation), providing a learning experience that would be difficult to replicate without explicit European endorsement. Perhaps the most relevant conclusion from this expert meeting was the relevance assigned to the clinical guidelines as the backbone of a coordinated network of cancer care. However, clinical guidelines are not useful unless compliance and patient outcomes are assessed after implementation in the network, and tailored to individual patients through clinical expertise, properly shared to maximise use.

Although the process is ongoing, several lessons have already emerged. First of all, the simple fact that this process could be carried out at all should be highlighted because it could be a model of good practice for the management of other rare diseases. Another point to emphasize is the wide consensus among clinical leaders in the field about the relevance of the process, as shown by their involvement from the very beginning; indeed, clinical leadership is a key factor in building a sustainable network of cooperation among health care providers. The need to involve patients' views through their representative associations should also be considered from the beginning. Finally, it has become clear that building a network of networks for a tumour such as sarcoma, with low incidence, complex management, and difficult clinical decisions about therapeutic options and outcomes, clearly associated with clinical experience of the multidisciplinary team involved in the process, is in fact a realistic objective for the EU due to the accepted European dimension of this approach. However,

the need for financial support and commitment to this endeavour from Member States should be highlighted. There is convincing evidence that coordinated networks with evidence-based clinical guidelines increase compliance with the good cancer care standards and lead to improved outcomes for patients (19,25). One key factor is to fund these networks properly, since otherwise efforts will be never sustainable and will fade away once demonstration projects are over. Another is to capitalise on the added value of existing informal research networks, which have been shaped by health professionals on actual needs.

Discussion

Several issues have been raised in dealing with the objectives related to cancer care. Perhaps the most relevant is the discussion on how to take advantage of the opportunity offered by EPAAC to exchange good approaches to cancer care organisation and to adapt and implement them in highly specific contexts. This chapter has focused on our activities in rare tumours and in network approaches to cancer care organisation, two areas that exemplify the challenges posed by these goals. Their achievement requires not only a careful consideration of organisational approaches and implementation issues, but also a shared belief in the usefulness of the approach chosen.

The case studies we selected for this chapter demonstrate the feasibility of innovative options, provided that certain conditions are met. First, relevant stakeholders should be involved from the beginning of the process, when the problem is defined. The alignment of managers, professionals and policymakers is needed to increase the chances of success. At a European level, this process is made more difficult by the complexity of involving all stakeholders (both national and EU) and considering different health resources and policies. However, it is telling that so many health systems, institutions and professionals have chosen the same options to deal with rare tumours and the coordination of the patient journey through different levels of care, indicating the usefulness of the network approach.

Another factor to be considered is the quality of the long-term cooperation among the stakeholders participating in the networks. Good implementation and consolidation of any model requires certain continuity in the approach used, but this must be balanced by the need for flexibility and innovation. These organisational approaches continue to evolve under the influence of political changes, among other factors, as shown for instance by the evolution of the networks in England. Flexibility is required, but it should be balanced with the need to consolidate procedures and methodologies in relation to the patients.

Another important aspect to consider is the harmonisation of information systems, crucial in promoting equitable access to good quality cancer care. In order to be able to compare health care processes and outcomes across different systems (even within the same country), variables within databases must be standardised. The EU has been proactive in this regard, promoting a number of initiatives:

- PARENT (Cross-border Patient Registries Initiative), aimed at supporting cross-border use of patient registry data for secondary purposes (www.patientregistries.eu);
- EUROCOURSE, based on population based cancer registries, which has worked in the use of clinical databases linked to the cancer registries (www.eurocourse.org);
- EURECCA, which is promoted under the leadership of ECCO, aimed at assessing the quality of cancer care based on audits of clinical practice with a population-based perspective (www.canceraudit.eu);
- RARECARENet project, which is undertaking a high-resolution/pattern-of-care study on rare cancers and will report on the feasibility of such study for rare cancers and on the quality of cancer registries as a source of information for studying patterns of care for rare cancers (www.rarecarenet.eu/rarecarenet/); and
- The proposal of a European Cancer Information System (ECIS), aimed at gathering all the relevant population-based data in a shared database (see Chapter 7).

Lastly, our partners have highlighted patient involvement as an important element in all projects. However, the reality is that their role in networks is not consistently defined in the case studies we have analysed. Although policy is increasingly oriented towards promoting the participation of patients in both formal and informal structures, there is still a lot of work to be done in translating these intentions into real patient involvement in setting priorities and organising cancer care.

Concluding remarks: lessons on European added value in cancer care and health care

Although most of our activities are still ongoing, the pursuit of the objectives laid out for us at the launch of EPAAC has brought to light several key lessons applicable to future European work in the area of cancer care and health care in general.

With regard to lessons specific to cancer care, perhaps the most relevant opportunity for joint European action has to do with the management of rare cancers; this is a highly pertinent health issue that affects many patients but which few countries can address on their own. The relatively small number of experts and patients with interests in a given tumour justifies the need to join forces, but it also facilitates the creation of manageable, cooperative structures that involve all stakeholders. Thus, great promise exists in terms of true European added value in the field of rare malignant tumours. However, realising that promise will require well-defined objectives, time and resources.

It has also become clear that organisational issues are very relevant at the EU level. Clinical pathways should be defined and understood by patients, clinicians and policymakers. Networks are emerging all over Europe as an innovative and efficient way to organise the patient journey at regional, national or EU level, but the best way to ensure patient involvement in the design and management of the networks remains an unresolved challenge.

More broadly, we can extract lessons from our work in cancer care that apply to European approaches to health care in general. First of all, it has become clear that involving a critical mass of institutions and clinical leaders is essential. This factor determines the expertise and resources available for the project, two vital ingredients to foster effective, evidence-based policy approaches. At the same time, a participatory process in which ownership is shared among key stakeholders can promote wider uptake and implementation than a process which is seen as exclusive or top-down.

Above all, we have learned that the *sine qua non* condition for the success of a European approach to health care is shared objectives among all (or at least most) stakeholders. Although common goals may be difficult to identify in a territory as large and diverse as Europe, they are an irreplaceable catalyst for cooperative action. The interest of our Work Package partners, including scientific societies, policymakers and patient groups, testifies to the feasibility of joint action when stakeholders work together on a project that they all see as both relevant and useful.

The role that the European Union plays in cancer care delivery in Member States is likely to remain limited for the foreseeable future, although the Commission's initiative to pilot an EU scheme for quality assurance of breast cancer services will be a key development. Social competencies including health care are firmly embedded in the national or regional context, where organisational arrangements can take into account the highly specific peculiarities of a given setting. However, Member States still face considerable common challenges, and in that sense, the EU is uniquely placed to help. It can foster cooperation among

diverse stakeholders, disseminate innovation and best practices, and coordinate joint responses to shared problems. Indeed, the *Directive on the application of patients' rights in cross-border health care* (26) clearly offers a voluntary way of assessing opportunities and building synergies among Member States that could be useful for patients with rare tumours. Several of the objectives reviewed in this chapter, such as the organisational experiences of different networks in cancer care across European countries and the feasibility of harmonising clinical guidelines could be helpful in carrying out this endeavour. In the end, rare cancers are so rare as to require international collaboration by definition, so this is an ideal area for the EU to express the added value of subsidiarity. Other initiatives from the Commission, such as the piloting of an EU scheme for quality assurance of breast cancer services, could be an interesting development in the near future (see ihcp.jrc.ec.europa.eu/).

Cancer, of course, is among the most pressing issues for patients and health systems in Europe, with an important impact on individuals, communities and health systems. We have explored the ways that cooperation in cancer care can contribute to guaranteeing equitable, high quality services for patients, regardless of their place of residence. Key features of our work have included the development of common goals, the participation of a wide variety of stakeholders, and close attention to translating the innovation found in one Member State or field of knowledge to other contexts and settings. While the tangible results of our work will only emerge after the conclusion of EPAAC, our experience has demonstrated the feasibility and desirability of a shared approach to common problems.

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Chapter 6

Information for action: building a unified European Cancer Information System to bolster cancer control

*Milena Sant,^a Riccardo Capocaccia,^b David Forman,^c Stefano Rosso,^d
Annalisa Trama,^a Sabine Siesling,^e Renée Otter,^f Camilla Amati,^g
Francesco De Lorenzo^g*

Main messages

- Relevant information on cancer is available, but its organisation and harmonisation is necessary to make it usable for health planners, doctors, patients and other stakeholders.
- Cancer registries should be at the core of a European Cancer Information System (ECIS), providing basic cancer indicators on incidence, survival, prevalence and patterns of care but these data need to be systematically linked to clinical, socioeconomic and population data.
- The first step towards an ECIS, the harmonisation of incidence and survival data, has been taken during EPAAC in order to update European cancer data and construct a common database computing incidence, survival and prevalence data.
- Specific conditions for data use still need to be considered, regulating confidentiality and ownership.

With the economic crisis straining health systems all over Europe, and with cancer incidence rising quickly as the population ages, efficiency and effectiveness are more important than ever, as are analyses on the contribution

^a Istituto Nazionale dei Tumori; Milan, Italy; ^b Istituto Superiore di Sanità; Rome, Italy; ^c International Agency for Research on Cancer; Lyon, France; ^d Piemonte Cancer Registry, European Network of Cancer Registries; Turin, Italy
^e Comprehensive Cancer Centre; Utrecht, the Netherlands; ^f Otter Oncology Consultancy; Leeuwarden, The Netherlands
^g European Cancer Patient Coalition; Brussels, Belgium

made by successful cancer policies to societal well-being. Thus, it is no wonder that cancer information interests everyone committed to the optimisation of cancer control, including citizens, policymakers, public health experts, oncologists, patients, data providers and researchers: it is the only way to provide meaningful responses to population needs.

A large amount of detailed information must be studied in depth to manage the complexities involved in cancer control:

- Multifaceted causal pathways and prevention measures
- Demographic trends (e.g., population ageing)
- Patient and tumour characteristics to determine best course of treatment
- The organisation of clinical pathways
- Increasing cancer incidence rates and improved survival
- Survivorship issues, including long-term toxicity, co-morbidity and recurrence
- Psychosocial and spiritual aspects that add different dimensions to patient care
- Cancer economics, crucial in addressing the rising costs and societal impact

Currently, there is great heterogeneity related to cancer control in Europe: from different cancer-related behaviours, to environmental risks, available resources, cancer care organisation, and comprehensive cancer plan implementation. At the same time, many neighbouring countries also share important characteristics. This variation offers a unique setting for cancer research and its application in health care activities, opening up opportunities to compare cancer policies under both similar and different economic, social, cultural and environmental circumstances. Learning from these differences is essential to developing coordinated European cancer policies, and to improving the effectiveness of the actions undertaken. The will and the rationale for building a common framework for data on cancer in the EU are described in the Portuguese presidency conclusions of 2007 (1), those of the Slovenian Presidency of 2008 (2), the 2009 Communication for an Action Against Cancer (3) by Commissioner Androulla Vassiliou, and the European Commission 2nd Health Programme 2008–2013 (4). Our main aim at EPAAC has been to contribute to the construction of a comprehensive **cancer information system for the European Union** (ECIS), an essential tool for developing effective public health interventions and addressing health inequities (Box 6.1).

Box 6.1 Definition of cancer information system

A 'Cancer Information System' is a public health and research infrastructure functionally connecting all institutions, people, procedures and resources; producing meaningful information from cancer data; and working within a common framework of concepts, methods, structures and technical standards. It harmonises the data produced by all these stakeholders and makes the information derived accessible to users under agreed conditions and regulations, providing as much knowledge as possible to facilitate interpretation of the dynamics of cancer in populations.

A cancer information system could greatly help national and European policymakers to develop effective cancer control interventions. First of all, it would enable up-to-date monitoring and future forecasting of cancer risks through incidence and mortality data, possibly disaggregated by detailed geographical area and biological disease characteristics. Through existing data produced by the health care system, it could also provide a systematic picture of the available resources and infrastructures deployed to control the cancer burden and to respond to the demands for cancer services. Survival data (possibly analysed by stage at diagnosis), biological characteristics of the tumour and data on type of treatment would allow evaluation of the performance and the final outcome of health services in providing optimal treatments. Linkage of health data with socioeconomic variables could enable measures addressing health inequities. Finally, a dynamic information system with a solid grasp on population-based data, but open to the progressive inclusion of newly relevant information and able to tackle new information challenges, will be necessary to avoid an enlarging gap between cancer research and cancer control activities.

Building a European cancer information system is a complex undertaking and requires political will at all levels: a comprehensive framework should regulate the coordination of the entire process of data gathering, quality control, management, analysis, dissemination and access. These functions must be sustainable over time and progressively implement innovations resulting from research. For these reasons, the process of constructing the future ECIS should be endorsed by each EU Member State involved. In 2009, the EPAAC Joint Action was officially mandated to deliver by 2013 a proposal laying the basis for a future European Cancer Information System, under the consensus of all cancer stakeholders (data providers, health professionals, governments, citizens, patients and researchers). In 2011, the Cancer Policy Support Group of the European Commission Joint Research Centre (JRC) was charged (5), among other tasks in the framework of the Horizon 2020 goals (6), with a neutral and technical role in assisting the discussion on an ECIS and in acting as a data

repository. It is our intention to illustrate here the state of the art in the field and the activities that have been carried out towards an ECIS, as well as those that have been started and will continue after the completion of EPAAC.

Understanding cancer information: data, registries and cancer information systems

The major advantage in dealing with cancer information in comparison to other diseases is the wide availability of patients' data due to the absolute need for specialist care required. These derive mainly from health care facilities, including administrative and clinical hospital records, pathology reports and pharmaceutical data. Cancer registries intercept many of the data flows generated by these sources and, also through their linkage with population sources (census files, household surveys, vital registration systems, organised screening registries), provide cancer indicators on incidence, mortality, survival and prevalence.

Population-based cancer registration is the continuous, systematic collection of a defined data set on all persons diagnosed with cancer, including the tumour characteristics, treatment and outcome, within confidentiality regulations and under quality criteria defined at both EU and global level for comparability of data (7). Information concerning quality of life, survivorship, cancer economics and functional parameters may also be collected. Data refer to an administratively defined population and are frequently sent to the registry from different units (e.g., public hospitals, pathology departments, haematological departments, medical records, radiotherapy databases, cancer centres, hospices, private hospitals, screening registries, other cancer registries, primary care facilities, nursing homes and death certificates) within a single institution or several institutions. Indicators derived from registry data are frequently accessible online or in specific publications and are usually made available by age, sex and type of cancer.

Other information is also available in Europe. Aggregated data on risk factors, early diagnosis, health care resources and socioeconomic variables are available from a number of sources, including the European Health Information Survey (EHIS), the Organisation for Economic Cooperation and Development (OECD) and EUROSTAT (a summary description of cancer data and information sources for European populations is provided in this chapter). However, despite the extensive amount of data collected and the obvious advantages in having access to it, there is no comprehensive platform or system that collates all cancer-specific information, complicating integrated research into this disease. This makes research much more difficult than it should be.

Users of cancer information in the EU

An ECIS would be instrumental for all major stakeholders in cancer control: researchers, clinicians, policymakers and citizens (including patients). First of all, the timely delivery of comparable clinical, biobank and screening data, combined with a more uniform and research-oriented implementation of ethical and data confidentiality standards, could provide a strong boost to cancer research across Europe and worldwide. The European population of 500 million is sufficiently large to enable the analysis of geographic variation and time trends by clinical, biological and demographic characteristics; evaluate the impact of environmental, social and organisational factors on cancer risk and outcomes; shed light on the effect of preventive actions; reliably test hypotheses regarding the role on outcome of health care services organisation and of adherence to national or European guidelines; and benchmark progress with innovative treatments or diagnostic tools in clinical practice.

At the clinical level, assessment and outcome tools exist that have been translated and validated in several countries. However, European collaborative efforts are required to develop these tools further and to make them more widely available (see below).

Likewise, assessment is a strategic necessity in public health planning. The availability of epidemiologic and public health indicators is necessary to help policymakers to prepare national cancer plans, but also to evaluate in due course the impact of the planned action at the population level. International comparisons improve knowledge on the effectiveness of cancer plans, particular needs related to specific disease groups or social categories, and accessibility to treatments and the availability of high-quality health care. In summary, without reliable cancer information, policymakers cannot plan appropriate prevention and public health interventions.

Citizens, and particularly patients, have an important stake in progress. Specific problems and needs associated with this have been reported and explained in several European forums, including the initial Europe Against Cancer programme, which was valuable in laying the foundations of a European strategy for cancer control. Patients still face great inequalities between and within Member States in terms of the development of national policies or strategies to tackle cancer and access to specialists, drugs and social services. There are no EU general principles or minimum standards that allow patients and cancer survivors to receive minimum health and social services under a cancer plan. Such principles and standards would help the EU Member States in a meaningful and systematic way to build a framework that is coherent yet flexible enough to take into account the specific requirements of all the diverse

interests. Cancer patient organisations in EPAAC and other EU projects have advocated for the development of a minimum portfolio of essential services for all European patients, with a framework to encourage cooperation and knowledge-sharing between centres of expertise, and a multidisciplinary approach to care to address the complex and diverse conditions that no Member State can address alone (see Chapter 5 on the Network for Information on Rare Cancers, RareCareNet (www.rarecarenet.eu/rarecarenet). Directive 2011/24/EU (8) on the application of patients' rights in cross-border health care has advanced an EU-oriented approach to the issue of minimum standards. The wide availability of cancer information could facilitate the implementation of minimum standards for health and social services based on good practice from around the continent. Cancer plans that take these standards into account will be better equipped to provide high-quality care for patients and citizens, who would also be enabled to monitor adherence to European norms with absolute transparency.

Spotlight on SEER: Comparing cancer information in the US and Europe

An extraordinarily wide spectrum of activities related to cancer information and data is ongoing in Europe, providing all the necessary components for the development of a cancer information system. However, a proportional advance of knowledge in the field of cancer epidemiology is not possible without optimising and integrating our deployment of resources. Perhaps the most relevant experience outside Europe is SEER (Surveillance Epidemiology and End Results programme, run by the National Cancer Institute in the USA, part of the National Institutes of Health (www.seer.cancer.gov). SEER is an authoritative source of information on population-based cancer epidemiology in the United States. It collects, analyses and disseminates cancer incidence, prevalence and survival data on about 28% of the US population. SEER statistics reflect the US population with regard to poverty and education, urban and rural groups, and racial/ethnic diversity (it presently covers approximately 40–50% of Latinos, Native Americans and Asian Americans, and 23% of African Americans). The registries in the SEER programme are required to collect information on demographic indicators, tumour site and morphology, stage at diagnosis, treatment and follow-up, as well as cause-specific mortality data from official US statistics. Annual updates in print and online help thousands of users (including health professionals, policymakers, patient groups and citizens) to obtain an accurate picture of cancer epidemiology. Individual anonymised data may be accessed under the condition that it be used for research purposes, but no information that could identify individual patients can be published. The

wide spectrum of information collected and continuously updated, as well as the accessibility of the data, makes SEER an invaluable source for population-based cancer research worldwide. A widely used measure of impact on research of any activity is given by the number of indexed papers arising from it. The worldwide impact of SEER programme is demonstrated by the 4500 peer-reviewed articles using the SEER Research Database that have been published in indexed scientific journals since the year 2000, generating more 130,000 overall citations (600 of these papers were published in 2012). Over the same period, the number of research papers integrating and jointly analysing registry data from the network of European registries does not exceed 500 (60 in 2012).

There is no reason that this should be so. The European scientific community is at the forefront of methodological research in population-based epidemiology and public health, from analysis and projection of incidence and mortality trends, to survival analysis, prevalence estimation, planning and performance of studies on prognostic determinants, as well as the study of social, organisational and economic inequalities in health. Even though far less funded, the productivity of cancer research in the European Union, measured in terms of scientific publications, is comparable, or even slightly greater, with respect to the United States (9). Moreover, many scientific publications produced in the EU are based on SEER, instead of on European cancer registry data.

The lack of a common framework for cancer information in Europe is a plausible explanation for Europe's smaller impact on global cancer research. Many different institutions collect different data with a varying degree of coordination. Incidence and mortality databases are maintained by the International Agency for Research on Cancer (IARC), while the EURO CARE project (www.eurocare.it) uses registry data to monitor survival, prevalence and patterns of care. Stage and treatment data are collected by different registries across the EU in the framework of the so-called 'high resolution studies'. General health-related data, necessary for an appropriate interpretation of cancer indicators, are organised within the EU health portal (ec.europa.eu/health-eu/index_en.htm). General and health specific economic data are collected in the OECD database (stats.oecd.org/).

Another problem we found was the degree of access to patient data. Micro-data at the individual level are the only relevant data in research contexts, as they do not limit study design but do enable the elucidation of the interactions between many causal pathways of disease or outcome as a function of the pattern of care; however, the scientific community's access to individual data at the European level is not easy. Today, research groups wishing to access individual data from European cancer registry databases for specific aims (e.g., EURO CARE or EURO CIM) can only do so following a request of consent via

relevant protocols among the interested registries, and only data from registries explicitly approving the protocol will be included in the released dataset. Due to the high number of data providers involved, this procedure ends up being quite bureaucratic, with multiple pitfalls that can stop the process. It also requires extra work for the contributing registries, which may become a problem if a high number of requests (as is desirable) reach them. Another disadvantage is the production of ad hoc datasets for each specific request, which may hamper the reproducibility of research results.

The results produced by the SEER system model demonstrate that, with the necessary adaptations to be tailored to the EU context, the potential added value of a unified information system would be enormous in terms of evidence-based public health research, not only for Europe but also for the EU Member States. The SEER experience cannot be immediately applied to Europe, since SEER covers a fraction of one jurisdiction and US federal law regulates SEER activities, whereas the European Union covers 28 countries that organise cancer registration activity in different ways. Moreover, the EU Member States still have different legislation on data protection (a common law should enter in force in the next several years). Finally, the 28 EU Member States present an extremely wide variation in funding for cancer information systems, but nothing as well-funded as SEER. Detailed data on health and cancer determinants in the USA relies on the National Health and Nutrition Examination Survey (NHANES), which doesn't exist in the EU. However, the differences in resources and jurisdictions do not mean, of course, that the same objective is not affordable or achievable in Europe, but that a higher degree of harmonisation and accessibility to cancer information should first become a priority in the European agenda.

Important efforts towards better coordination in Europe have been promoted in recent years. For example, the FP7 ERA-net project EURO COURSE (www.eurocourse.org) had among its deliverables the development of a European Cancer Observatory (ECO) (10), including the formation of a comprehensive programme of work on cancer intelligence. This website for the dissemination of registry-based indicators was built on the existing GLOBOCAN platform (globocan.iarc.fr) and the former ECO site, hosted by IARC. The ECO website, now publicly available, also provides user-friendly and timely access to data on European cancer registries, with considerable potential for exploring similarities and differences in cancer epidemiology (incidence, mortality, 5-year prevalence and survival) according to predefined groupings and formats, at national level or at regional/registry level. It allows geographical comparisons by cancer site, age and time period. In several cases, registries are also enriched by linkage between clinical registries (good examples can be found in Nordic countries

and in the Netherlands). Despite these laudable initiatives, however, researchers still lack access to a single quality-controlled information system integrating all relevant data in a systematic and continuous way.

Finally, in the year 2011 the European Commission Joint Research Centre (JRC), the Commission's in-house science service, was identified to help coordinate and improve cancer prevention, control and care processes across the EU via the standardisation and harmonisation of good practices and the establishment of a cancer information system. JRC is independent of all national, private and commercial interests and has a proven track record (since 1957) in the harmonisation and standardisation of scientific/technical processes and systems. It will coordinate the implementation of ECIS in full collaboration with all the major stakeholders to leverage maximum impact and build on the foundations laid by earlier projects. In particular, it will support the governance and technical coordination processes and will take on the responsibility of releasing the official cancer statistics in liaison and agreement with the stakeholder community.

Current hurdles in creating a shared system

Despite its undeniable benefits, and the recent actions carried out at the EU level toward a cancer information system, there are a number of scientific, technical and – even more challenging – policy and legal difficulties that must be addressed in order to develop it (Table 6.1).

As described in full in Chapter 1, the scientific challenges have been at the centre of our work in EPAAC, and a number of pivotal steps have been made in the areas of data availability, data harmonisation and linkages, and consensus discussions to develop the basis for an ECIS. The next step is to pool existing resources and experiences in that line of action.

As for policy-related issues, the EU Parliament's Directive 95/46/EC on Data Protection was developed to safeguard online privacy rights more tightly in 2012 following comprehensive reform (11). In response, the EURO COURSE produced a position paper (12), and guidelines were released by the European Network of Cancer Registries (ENCR) to offer an ethical framework for interpretation also to clinical registries. If the ECIS could link a recognised scientific authority to an explicit commitment from national authorities, these issues would be much more easily tackled. US SEER Data access conditions do not differ much from conditions to access the European Surveillance System (TESSy (13)) on infectious diseases maintained by the European Centre for Disease Prevention and Control (ECDC). Here, under the EU directive 851/04/EU (14) and decision 2119/98/EU that governs the ECDC and its relationship

Table 6.1 Science- and policy-related hurdles to an ECIS

Science-related	Policy-related
Incomplete harmonisation of incidence and survival data collection procedures and validation rules	Restrictive privacy protection regulations Lack of legal mandate from Member States to share cancer surveillance data
Lack of available clinical data at population level (kind of hospital, use of regional/national guidelines, etc.)	Gap between the potential demand for data from the cancer research community and data accessibility
Poor linkage of clinical registries and cancer registries	Lack of sustained funding
Poor linkage of tumour- or biobanks and cancer registries	Competition for scarce resources Difficulty in improving/upgrading information
Lack of available data on costs and economic burden of cancer for health planning purposes	Discontinuity of project-based activities Absence of mechanisms to protect the intellectual property of data production
Lack of an organised and structured EU statistical analysis capacity	
Sub-optimal EU-wide interaction among specialties within the cancer community	

with national notification systems, data on infectious diseases in Europe are collected, analysed and disseminated based on the compulsory notification by the physician or hospital. To request an extraction of case-based/aggregate data from TESSy, a signed request with applicant details and a description of the proposed study protocol is necessary. Likewise, in the EU, difficulties could be solved by an institutional mandate for sharing cancer data. Conditions already in place that balance privacy regulations and data access for research in the framework of infectious diseases comprise a working example that could be used for developing regulation to improve accessibility of cancer data (Box 6.2).

Building a European Cancer Information System

Where to start? Sources of cancer data and their availability in the EU

As a first step in our work in EPAAC, we undertook a review of European activities (including EU and international projects¹ on health and cancer information and databases) to map the availability and sources of relevant cancer indicators in Europe according to the list originally proposed by EUROCHIP (www.tumori.net/eurochip) (Table 6.2).

¹ ECHI, EUROCHIP, EUROCOURSE, RARECARE, HAEMACARE, ECN, WHO, OECD, IARC, EUROSTAT, ECO, ENCR

Box 6.2 Addressing policy-related obstacles to an ECIS

To address policy-related issues, we highlight the following needs:

Improved coordination among countries to share resources and transfer good national experiences

Harmonisation of research projects at EU level, considering continuity, sustainability and data ownership (see information on pilot projects 2 and 3 in Chapter 7)

Establishment of legal and institutional basis (under the consensual decision of single countries) to develop an ECIS, enabling it to receive and redistribute the relevant data and information. One first step in this direction would be the joint agreement of a number of pioneer Member States to develop a common free access database, including a limited number of health and economic indicators, as a starting point towards the construction of an ECIS

Prevention indicators

Information on the behavioural determinants of cancer is provided by the European Health Interview Survey (EHIS). The EHIS collects information from the general population on health status, health care and health determinants as well as background information on demographic and socioeconomic variables. Among the large set of indicators are several of those propounded by EUROCHIP-1: cancer screening, body mass index, smoking habits, alcohol intake, and fruit and vegetable intake. Managed by EUROSTAT, the EHIS will be conducted every five years, with a detailed analysis of the results of each wave to assure more comparable results and complete time series in the future.

A summary of the problems that occurred during the first wave of EHIS are included in a report (16). In general, the questionnaire was long, complicated and full of skips, causing difficulties, mistakes and lengthy interviews. Questions could be misunderstood, and comparison was impaired by linguistic or health system differences. Too long or too many reference periods applied in one questionnaire caused memory recall problems. There will be always a place for improving the quality of the current health surveys, and the national problems faced during the first wave of EHIS should be taken into consideration to obtain the best possible harmonisation for future implementation of the surveys.

Complementary to the EHIS, the European Health Interview & Health Examination Surveys Database presents an inventory of national and multi-country health surveys implemented in EU Member States as well as EFTA countries, EU Candidate Countries and the USA, Canada and Australia. The types of surveys in the database include Health Interview Surveys (HIS), Health

Table 6.2 EUROCHIP cancer indicators

Prevention	Epidemiology & Cancer Registration	Screening	Treatment & Clinical Aspects	Macro-social and Economic Variables
Lifestyle	Screening examinations	Screening examinations	Health system delay	Social indicators
1.1. Consumption of fruit and vegetables	2.1. Population covered by high-quality cancer registries	3.1. % of women that have undergone mammography (breast cancer)	4.1. Delay of cancer treatment	5.1. Educational level attained
1.2. Consumption of alcohol	2.2. Cancer-incidence rates, trends and projections	3.2. % of women that have undergone cervical cytology examination (cervical cancer)	Resources	5.2. Gini index
1.3. BMI* distribution in the population	2.3. Cancer relative survival-rates, trends and projections	3.3. % of persons that have undergone a CRC ^s screening test	4.2. Distribution of radiation systems in the population	Macroeconomic indicators
1.4. Physical activity attitude	2.4. Cancer prevalence proportions, trends and projections	National evaluation in HIMP of organised mass-screening process indicators	4.3. Distribution of diagnostic CATs in the population	5.3. GDP
1.5. Tobacco survey: prevalence of	2.5. Cancer mortality rates, trends, projections and person-years of life lost due to cancer	3.4a. Organised screening coverage	4.4. Distribution PETs** in the population (for future)	5.4. Total social expenditure
a. tobacco smokers among adults	2.6. Stage at diagnosis – % of cases with:	3.4b. Screening recall rate	4.5. Distribution of magnetic resonances in the population (for future)	5.5. Total national expenditure on health
b. tobacco smokers among 10–14 year olds	a. early diagnosis	3.4c. Screening detection rate	Treatment	5.6. Total public expenditure on health
c. ex-smokers	b. metastases	3.4d. Screening localized cancers	4.6. Compliance with best oncology practice	5.7. Anti-tobacco regulations
Environment & occupational risk	d. exposure to environmental tobacco smoke	3.4e. Screening positive predictive value	Palliative care	5.8a. Public expenditure for cancer prevention on anti-tobacco activity
d. exposure to environmental tobacco smoke	a. early diagnosis	3.4f. Screening benign/malignant biopsy ratio	4.7. Use of morphine in cancer patients	5.8b. Total expenditure for population-based cancer registries
1.6. Exposure to sun radiation	b. metastases		4.8. % of patients receiving palliative radiotherapy	5.8c. Total expenditure for organised cancer-screening programmes
1.7. PM10 ¹ emissions				5.8d. Public expenditure for cancer drugs
1.8. Indoor exposure to radon				5.8e. Total expenditure for cancer research
				5.8f. Estimated cost for one cancer patient

Table 6.2 CONTD

Prevention	Epidemiology & Cancer Registration	Screening	Treatment & Clinical Aspects	Macro-social and Economic Variables
Environment & occupational risk (contd)		National evaluation in HIMP of organised mass-screening process indicators (contd)		Demographic indicators
1.9. Prevalence of occupational exposure to carcinogens		3.4g. Screening interval cancers		5.9. Age distribution in 2010, 2020 and 2030
1.10. Exposure to asbestos: mesothelioma incidence and mortality trends		3.4h. Screening specificity		5.10. Life-table indicators
Medicaments				
1.11. Prevalence of use of HRT‡ drugs				

Source: (15)

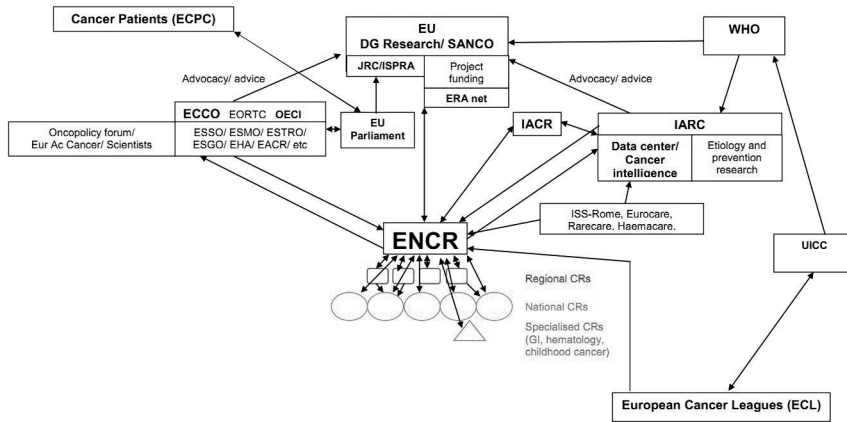
*BMI: body mass index; †PM: particulate matter; ‡HRT: Hormone Replacement Therapy; §CRC: Colorectal cancer; ** positron emission tomographies

Examination Surveys (HES) and combined HIS/HES Surveys. In 2011 there were 218 HIS, 14 HES and 27 combined HS/HES Surveys in the database. HIS surveys included in the database have mainly been executed in 1991–2009, HES in 1999–2008 and combined HIS/HES in 1995–2009. With regard to other cancer-related prevention indicators, all but two are available in the sources mentioned in this section: exposure to sun radiation and prevalence of occupational exposure to carcinogens.

Epidemiology and cancer registration

Cancer registries are the main (often the only) source for incidence, survival and prevalence indicators. Given that comparable disease-specific sources of data are not available for any other major disease, national and local registries are a unique and valuable source of health information. Indeed, the few examples of structured health databases in Europe today are largely based on cancer registry experiences or have been set up under their initiative. Traditionally used in aetiological research as a means of enhancing our knowledge on risk factors for cancer, registries also provide statistics on incidence for the purposes of assessing and controlling the impact of cancer in the community as well as a means to monitor and assess the needs for screening and early detection programmes within a population. Moreover, they are used to evaluate and monitor screening programmes already in place. Population-based cancer registration constitutes an effective and relatively cost-efficient method for providing information for planning, monitoring and implementing cancer control measures and care guidelines and highlighting differences in survival and quality of care. It offers a huge opportunity for public health research, bridging the gap between administrative control and research; since the early 1940s, cancer registries have been acknowledged as an important tool for cancer research and control across Europe.

Given the importance of cancer registries, many efforts have been spent to monitor and improve the quality, type and coverage of the information they provide. In order to optimise comparability of cancer incidence data, promote cancer registration in Europe, form the basis for the continuous monitoring of the cancer burden and foster the use of cancer information for research and planning, the ENCR was constituted in 1990 under the European Commission's Europe Against Cancer programme (17), jointly with the Association of Nordic Cancer Registries (ANCR), the International Association of Cancer Registries (IACR), the Latin Language Registry Group (GRELL), and IARC, where the secretariat was first established (Figure 6.1).



Wp9
 Schematic view of Oncological & Health Policy
 Environment of European Network of Cancer registries
 (ENCR) Version October, 2012



Figure 6.1 Organigram of the European Network of Cancer Registries

Source: (18)

In order to better support the Joint Research Centre coordinating role in cancer control activities and the development of ECIS, the secretariat of ENCR was transferred to JRC in 2012. As a first concrete action aimed at creating a harmonised network of cancer registry data, an ENCR Workshop on cancer registry quality checks was organised and hosted at JRC. The workshop focused on protocols for cancer registry data – including but not limited to survival data quality checks – with the overall goal of designing a common tool for checking prevalence, incidence and survival data.

Today, more than 200 cancer registries are active under ENCR in Europe. Data collection systems in the EU reflect the specific organisation of national health systems, and barriers persist in data access, so it is difficult to move from the national to the European scale as not all indicators are comparable across the EU. Registries presently provide most epidemiologic data on cancer, yet they are underfunded, mostly understaffed, struggling with national and European laws on protection data, or launched without proper planning. Therefore, data are not easily accessible to everybody (see EUROCOURSE for more information).

In recent years, the successful collaboration of the cancer community and policymakers has ensured greater attention towards population-based cancer registration, and this is reflected in the public health agendas across the EU. After the European Council Conclusions for the new European Health Strategy

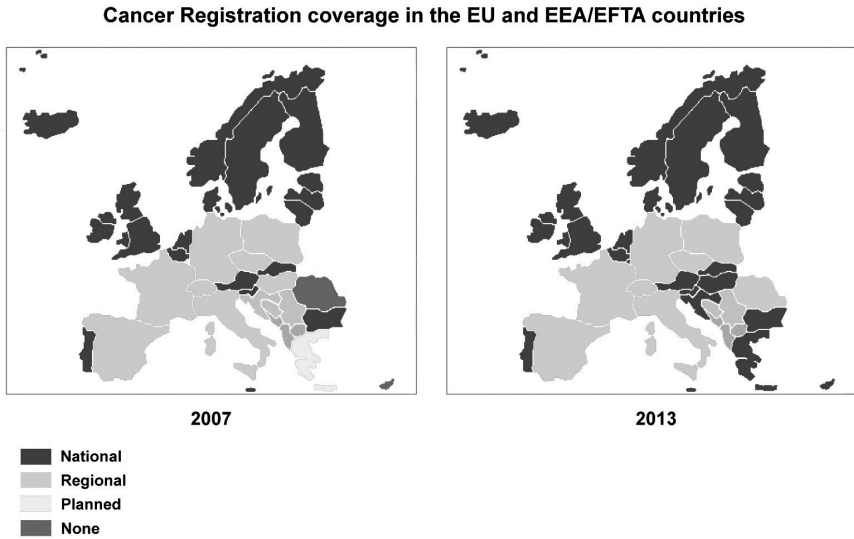


Figure 6.2 CR coverage in EU and EEA/EFTA countries in 2007 and 2013

Source: 2007 data: (19); 2013 data: EPAAC Cancer Information Work Package

Note: at the time of going to press, the Hellenic cancer registry had just completed its first year of operation; national coverage had not yet been reached.

in 2008 indicated that EU Member States should develop National Cancer Control Programmes, with cancer registration highlighted as a statutory requirement, important developments in the establishment of cancer registries have been observed (Figure 6.2).

In Romania, since 2008 following Ministry of Health Order no. 2027/26, regional cancer registries for each of the eight development regions work in alignment with ENCR standards for data collection, classification and codification (20); in 2009 the Cyprus Cancer Registry became a Ministerial organ (21); in 2012, Greece started the Hellenic Cancer Registry as the first action of the fifth axis of intervention of its National Cancer Plan 2011–2015 (22), and the National Cancer Registry of Luxembourg started in 2013 (23). Today, cancer registries cover the entire population in 23 of 31 (28 EUMS+3 EEA/EFTA) countries: Austria, Bulgaria, Belgium, Croatia, Czech Republic, Cyprus, Denmark, Estonia, Finland, Ireland, Latvia, Lithuania, Luxembourg, Malta, the Netherlands, Slovakia, Slovenia, Sweden, the United Kingdom, Hungary, Portugal, Iceland and Norway. For different reasons, in Italy, Spain, France, Germany, Poland, Switzerland, Romania and Greece, there is only partial population coverage, varying from one to nearly all regions. According to the results of EUROCARE-5, in 2000–2007, 50% of the population was covered by cancer registration.

The overall quality of data was satisfactory: less than 1% of total cases were excluded from the EURO CARE database due to major errors, cases with death certificate only were around 3%, and cases lost to follow up were 1% overall; 90% cases were microscopically verified, and approximately 1% overall had a poor morphology specification. By contrast, information on stage was inadequate and varied according to tumour site and registry: the highest figures, not exceeding 50% of cases with available stage were for breast cancer; for colorectal cancers stage was available for approximately 35% of cases, whereas for other solid cancers stage was available in less than 20% of cases. Gradually, gaps in coverage and quality are being filled thanks to the proactive collaboration with several EU initiatives, including EPAAC, and scientific support is continuously provided at EU level to ensure the best standards (Box 6.3).

An up-to-date analysis of the situation in all European cancer registries and their potential role in cancer information is available through the results of the ENCR questionnaire, 'Overview of Cancer Registration in Europe' (Box 6.4).

Main indicators provided by cancer registries

Incidence

Incidence refers to the number of new cancers occurring in a specified population over a year, usually expressed as the number of cancers per 100,000 population at risk (i.e., ovarian cancer incidence refers to incidence per 100,000 females). The ninth volume of *Cancer Incidence in Five Continents (CI5)* covers new diagnoses of cancer from 1998 to 2002 in 100 Registries in 29 countries of the European Region (24). Inclusion in the series is a good marker of the quality of an individual registry's data. The online CI5 databases provide access to detailed information on the incidence of cancer recorded by registries (regional or national) worldwide in two formats:

- CI5 I-IX basic data published in the nine volumes of CI5
- CI5 plus annual incidence for selected registries published in CI5 for the longest possible period

In addition, ECO provides contemporary estimates (from 2008) on the incidence, mortality, prevalence and disability-adjusted life years (DALYs) for all major types of cancer in all 28 EU Member States and EEA/EFTA.

Survival

Population-based survival data can provide insight into the effectiveness of health care systems. They usually provide 'relative survival', which is adjusted by the competing causes of death in the same area, gender and age group to

Box 6.3 Spotlight on cancer registries in Greece, Luxembourg and Bulgaria

The Hellenic Cancer Registry (HCR), based at the Hellenic Centre for Disease Control & Prevention, connects all public and private hospitals in the country, registering all incident cancer cases with official permission (Decision No. 1116/13-7-2012) by the Hellenic Data Protection Authority for the lawful processing of personal sensitive patient data as regards its purposes. Cancer notification at the time of going to press was based on paper, but it will switch to electronic notification by the end of 2013. The restructuring of the HCR has received funding from the National Strategic Reference Framework Programme 2007–13. Part of the National Cancer Plan 2011–15, the HCR aims to produce reliable information on the burden of cancer so that effective policies for cancer control may be developed, implemented and evaluated in Greece.

In Luxembourg, implementation of the cancer registry began in 2011 and is now complete*. The registry is based at the Centre for Public Health Research. As of 2013, all cancer incident cases are registered, (incidence on breast and colorectal cancer began on 1 January 2012). The aims of the cancer registry are to provide information for strategic planning and evaluation of the screening programmes and the national cancer plan, as well as to give feedback to clinicians concerning quality of care and to facilitate collaborative research with other countries.

In Bulgaria, on the other hand, a national cancer registry and 13 regional registries have been active since the 1960s and have been providing cancer data of good quality with numerous international collaborations. However, a reorganisation of cancer care that started in 2011 may lead to deterioration of registry data in the country, lack of interest from the policymakers, lack of vital funding and limited use of cancer registry data for cancer control purposes (personal communication with Nadia Dimitrova, Director of the Bulgarian Cancer Registry).

*These include the set of data to be collected (using definitions available at EU level), the IT system in hospitals and clinics (public and private) to collect and deliver the data, the IT system for collecting the data at national level, the trained cancer registrars, the organisation of the CR with a scientific board, a surveillance board, the information leaflet for the patients, a website and a law (Reglement Grand Ducal) was awaiting approval in April 2013 by the highest responsible civil state body

which the patient belongs. However, survival is a complex indicator: it may reflect earlier diagnosis, over-diagnosis or later death. A potential artefact influencing population-based survival data and the interpretation of differences across areas and over time is that of lead time bias. Diagnosis at an earlier stage can increase survival by simply anticipating the date of diagnosis, without postponing the date of death. In this case, longer survival associated to a more favourable stage distribution is not an advantage for the considered population. In 1989, EURO CARE² started to monitor, analyse and explain between-

2 A first monograph was published in 1995, with data on cancer patients diagnosed between 1978 and 1984 in 12 countries. The second monograph (1999) included data on cancer patients diagnosed between 1985 and 1989 in 17 EU countries, the third (2003) covered patients diagnosed between 1990 and 1994 in 22 countries. The EURO CARE-4 focused on cancer patients diagnosed between 1995 and 1999, and was based on data from 23 European countries.

Box 6.4 Overview of Cancer Registration in Europe questionnaire***Elements covered**

starting year of the different cancer registries
 budget and funding
 data sources used
 registration criteria
 presence of cancer screening programme in relevant area
 method of diagnosis
 tumour stage information
 treatment information
 follow-up information
 available guidelines
 registry output

Results (50% of the 206 invited ENCR Members responded)

Substantial heterogeneity in many aspects of cancer registration, including financial & legal support, access to data, recorded information & output production

Relatively well-harmonised data sources, eligibility criteria, classification and coding.

50% of participating registries reported per capita spending on registries to be under 3% of national health expenditure

Best practices include cooperation with specialists, linkage possibility, availability of key patterns-of-care indicators, completeness of registration, production of peer-reviewed research studies and active involvement in international studies.

Conclusions

In order to promote best practices, support to individual registries is needed at regional and national level and to ENCR at international level (e.g., the collection of stage in relation to incidence, survival, prevalence and treatment).

* developed jointly with the ENCR, the EURO COURSE and the EC funded EUROCHIP-3 project

country differences and trends in cancer survival, and it still provides the most systematic data available on the patterns of cancer survival in Europe (25). The most recent study (EURO CARE-5) has collected incidence data up to 2007 for 29 countries in Europe (EU and EEA+ EFTA), along with last known vital status as of 31 December 2008 or later (Figure 6.3).

More detailed information is available on the EURO CARE website (www.eurocare.it). The EURO CARE-4 project also provides detailed information on incidence, prevalence and survival on haematological malignancies and on rare cancers in the framework of the **Cancer Registry Based project on**

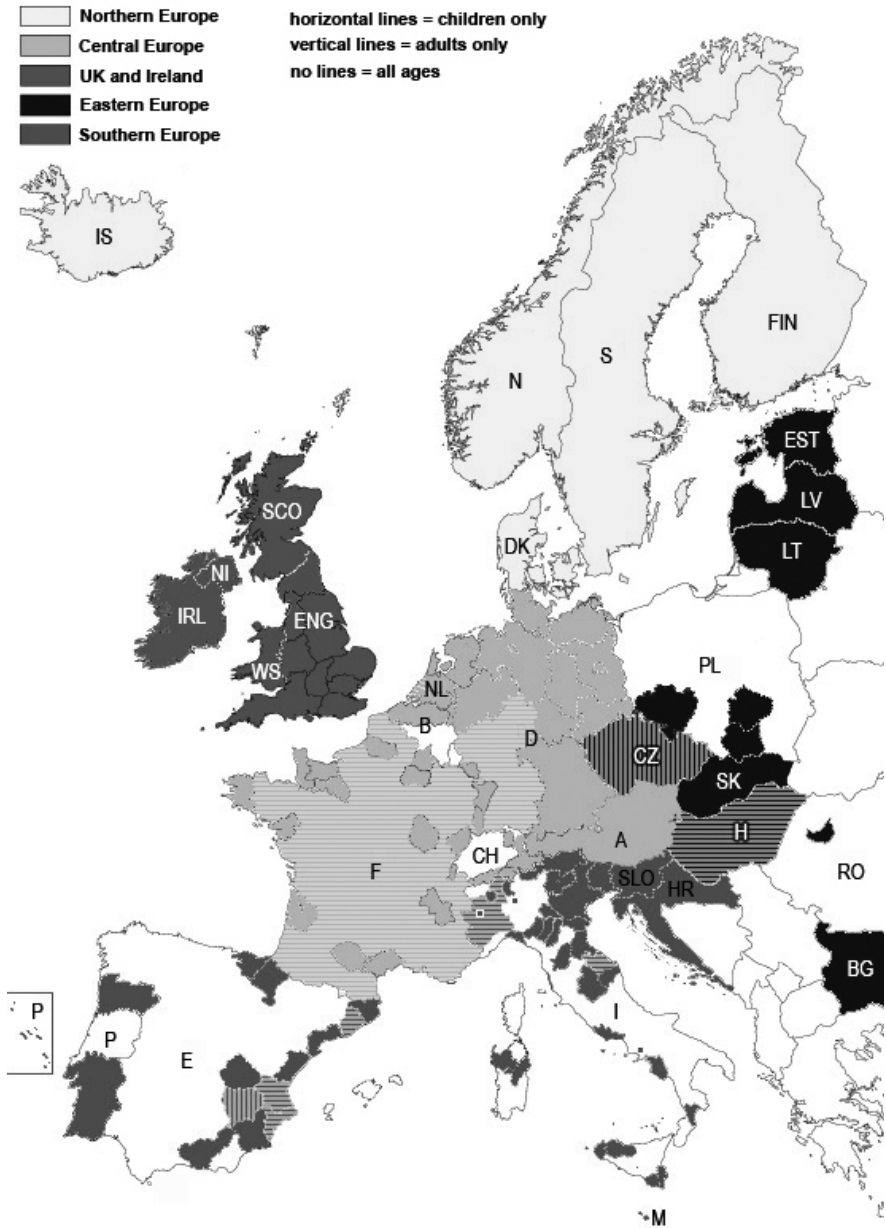


Figure 6.3 Adult and childhood cancer coverage participating in EURO CARE-5

Source: www.eurocare.it and Cancer Information Work Package, EPAAC

Haematologic malignancies (HEAMACARE) and Surveillance of rare cancers in Europe (RARECARE) projects, respectively.

Prevalence

Complete prevalence refers to the number of persons living with a previous diagnosis of the disease, regardless of how long ago the diagnosis was or whether the patient is still under treatment or is considered cured. *Partial prevalence* limits the number of patients to those diagnosed during a fixed time in the past. GLOBOCAN provides prevalence of cancers based on cases diagnosed within one, three and five years, as they are likely to be of relevance to the different stages of cancer therapy, namely, initial treatment (one year), clinical follow-up (three years) and cure (five years). Data is available for the adult population only (≥ 15 years) in 40 European countries (26). The EUROPREVAL study provides complete prevalence data on stomach, colon, rectum, lung, breast, cervix uteri, corpus uteri and prostate cancers, as well as skin melanoma, Hodgkin's disease, leukaemia and all malignant neoplasms combined for the end of 1992 in Austria, Denmark, Estonia, Finland, France, Germany, Iceland, Italy, Poland, Slovakia, Slovenia, Spain, Sweden, Switzerland, the Netherlands and the United Kingdom (27). The RARECARE project provides partial and complete prevalence for rare and common cancers in Europe at the end of 2002 (28).

Mortality

Mortality refers to the yearly number of cancer-specific deaths over the whole population in an administratively defined area. The available mortality data are more comprehensive than incidence data – the WHO mortality databank contains national cancer mortality data for 35 countries in the European Region, available over extended periods of time for many of those countries. However, mortality data are affected by several problems, for instance the degree of detail and accuracy of the recorded cause of death and the completeness of death registration. These are known to vary considerably between countries and over time. In addition, mortality statistics include deaths occurred in a given year, regardless of length of survival, from a few months to many years after diagnosis. Detailed mortality data at a regional level, as available from EUROSTAT, provide valuable information of uniform quality which at present is not sufficiently known or adequately utilised.

Screening

The EHIS provides information on participation in organised or voluntary screening tests (mammography in the past two years, Pap smear test in the past three years and a colorectal cancer screening in the past two years). Information on breast and self-reporting cervix screening uptake are available for 18 of the 20 countries participating in the EHIS (information missing in Switzerland and

Norway), while colorectal screening rates are available in 16 (all but Austria, Estonia, Switzerland and Norway). Administrative sources based on screening programme data or registry-based information would be preferable to EHIS-based data, as the latter will be influenced by recall and sampling biases.

In Europe, most programmes for cancer screening have developed their own screening information systems for running day-to-day operations, managing quality, monitoring and evaluating services, with no explicit priority on promoting an exchange of information between programmes in different countries.

The European Network for Information on Cancer (EUNICE) has proposed a monitoring tool capable of calculating a selection of key performance parameters and early impact indicators from the European Guidelines, which could be used to compare screening programmes across Europe on a regular basis. The web-based data warehouse EUNICE Breast Cancer Screening Monitoring (EBCSM) was tested for its initial application in 10 national and 16 regional programmes in 18 European countries. The results demonstrate the feasibility of pan-European screening monitoring using the EBCSM data warehouse, although further efforts to refine the system and to harmonise standards and data collection practices will be required to fully include all European countries (29).

Apart from the EHIS, information on screening programme coverage at the EU level, like information on screening programme implementation, varies among the different screening programmes available in each country. Thus a comprehensive overview of cancer screening programme coverage and implementation in Europe is mainly provided by the periodic report on the implementation of the Council Recommendation on cancer screening. Organised screening programmes are presently recommended (breast, colorectal and cervix uteri cancers) and are in place or planned in many countries, and their implementation in other regions is encouraged by EU recommendations. While the quality of mass screening should be supported by professional training (see Chapter 4) and continuously monitored by specific process indicators within the programme, the existence of a population-based cancer registry is indispensable for evaluating the efficacy of the programme in terms of reduction of mortality and incidence of invasive lesions.

The evaluation of screening programmes would be greatly facilitated by the availability of screening indicators in an ECIS, which would allow the joint analysis of screening indicators with trends in incidence, mortality, patterns of care in the population. For other cancers, such as prostate and lung, there are no recommended tests for early diagnosis. However, the prostate specific antigen

(PSA) for early diagnosis of prostate cancer has been widely used in Europe, leading to a change in the prostate cancer epidemiology (26). Information on PSA testing use in Europe is not available. It could be important to monitor the use of such testing, and the EHIS could be a way to collect such information. Although the stage at diagnosis is not a tool to monitor the efficacy of screening, its systematic collection in the cancer registry regions where screening activities are ongoing would help monitor the screening programmes. Additional indicators should be identified by means of the cancer information system and should comply with the European quality assurance guidelines for breast, cervical and colorectal cancer screening as well as with recommendations by ENCR, EUNICE and EUROCOURSE workgroups on screening.

Treatment and clinical aspects

Information on medical equipment (computed axial tomography, magnetic resonance imaging unit, positron emission tomography scanners, radiation systems) and frequency of surgical procedures (hysterectomy, prostatectomy, breast conserving surgery, mastectomy) is available from EUROSTAT (30) and OECD (31). These data come from administrative sources and are not always collected according to uniform criteria (administrative data depends on the organisation of the health care system in each country), raising question on comparability. Only in very few cases (e.g., Belgium since 2005) are national data available on multidisciplinary teams responsible for treating the patient, although the Organisation of European Cancer Institutes (OEI) has data for some hospitals in different countries as part of the audit system. For example, regarding the medical technology devices for United Kingdom, data refer only to devices in the public sector; they do not include equipment in the private sector (resulting in an underestimation). For Spain, the data relate only to devices available in hospitals; they do not include equipment in other health care facilities (also leading to an underestimation).

Information on stage and treatment is not routinely available from cancer registries, clinical or administrative files. However, for a limited number of registries the questionnaire ‘Overview of Cancer Registration in Europe’ includes items dealing with **stage**, diagnostic and treatment **delay** and **compliance** with selected clinical guidelines. In some countries, extra work and funds are needed especially to provide information on compliance with cancer guidelines. To promote the collection of variables for the three indicators in European Registries, EUROCHIP-3 has published the following recommendations (32):

- To further study the cancer registries reporting collection of stage, diagnostic and treatment delay, and compliance with selected clinical guidelines in

order to determine their practice and to encourage other registries to follow their lead.

- To promote collection of data generating stage, diagnostic and treatment delay, and compliance with selected clinical guidelines according to the ENCR rules and definitions, in order to make useful and relevant comparisons over the years between EU countries.

The EUROCARE group has published several high-resolution studies on stage at diagnosis, diagnostic procedures and treatment. As mentioned above, these data, not routinely collected by most registries, can help to explain the differences in survival on the basis of disparities in diagnosis and/or major treatments between regions. These studies have provided information on breast (33), colorectal (34), lung (35), prostate (36), stomach (37), testicular cancers (38), and melanoma and lymphoma (39) management in participating countries. Presently, high-resolution and patterns-of-care (POC) studies are ongoing in several Member States, focusing on different cancer types. POC studies aim to evaluate the dissemination of state-of-the-art cancer management into community practice and to explain differences in outcomes.

Within EPAAC, collaborations were developed for the constitution of an Outcome Research Forum, to describe, interpret, and predict the impact of interventions and other factors on final outcomes of importance to decision-makers, including the pilot launch of European High Resolution Studies (see description in Chapter 7). Within an eventual ECIS, it will be essential to ensure the systematic provision of information on stage and treatment (similar to what is presently available within the individual records included in the SEER database). Information on resources (medical equipment and surgical procedures) should also be available, with a clear description of the sources of the information. The limitations arising from data incompleteness and low comparability should be clearly mentioned.

Macro social and economic variables

EUROSTAT provides information for all EU MS on GDP and total public expenditure on health as a percentage of GDP, while WHO provides an overview of the anti-tobacco regulations in its tobacco control country profiles (40). Information on estimated **cost per cancer patient** is not presently available. However, the OECD has proposed a methodology to collect such data in the System of Health Accounts framework (41) using national health accounts as sources, and it is also performing studies on these sources across Europe to estimate comparable direct cancer costs. At present, the direct costs which can realistically be collected and compared refer to hospital costs.

Eurostat aims to produce data on expenditure by disease at EU level and obtain patient-level data with information on patient and treatment characteristics, actual resource use and reliable price/cost data, including the provision of sound data on private expenditure. It would also address the collection of indirect costs data, such as linkage to years of life lost/loss of potential years of work. Data on expenditure by disease can contribute to health systems' performance analysis through the provision of data on how much money is spent on preventing and treating particular diseases, differentiated by age and gender. The action should take into consideration the increasing health care needs of ageing populations in Europe.

Additional indicators that were not included in the EUROCHIP list but should be part of an ECIS relate to the area of cancer survivorship, including all aspects of cancer care and survival occurring after diagnosis and first course treatment phase. Standardised quality-of-life indicators are collected by most clinical studies, as there is evidence they can influence cancer outcomes and patients' prognosis; however, information on quality of life is not readily available to cancer registries. The feasibility of collecting standardised indicators of psychosocial distress using the IPOS (42) tool (developed for screening and diagnosis) should be investigated. It will also be essential to identify data needs for ongoing follow-up and confidential monitoring of cancer survivorship issues (e.g., treatment course and outcomes, quality-of-life indicators, long-term effects of diagnosis and treatment) and to increase the capacity of surveillance systems (including cancer registries) to track such information.

Given the increasing consensus across European health care institutions that proceedings should incorporate the patient perspective in all disease phases, survivorship is a field of major interest for patients' organisations. However, the research area could also benefit from the involvement of patients by developing studies based on their stated needs. The role of patients in this process needs to be better defined in order to allow them to be actively engaged in the relevant aspects. In EPAAC, the involvement of cancer patients' organisations has highlighted the need for identifying a minimum set of services that should be provided to all EU patients. The availability of an open access ECIS will help in this effort by contributing to define standards of minimum health and social services that should be included in cancer plans. Member States can then take into account the needs of cancer patients and survivors in their policies more effectively. In particular, international standards for care and rehabilitation are very relevant given the growing expenditure on health care in a context of economic crisis.

Unifying definitions and presentation of epidemiologic indicators to facilitate comparison of data in the EU

Simultaneous consideration of incidence, prevalence, survival and mortality indicators is of tremendous informative and interpretative value, and observed and/or estimated values of these indicators should be made available as much as possible at the national or sub-national levels. However, this requires that all indicators refer to the same population, which is not presently the case in Europe. Here, these four indicators are provided by different sources, with different coverage and inconsistent tumour definitions. Furthermore, they are only available to the public from different publications and websites. As part of its activities, EPAAC is taking steps to overcome this situation, building a dataset of indicators defined on exactly the same populations and time periods and with the same disease definitions. IARC and EUROCCARE agreed on a protocol for convening their data to build such a dataset and for disseminating it in one location: the ECO website at IARC (Table 6.3).

The European Cancer Observatory

A web-based tool for the dissemination of cancer indicators derived from registry data have been developed by ENCR and IARC, largely within the EUROCCOURSE project. The ECO is structured to provide a comprehensive system of information on the cancer burden in Europe. Its design and functionalities are an excellent and advanced starting point for the dissemination, through the progressive inclusion of a wider set of indicators, of the cancer data collected and organised by ECIS. ECO is presently made of three distinct websites: EUCAN (national estimates), EUREG (registry data) and EUROCCIM (downloadable data):

- EUCAN presents national estimates of cancer incidence, mortality and prevalence for 24 major cancer types in 40 European countries for 2012. The standard methodology used may have produced results different from those developed by national bodies.
- EUREG permits the exploration of geographical patterns and temporal trends of incidence, mortality and survival observed in European population-based cancer registries for 35 major cancer entities in about 100 registration areas.
- EUROCCIM will allow the user to define, extract and request data sets provided by the participating cancer registries. At time of going to press it was under construction.

Table 6.3 Agreed conclusions adopted by EURO CARE and IARC on common dissemination of cancer burden indicators

	Incidence	Mortality	Survival	Prevalence
Data sources	Cancer registry data and national EUCAN estimates	WHO official mortality data	Cancer registry data	Limited duration and complete prevalence from EURO CARE cancer registry data. National 5-yr prevalence estimated from EUCAN
Indicators	Crude, age specific, and age standardised rates	Crude, age specific, and age standardised rates	Observed and relative survival indicators at 1, 3, and 5 years from diagnosis, by five age classes and age standardised (ICS*)	Prevalence rates at 3, 5, 10 and 15 years from diagnosis and complete, by 5 age classes and all ages
Periods of reference	Observed incidence and mortality rates will be provided for the year 2008		Survival will be provided for cases diagnosed in 2000–2007, followed up to December 2008	Prevalence at 1 st January 2008 using 1993–2007 incidence rates and follow-up data
Cancer sites	45 cancer site groupings provided by EURO CARE will be adopted.			
Geographical areas	Three levels of detail will be provided: countries, national pools of registries, and single registries. Country level will provide figures on the entire national population. National pools will be based on observed cancer registry data and will include only registries providing follow-up information, allowing estimates on survival and prevalence in addition to, and consistently with, incidence and mortality. National pools coincide with countries where national registration is in place. Furthermore, national data will be aggregated at the EU and European regions levels.			

ICS: International Classification for Standards

Creating consensus among national, sub-national and supranational stakeholders

In order to provide a framework for the ECIS proposal design under the aegis of the Joint Action EPAAC, our team on cancer information formed a writing committee, involving the key cancer data stakeholders to ensure a proactive communication flow and mutually beneficial objectives. The ECIS writing committee included the EPAAC coordination representatives from Slovenia, the Information coordination group, the IARC, the ENCR, the project EURO CAN platform (43), and observers from political authorities. The JRC

participated from the beginning in the writing committee meetings as well as in the drafting of the ECIS proposal. The group gathered twice a year in 2011 and in 2012. Dissemination of material for comments among all EPAAC experts was regularly ensured; subsequent drafts of the ECIS were presented at the EPAAC Steering Committee of Berlin in March 2012, and at the Rome Open Forum 2012. On this occasion, the most relevant cancer registration experts from almost all of the EU+EEA and EFTA countries participated. An updated version of the ECIS document was circulated to all EPAAC partners in July 2012 and to the registries of the ENCR in August 2012. The document was further discussed in September 2012 at the ENCR meeting in Cork, Ireland. Technical, political and scientifically relevant inputs were sent from Austria, Germany, Finland, the Netherlands, France, Poland, Spain and the United Kingdom to enrich the process. An updated version of the document was presented to DG SANCO and JRC in January 2013, and the proposal was approved as an EPAAC output. Thanks to the EPAAC platform, close coordination among all ongoing activities was maintained, with the objective of sharing any progress made during the EPAAC contractual time by the cancer data community (i.e., the optimisation of the use of cancer registry data, the integration of registry data with other sources of information, such as the health care system or demographic and socioeconomic data). EPAAC has collaborated with all relevant DG SANCO projects: the Joint Action's European Community Health Indicators (ECHI), the Cross-Border Patient Registries (PARENT) and the European Union Committee of Experts on Rare Diseases (EUCERD), as well as the European Organisation for Rare Diseases (EURORDIS).

A roadmap to ECIS

During the course of our work, it has become clear that ECIS activities must be implemented as much as possible by pooling existing resources and experiences from European institutions that are already involved in cancer information and data dissemination, most of which have already developed the knowledge, skills and instruments to carry out the tasks foreseen. The main tasks of an ECIS, then, do not imply collection of new data, but rather reorganisation and better coordination of existing activities. We identify five main types of tasks to be carried out under ECIS, and summarised in the list below.

Data management: Each dataset (i.e., a collection of data containing the same information for many individuals or individual data units) flowing into ECIS needs to be organised according to a unique and coherent structure. This task requires close interactions with the many data providers (i.e., the institutions

that collect and submit the same data from different populations or geographical areas).

Data quality control: Continuous improvement of both quality and data standardisation are crucial for reporting, planning, research and comparative analysis, as these measures are the only means to obtaining reliable data.

Datasets organisation: A user-friendly pathway should be implemented to structurally connect different datasets (e.g., cancer incidence and risk factors distribution across populations, or provision of health care services and survival) and allow the user to access them from a shared platform.

Data analysis: A plan of analysis for the main outcomes should be systematically and periodically laid down. Efficient management of problems related to the variability of data and definitions often require statistical modelling and ad hoc methods (e.g., incidence and mortality analysis, survival analysis, prevalence analysis, high resolution studies, national estimates for countries with partial cancer registry coverage, time trend analyses, cancer burden forecasts, joint analyses).

Data dissemination: The ECIS would be a key epidemiologic infrastructure for the European Research Area. Results should be dissemination through many channels: general and specialised publications, press, leaflets, and web-based tools. The datasets included in ECIS should be available to different users, according to specific permissions and credentials. Three level of dissemination should be foreseen:

- a set of core pre-calculated cancer indicators presented mainly in graphic format, with explanatory notes directed to the general public, policymakers and media;
- a wider set of pre-calculated indicators, of the highest level of detail, including metadata on sources, data quality and comparability, estimation methods, and underlying assumptions, to be used by health professionals;
- quality-checked individual records: the only data fully adequate for in-depth research activities and which do not suffer the severe limits of data tabulated according to pre-defined variables and categories.

Possible organisational options

For each of the ECIS functions envisaged, a set of practical options was formulated and analysed according to advantages and disadvantages (Table 6.4).

Table 6.4 ECIS organisational options and considerations, by function**Table 6.4a** Database management**Database Management**

The data flowing into ECIS need of course to be organised conforming to a unique and coherent structure. This does not necessarily imply building a single centralised data repository. Use of web-based remote connection to distributed data repositories is a possible alternative.

Description	Advantages	Disadvantages
Centralised Data providers prepare files and submit them to a single location (central data management, CDM): data files are stored under safety & protection agreements	Simpler and well-experienced implementation Easier to keep consistency among registry-specific datasets (periodic cleaning, updating and definitions) Well defined responsibility	Possible progressive difference (drift) between central and local data Needs wide political consensus
Distributed Data providers prepare the files, and the central body (CDM) accesses them via web-based remote connection	Avoids formal data submission of data to a third party Providers keeps strict control on the use of their data	More labour demanding for all those involved, intensive networking and computationally complex Any necessary change indicated by the CDM must be applied by providers in the accessible area Intense interaction between data providers and CDM needed

EPAAC conclusions

The two solutions imply trade-off between practical and policy-related considerations. The final resolution has to be identified for each type of data through agreement between ECIS management and data providers.

Conclusions

The potential benefits entailed in the development of a European Cancer Information System are tremendous. Research – so essential to broader efforts of cancer control – is a cumulative effort, guided by knowledge acquired by predecessors and peers. In this context, data and information are the most precious of commodities; the more information researchers have, the better equipped they are to enrich the knowledge base on the causes of cancer, the mechanisms of carcinogenesis, and most important, effective options for prevention and treatment. Likewise, an ECIS would strengthen the political commitment to cancer control, providing accessible information on the progress that countries are making in comparison to the past and to neighbouring countries. The delivery of evidence-based approaches to cancer control would be facilitated, and health system responses to cancer control would be strengthened.

Table 6.4b Data quality control**Data Quality Control**

Quality controls necessarily require a close interaction between the data providers and the coordination centre: the former to assure the correspondence between the coded data and the original information, the latter to oversee the overall consistency of all the data contributed to the ECIS database by the different providers.

Description	Advantages	Disadvantages
<p>Centralised Checks are carried out at the central level; records with errors or implausible data are sent back to be checked and corrected or confirmed</p>	<p>Assures better consistency of the whole database between data providers Provides external 'double checking' of the data</p>	<p>Requires heavy exchanges of data between CDM and data providers Not particularly useful for evident errors in single data items (e.g., wrong codes or inconsistency in dates)</p>
<p>Distributed Checks are carried out locally before submission (also by web)</p>	<p>More practical, quicker, less time and labour consuming</p>	<p>More resources needed at local level for quality controls Much more difficult to ensure homogeneity Not possible to check the consistency of data between different data providers</p>

EPAAC conclusions

The most efficient approach may be a combination of the two levels. A first set of automated data checks can be envisaged at the local level for trivial errors requiring a univocal correction (e.g., wrong sequence of dates, incompatible gender-organ association); detection of errors would require correction in order for the record to be accepted. Centralised controls could detect less clear error conditions, which may need to be examined comparatively with other records or with other datasets (e.g., implausible incidence or survival differences between similar populations).

In particular, Europe has much to gain from better coordination and collaboration. The plurality of cultures, health systems and policy approaches is fertile ground for all kinds of cancer research, from basic and clinical to translational and epidemiologic, and the establishment of global, national and regional networks will not only help to identify the best practices in the continent, but also to implement them at low cost in the countries struggling the most to meet this challenge.

Despite this unarguable promise, the development of the European cancer information system will need constant and vigorous efforts. The road towards an integrated and comprehensive ECIS seems to be quite challenging, but it is important to acknowledge certain positive prospects, including developments promoted by the JRC in close cooperation with ENCR, IARC and other key stakeholders, including our EPAAC Cancer Information team (44).

Table 6.4c Data analysis**Data Analysis**

The systematic analyses aimed at providing indicators, specific reports, and data descriptors on a regular basis require some form of centralised planning. This could be achieved via several forms of organisation.

Description	Characteristics
<p>Centralised Analyses carried out by an epidemiologic and statistical team working at the ECIS coordinating centre (the team would have unrestricted access to the ECIS database, using a set of agreed data analysis procedures to calculate the set of indicators necessary to update the ECIS website annually, to draft periodic reports and to provide the more general description of the latest data).</p>	<p>Particularly appropriate for the provision of core, consolidated indicators (e.g., point estimates of incidence, prevalence, survival and mortality)</p>
<p>Distributed Analyses could fall under the responsibility of a group of partners organised into a Data Analysis Network to be considered as part of the ECIS. Partners would have access to the central database to carry out a specific set of analyses with the appropriate quality controls on the entire European dataset and to deliver the planned set of statistics and indicators.</p>	<p>Appropriate for systematic and periodic complex analyses that require statistical modelling, other advanced methods, or for the development of new methods</p>
<p>Ad hoc Analyses carried out by entrusted external bodies</p>	<p>Appropriate for well-delimited tasks, to be carried out in response to specific requests (such as experimental analysis of new datasets included in ECIS, or reports on very specific topics)</p>

EPAAC conclusions

The three types of ECIS data analysis organisational modalities are not mutually exclusive. They should be combined where necessary to implement any given programme of data analysis in the most appropriate and effective way, thus optimising the use of knowledge and time in cancer research.

It will be conditioned by available resources, time constraints, and institutional limitations and concerns. These factors will influence the technical configuration of ECIS, and it is up to the European Commission, Member States and cancer information institutions to analyse the options we have formulated and to build on the conclusions reached over the course of EPAAC (a detailed report of our findings will be published following the conclusion of EPAAC). However, as part of a multidisciplinary and multinational partnership, the our team on cancer information is strongly in favour of solutions capable of promoting the widest participation among different specialties, countries and institutions, to perform the anticipated ECIS activities and to access ECIS data and information. The Joint Research Centre (JRC), the European Commission in-house science

Table 6.4d Individual data dissemination**Individual data dissemination**

ECIS will be a key epidemiologic research infrastructure for the European Research Area. As such, it will have to make data available at the highest level of detail possible. Three main different mechanisms for data release can be envisaged.

Description	Advantages	Disadvantages
<p>Consent from data providers In order to release individual patients' data from EU databases, provider consent is requested via the circulation of relevant protocols, and only data from registries explicitly approving the protocol can be included in the released dataset.</p>	Current system; no modifications required	Heavy bureaucratic and organisational load at both ends
<p>Approval by a central committee A committee is delegated by data providers to evaluate research study protocols requests under general and pre-defined criteria. The positive evaluation by the committee is the sufficient condition for the delivery of the requested dataset.</p>	More effective use of time and resources than asking consent from each data provider	Appropriate mechanism for committee definition and rules of operation have to be agreed
<p>Free public use An online, public use dataset (similar to that provided by the US-SEER). Variables to be included in such a dataset and their level of detail should be carefully designed to avoid the possibility of disclosing individual patients' data. It should be possible for the provider to refuse public data access.</p>	The availability of individual records for driven analyses will constitute a major advance with respect to the data now available from EU projects, which are accessible only in tabulated form.	Data privacy regulations are different across the EU, and in many EU countries they are more restrictive than in the USA.

EPAAC conclusions

The three outlined procedures are of course schematic and can be combined in several ways. They do not differ from each other with respect to data privacy and protection issues, since all of them foresee the delivery of individual patients' data. Rather, they provide different practical solutions with different trade-offs between an increasing level of openness and distribution of the data and a decreasing control of providers on the use of their own data. Data to be included in research datasets must be consistent with the privacy protection laws in all the contributing countries. Rules for assuring confidentiality must be developed in accordance with EU legislation.

In order to test practical solutions and the feasibility of an open access database, a pilot version of the database could be implemented on a voluntary basis. Providing that a critical mass is reached, the spread of this instrument may encourage all European registries to participate. The dataset could be periodically updated with an allowance for including newly adhering registries.

service, is an important instrument for ensuring the fundamental sustainability of ECIS and coordinating its further development. JRC is working in close collaboration with all the major stakeholders, including ENCR, other networks of European scientific institutions (such as those involved in EURO CARE), and IARC, to define the best effective options on all the major ECIS functions.

In our exploration of the panorama of cancer information, the importance of utilising and coordinating European expertise on cancer has become abundantly clear. Building on the most comprehensive existing cancer registry network, we can together improve geographical coverage and data quality, as well as facilitate a variety of European collaborations in epidemiologic and clinical cancer research. To achieve these goals, cancer information stakeholders need a clear framework and ground rules in order to work in synergy for the optimal use of existing databases for cancer monitoring and cancer research. A European repository with updated and timely data and optimally trained health scientists will provide a necessary tool in combating cancer, thereby elevating the quality of services available to cancer patients to the highest possible level and facilitating long-term planning and decision-making. Perhaps more than any other issue attracting calls for better coordination and cooperation among Member States and partners, information without borders will be key to unlocking European potential to cancer control.

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Chapter 7

Towards innovative models to improve cancer research coordination and outcomes in Europe

Julio E. Celis,^a Anna Rouillard,^a Ingrid van den Neucker,^a Maria Ferrantini,^b Silvia Paradisi,^b Carlos Segovia,^c Teresa Corral,^c Rosana Peiró,^d Dolores Salas,^d Christine Berling,^e Fabien Calvo,^e Agnès Buzyn^e

Main messages

- Priority-setting in European cancer research, led by the scientific community and involving the widest possible range of stakeholders, is an important starting point for coordination initiatives.
- There is no 'one-size-fits-all' solution to coordinating research into all areas of knowledge; tailored responses are needed, adapted to the respective area of cooperation and the needs of the professionals and citizens involved.
- Lessons learned from coordination initiatives at national and European level may be used to help develop novel and pragmatic solutions.
- Strong commitment and support from the European Commission and other EU bodies is needed in order to facilitate coordination of cancer research between funding organisations.

Introduction

The call for more efficient coordination of cancer research in Europe dates back to Commissioner Busquin, who in September 2002 supported the creation of a

^a European CanCer Organisation; Brussels, Belgium; ^b Istituto Superiore di Sanità; Rome, Italy; ^c Institute of Health Carlos III; Madrid, Spain; ^d Centre for Public Health Research; Valencia, Spain; ^e Institut National du Cancer; Boulogne-Billancourt, France

European Research Area (ERA) for cancer (1). Cancer research in the European Union was fragmented and often duplicative, and there was a clear need for developing a global strategy that could facilitate the development of major advances and their delivery to civil society. Barriers to collaboration between Member States needed to be identified and addressed to expedite cross-border collaboration. The opportunity for such a change was provided by the Sixth Research Framework Programme (FP6), which represented the first explicit support for clinical research by European institutions.

In 2006, the Eurocan+Plus Project was launched within this framework to explore the feasibility of improving cancer research in Europe through better coordination of stakeholders, thereby delivering optimal cancer care to patients. The largest ever consultation of researchers, cancer treatment facilities, administrators, public health and health care professionals, funding agencies, industry, patients' organisations and patients in Europe, Eurocan+Plus highlighted the importance of dialogue between funders and scientists for the conceptualisation of models to meet the needs of the entire community, as well as the need to involve patients in the identification of priority areas for cancer research coordination. The project stressed the need to improve collaboration between basic/preclinical and comprehensive cancer centres (CCCs), institutions in which care and prevention is integrated with research and education, and it proposed the creation of a platform for translational cancer research composed of interconnected cancer centres with shared infrastructures and collaborative projects to facilitate rapid advances in knowledge and their translation into better cancer care (2). Furthermore, the project proposed the creation of an ERA-NET to support translational cancer research.

The Seventh Framework Programme (FP7) built on the foundations laid by FP6 and increased the focus on personalised cancer care (3). Both the EurocanPlatform, a Network of Excellence of cancer centres, and the ERA-Net on Translational Cancer Research (TRANSCAN), a consortium of funding organisations, received funding in FP7, and their activities are still in progress.

Recently, the Innovation Union – Europe's strategy for growth – has pledged to bring discoveries to the market/bedside more quickly (4). However, translating discoveries into clinical applications has proven complex, as there are many barriers that hinder the process and slow down the development of innovations. To name a few, these include (a) the complexity and length of the innovation cycle, a chain with defined phases and check points, which involves changing teams, multidisciplinary, infrastructures, clinical trials, regulatory and intellectual property issues, as well as educational matters; (b) the number of stakeholders involved and a fragmented scientific community; (c) insufficient research coordination at national, regional and EU level; (d) sustainability issues

in research funding; and (e) lack of models to incentivise and reward team efforts. In view of the spiralling costs of cancer care and the increasingly ageing population, decision-makers need to prioritise cancer research coordination in order to create innovations that bring benefits for European citizens, the health care system, and the economy in general. Health is wealth! (5)

With the firm conviction that coordination is the only way to address these challenges, the EPAAC partners in charge of research coordination undertook the task of developing a concerted approach for coordination of one third of cancer research, amounting to around €1.5 billion, from all funding sources across the European Union by 2013. Given the limited duration of the project and the level of resources allocated to this ambitious goal, the partners decided to focus their efforts on selected areas/topics where there was a clear need and desire for coordination.

In the next section, we describe the innovative approaches that have emerged from our work. Even though full methodologies for coordination in specific areas are still under development, preliminary progress has been promising, and new partnerships and pilot projects have the potential to change the way cancer research is carried out between Member States.

An innovative approach to cancer research coordination: setting the stage and objectives

In general, priorities for funding of cancer research are frequently set at the national or regional level in the 28 EU Member States, and there are enormous disparities in methodologies, priorities and financial resources between countries, although there is now a general trend towards national coordination, at least in some countries. Lack of coordination leads to duplication of research efforts, knowledge gaps, ultimately limiting the overall progress against this disease.

Major health challenges such as cancer cannot be addressed without strategic, long-term, and evidence-based policies to support, guide and sustain research efforts. National Cancer Control Programmes (NCCPs) are the main instrument promoted by the World Health Organization (6); their development is a highly conceptualised pursuit that hinges on evidence-based strategies, that is, service delivery mechanisms and cost-effective interventions based on the latest scientific evidence (see Chapter 8). In this sense, NCCPs are undoubtedly a positive development and can contribute to better integration of health systems. However, the breadth and scope of the cancer challenge in Europe merits a move from national and/or regional efforts to continent-wide collaborations, and a concerted effort involving all stakeholders is viewed as essential to speed

up the conversion of laboratory discoveries into new treatments and diagnostics (7).

Taking into account the above considerations, our team prioritised the participation of all stakeholders in the cancer continuum (governmental funding organisations, patients, charities, industry, scientists and clinicians) to tackle the problem. The European Cancer Organisation (ECCO) (www.ecco-org.eu) – an umbrella organisation that embraces more than 50,000 cancer professionals working at various stages of the cancer continuum, from basic and clinical research to patient treatment, care, and education – was entrusted with the task of leading EPAAC's work on cancer research. From the outset, ECCO underlined the need for coordination to be fostered in areas of real benefit and sought to build on synergies between countries and organisations across cancer research and care.

Together with its Associate Partners, the French Institut National du Cancer (INCa) (co-leader of the project team), the Italian Istituto Superiore di Sanità (ISS), the Spanish Institute of Health Carlos III (ISCIII) and the Spanish Centre for Public Health Research (CSISP), ECCO affirmed a joint commitment to approach this ambitious undertaking in a spirit of innovation and inclusiveness, agreeing on three specific objectives:

- To identify and prioritise areas in cancer research across the continuum that will benefit from coordination and cross-border collaboration;
- To identify mechanisms for a concerted approach for coordination of one third of cancer research from all funding sources by 2013;
- To develop research coordination pilot projects in selected areas as proof of concept for the above mechanisms.

Progress made towards achieving these objectives is described below, with a specific focus on the innovative methodologies made possible by the partnership approach.

Identification and prioritisation of areas in cancer research that could benefit from coordination and cross-border collaboration

Using an inclusive approach to bring in all relevant disciplines to the discussions, we first sought to identify and prioritise areas of cancer research that could benefit from European coordination. Input was sought from the cancer research community (researchers, clinicians, public health experts, industry and patients) as well as from funders.

The first step in the process was to define categories for a questionnaire to be used in a wider consultation process. For this task, we approached the

European Academy of Cancer Sciences (EACS), an independent advisory body of eminent oncologists and cancer researchers and an EPAAC collaborating partner. Fellows of the Academy gave precise examples of cancer research areas in which coordination would be beneficial. Based on their advice, we structured our questionnaire around the following research categories: basic, translational, clinical, population science and prevention, nursing, supportive and palliative care, and quality of care.

Identification and prioritisation of areas in cancer research following consultation with the cancer community

Over 200 experts from the cancer field, including patients, researchers, epidemiologists, public health experts, biotechnology experts, immunologists, clinicians, nurses and allied professionals, pathologists and industry representatives¹ gave feedback through the questionnaire. Respondents were asked to prioritise the categories of cancer research by the perceived need for coordination at European level and to provide precise examples of how coordination could benefit specific areas or topics within these categories (Table 7.1). The percentages indicated in the right hand column represent the proportion of respondents who believed there is high value in European coordination in the respective area of cancer research. For the three topics highlighted in red (subsequently chosen as areas for the development of pilot coordination projects), respondents' recommendations for sub-topics are specified.

Broader consultation of funding organisations: funding landscape and lessons learned

In parallel to identifying and prioritising areas of cancer research for coordination, we consulted cancer research funding organisations to gain insight into the funding landscape at the level of individual European countries. The European Research Managers' Forum's Second Cancer Research Funding Survey (8) provides an overview of direct cancer research spending by funding organisation in Europe. However, an understanding of mechanisms for decision-making, funding and execution of cancer research were considered central to our work, as were actual immediate and short/medium-term priorities in the different areas of cancer research. Information was collected from 48 organisations, both public and private, in 18 Member States (Box 7.1).

¹ The questionnaire was distributed to the following organisations: Federation of the Societies of Biochemistry and Molecular Biology, European Molecular Biology Organisation, European CanCer Organisation member societies and Patient Advisory Committee, European Molecular Biology Laboratory, European Federation of Biotechnology, European Federation of Immunological Societies, Organisation of European Cancer Institutes, European Society of Pathology, EurocanPlatform, European Academy of Cancer Sciences, International Epidemiology Association – Europe, European Federation of Pharmaceutical Industry Associations, European Association for Bio-Industries, European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry, EUCOMED, European Cancer Patient Coalition, European Patients Forum, EPPOSI, European Cancer Leagues, European Public Health Alliance

Table 7.1 Priority areas for cancer research coordination

Area of cancer research	% of respondents indicating priority area for European coordination	
Cancer therapy	61	
Biomarkers	58	
Biobanks	58	
Clinical trials (academic)	54	
Gaps in translational research	54	
Clinical trials aiming at personalised cancer medicine	52	<ul style="list-style-type: none"> - Prospective clinical trials on stratified patient populations for validation of treatment predictive biomarkers (predictive biomarkers/genetic tests) - Early clinical trials for new diagnostic methods and treatments
Cancer genetics, epigenetics and genomic instability	52	
Biomarker development	52	
Personalised medicine (mechanism-driven and molecular target oriented) for early detection and treatment	50	
Gaps in clinical research	50	
Gaps in basic research	49	
Improving links in the research and innovation chain	48	
Infrastructures	47	
Omics and bioinformatics	46	
Tumour micro-environment	46	
Advanced clinical trials structures adapted to biologically driven clinical trials	45	
Technology Platforms	45	
Invasion and metastasis	45	
Novel drugs and diagnostic developments	44	
Screening	43	
Cancer epidemiology	43	<ul style="list-style-type: none"> - Incidence - Mortality - Survival
Outcome of cancer treatment	42	

Table 7.1 contd

Area of cancer research	% of respondents indicating priority area for European coordination
Mechanism of resistance to drugs	42
Signal transduction	42
Clinical research involving hospital and comprehensive cancer centres at European level	42
Technologies	41
Key cell biology processes	40
Assessment of new technologies	38
Clinical epidemiology	38
Biobanking	38
Health impact of environmental and life style factors	37
Registries and databases	37
Complete clinical cancer registries	36
Rare/uncommon cancers	36
Outcomes research	35
	<ul style="list-style-type: none"> - Interdisciplinary and cross-institutional approach for bridging clinical research and implementation and evaluation in clinical care - Analysis for identification of best practice - Evaluation of outcomes and health economy of specific targeted drugs
Evaluation of interventions	35
Communication	34
Inequalities in cancer	31
Pharmacological prevention studies	29
Symptom management	29
Integrated approaches	29
Computing	28
Epidemiological studies	28
Coordination of clinical databases and registries with common nomenclature and standard operating procedures	28
Large cohorts	27

Table 7.1 contd

Area of cancer research	% of respondents indicating priority area for European coordination
Randomised trials	26
Advocacy	26
Studies in the organisation of cancer care	26
Health economics studies	25
Clinical epidemiology databases structures	25
Palliative care	25
Patient safety	24
Patient/family/carer involvement	24
Nursing and workforce	23
Quality assurance	23
Coordination of evidence-based guidelines	23
Implementation studies	22
Monitoring/cancer care evaluation systems	22
Systems for systematic collection of data on Patient Recorded Outcome Measures in cancer (PROMs)	22
Technological platforms/networks	21
Survivorship	21
Assessment and patient reported outcomes	20
Inequalities	20
Technology/e-health	18
Health economy structure	17
Descriptive epidemiology	17
Behavioural research	16
Economy research	15

Moving towards pilot projects in selected areas of cancer research: the process

Meeting with Member States/Associated Countries and DG Sanco on Cancer Research Coordination (Berlin, March 2012)

In collaboration with the European Commission's Directorate General for Health and Consumers (DG SANCO), ECCO organised a meeting of national cancer research funding organisations soon after the responses to the questionnaires were received. The objective of the meeting was to assess possibilities for increased coordination and cooperation in cancer research. The

Box 7.1 The cancer research funding landscape in 18 EU Member States**CANCER RESEARCH FUNDING**

Many countries are unable to give figures on how much money is spent annually on cancer research, due to

- Lack of comprehensive global overview of cancer research funding bodies
- Minimal or no communication between funding bodies
- No specific budget lines for cancer research

The majority of cancer research at national level is researcher-driven rather than directed

Very few countries have dedicated coordination bodies. Others have varying degrees of coordinated cancer research activities, for example through comprehensive cancer centres, cancer clusters, infrastructures such as platforms, biobanks and registries, joint initiatives between funders, charities and industry, public-private partnerships, etc.

Obstacles to coordination of cancer research funding at national level include:

- Financial constraints including scarce resources for coordination
- Lack of communication at government level, including between relevant ministries
- Divergent agendas of ministries
- Fragmented organisation of political competencies, for example different ministries dealing with different types of research
- Research programmes' budget lines allocated to health research in general, rather than to individual diseases
- Time and resource-consuming nature of coordination of large consortia
- Cultural and psychological factors (e.g., competition for funding among researchers as well as institutions).
- Sub-optimal communication between researchers and funders
- Lack of information on what research is being carried out and by whom
- Different objectives of funding organisations due to the various stakeholders behind them and different sources of funding
- Decision timelines and priorities, which are specific to each organisation
- Regulation and governance issues

Many countries are involved in transnational collaborative initiatives in cancer research, but mostly only through projects and networks supported by the EU. Very few countries are involved in bilateral, multi-lateral or regional coordination of cancer research.

CANCER RESEARCH DECISION-MAKING

Responsibility for decision-making and priority-setting in cancer research funding does not fall within the same body in each country.

Timelines for decision-making in cancer research vary from country to country, although it is common for priorities to be set and projects granted funding within one year.

Box 7.2 Guiding principles for European coordination of cancer research

Coordinate in areas where there is real benefit, taking heed of priorities set by the scientific community in particular, acknowledging and addressing inequalities between Member States and taking into consideration disease burden, clinical impact and economic impact. Public sector bodies should take responsibility for coordination between areas such as prevention and public health research as well as rare disease research.

Understand what is already in place and identify and build on synergies

Build up infrastructures such as platforms, biobanks and registries

Coordinate based on shared values and philosophies

Create goodwill between stakeholders, enabling actors to participate in coordination initiatives on a voluntary, **a la carte** basis and in a bottom-up rather than top-down manner.

Use an inclusive approach, involving all cancer research stakeholders including patients, leagues and charities, research institutions, funding organisations, university hospitals and industry

Encourage regional coordination, e.g., regional clusters and projects for similar interests and where cultural similarities facilitate coordination

Integrate strategies for cancer research and care, increasing links and coordination between basic and clinical research and between institutions as well as between research and care

Promote better communication between decision-making bodies involved in cancer research

Allocate finances to coordination between infrastructures and activities

Use EU instruments to bring funders and scientists together, accompanying coordination initiatives with leverage funds and ground rules

Ensure the correct policy environment for improved coordination, including addressing legal and regulatory barriers

Recognise National Cancer Control Programmes as tools for improving coordination

majority of countries present were favourable to transnational cooperation, and during the course of the discussions, a series of important guiding principles for coordination emerged (see Box 7.2).

Research Forum (Brussels, July 2012)

Following the analyses of both questionnaires and oral feedback given by funding organisations at the Berlin meeting, we turned to discussing possible ways forward

for the realisation of novel coordination approaches through pilot projects. Two areas deemed highly relevant for potential coordination initiatives were clinical trials aiming at personalised cancer medicine and outcomes research. These areas were considered innovative in that they do not overlap with past or ongoing initiatives undertaken at European level, and of added value as they contribute to efforts already prioritised and funded at national level. Importantly, behind these areas there was a Member State willing to spearhead the process.

A Research Forum was thereafter organised by ECCO, in which panel discussions set the scene for interactive sessions among funders, researchers, clinicians, patients, industry, public health experts and policymakers on novel approaches to cancer research coordination, with a focus on the two possible areas for future coordination actions. Participating Member States were asked to indicate how their organisation could play a role in driving forward such coordination. One session was dedicated to exploring various models of ongoing cancer research coordination in Europe – at national, regional and European levels – and to understanding the extent to which these models could be adapted, extended or duplicated to further enhance European coordination. There was agreement that the two suggested pilot coordination areas should be pursued, and that prevention and public health research, another highly relevant and important area, should be prioritised for another pilot coordination project.

Follow-up workshop (Paris, October 2012)

Following the Research Forum, the three pilot project ideas were further elaborated between experts at a follow-up workshop in Paris hosted by INCa, the purpose of which was to discuss concrete steps towards their implementation and to design a tentative roadmap. The next section is a presentation of the three pilot coordination projects, including recommendations and requirements for implementing them at European level. It should be noted that these pilots are, in some cases, still pending detailed articulation by project management, including the sources of the specific funding that will support their implementation.

Current status of pilot projects

Pilot project 1: Pan-European coordination of cancer research through expanding and/or combining innovative national programmes

Individuals responsible for the conceptualisation and development of the pilot project²: Christine Berling, Béatrice Bussière, Agnès Buzyn, Fabien Calvo

² Institut National du Cancer; Boulogne-Billancourt, France

A new ambition for cancer research coordination

Through the intelligence-gathering exercises and stakeholder meetings carried out within EPAAC, it became pertinent to test a novel approach to European cancer research coordination by opening to other countries or interfacing national coordination programmes that have proven of highest utility. The background hypothesis was that a shared European vision across funding organisations in face of the 'fairness and efficiency' dilemma of resource arbitration would certainly be facilitated in areas where a national track record exists of coordinated initiatives that have spurred research outcomes.

The area of clinical research, which has profoundly evolved over the last decade with the identification of molecular targets and cancer sub-types, is of particular interest for future coordination efforts (Table 7.1). Studies are now decisive for product development from the early phases of clinical development, considering the increasing complexity of developing targeted agents and their biomarkers for selected patients. Hurdles and bottlenecks are well known, and new treatments should come from innovative trial design and risk-based algorithms, as well as new models of partnership and funding (9). Public-private partnerships have become critical to both industry strategies and public authorities in meeting this challenge, as evidenced by the increasing number and variety of such partnerships (10). Interestingly, new models of partnership between the pharmaceutical industry and academic institutions are broader in scope than traditional collaborations, which assemble around a clinical trial protocol on an ad hoc basis (11).

Large countries have started to channel clinical cancer research activities through coordinated networks and programmes to incorporate translational medicine in the design of clinical trials, with the ultimate goal of improving the patient outcomes.

We saw particular promise for coordination in these patient-centred national programmes, which have been built on new standards and upgraded infrastructures to integrate clinical research and biology into the decision-making process. In addition to delivering evidenced-based services, they provide access to clinical and scientific expertise as well as professional resources through a single portal. The French CLIP² (INCa Accredited Centres for Early Phase Clinical Trials) and the British Alliance programmes stand out in the area of early phase therapeutic cancer research, promoting fair access for patients to innovation throughout the country. The French organisational framework for therapeutic cancer research (see Box 7.3) has attracted a great deal of attention worldwide, both from public and private stakeholders, as it opens the path to innovative treatments and has firmly established grounds towards precision/personalised medicine. It has proven a very positive undertaking for all involved partners.

Box 7.3 INCa's national programme for early-phase therapeutic cancer research/CLIP² programme

The start of the CLIP² programme

The INCa programme was initiated with collaboration with the Cancer Therapy Evaluation Programme of the US National Cancer Institute. It organises phase I/II clinical trials on drugs under development by pharmaceutical companies.

Status and funding were awarded to 16 centres (called CLIP² – INCa Accredited Centres for Early Phase Clinical Trials) to strengthen France's early-phase clinical organisational frame. CLIP² functions as a network with wide geographical coverage. Implementation of a quality assurance programme and a collaborative approach ensures that all centres meet required standards. It has close links with biobank resources and molecular genetics infrastructures. This organisational framework allows state-of-the-art, biomarker-driven, early-phase trials to be delivered in a competitive timeframe, constituting a key asset as early-phase studies become more stratified.

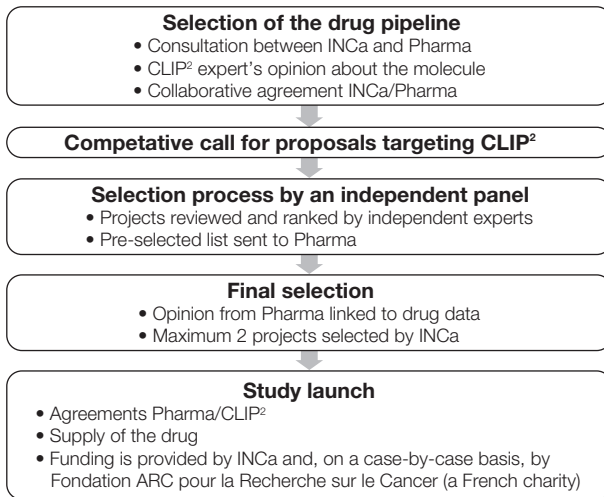
Purpose and organisation

The CLIP² programme is based both on the above organisational framework and on public/private partnerships with the pharmaceutical industry. It has been purposely designed with simplified procedures and short timelines (the whole process, from the selection of the drug pipeline to the launch of a specific study, doesn't exceed 11 months) to spur the development of new anti-cancer agents and facilitate the evolution of stratified medicine. It grants support to academic trials through an independent, peer-reviewed, competitive process. The scope of trials considered focus on indications outside the company's main programme. As of April 2013, the programme involved 7 molecules from Novartis, Pfizer, Lilly, Roche and Transgene.

Programme's strengths

One very innovative feature of the programme is that it is primarily based on a social choice for product development and gives patients with no alternative treatments accelerated access to new drugs under development. This programme supports independent academic clinical studies only. The rigorous selection of the expert sites as well as the plan for oversight, monitoring and on-site auditing of participating sites and dedicated financial support has increased the quality of clinical studies and infrastructures. Each step of the implementation process has been standardised; issues of data ownership, intellectual property protection, financial compensation, publication rights, etc., are defined upfront in template agreements. All centres agree to abide by the provisions of the agreements, which expedite the process. Communication between partners is smooth, and industry is involved at key steps. Projects are tightly managed to ensure they progress according to the timelines.

Programme steps



In the United Kingdom, the Alliance programme for academic sponsored trials is coordinated by both the National Cancer Research Network (NCRN) and the Experimental Cancer Medicine Centre (ECMC) network (12). This network-based organisation provides researchers with practical support to facilitate cancer clinical studies. Selection of the drug pipeline for the Alliance

programme involves researchers from the Clinical Studies Groups (which represent a central component of the new framework for clinical cancer research in the United Kingdom), the ECMC, and industry leadership. The scope of the trials considered is for indications outside the main company programme, mostly randomised phase II designs, combinations and radiation therapy. It is very similar to the French CLIP² programme (see Box 7.3), with an academic peer-review system for project selection; project coordination through accredited clinical trial units and academic sponsorship. ECMC is a network of 18 centres of excellence in translational research, specialised in early phase trials like the French CLIP² network.

Below, we review how European coordination may be spurred by bridging national innovative programmes in early phase clinical research, and we propose some principles for extending this particular coordination initiative to the European level.

A way forward for Europe

Early phase clinical research has great potential in terms of coordination, and the British Alliance and French CLIP² programmes are internationally recognised as successful models of national coordination. In particular, these network-based organisations have increased research activities and clinical trials accrual, and could lead to reducing major variations in patient survival across regions through strengthened patient care (13, 14). Other examples of clinical networks outside Europe have shown to significantly reduce the early mortality and improve overall survival (15). These programmes are also highly regarded by industry as appropriate tools to increase Europe's attraction for the health industry. No single model suits all countries, but common key features may be drawn from existing national experiences to extend such programmes between European countries and foster coordination.

In October 2012, EPAAC representatives met in Paris with leading research funding organisations to discuss the proposed coordination modalities. An overview of the French CLIP² programme, the UK Alliance programme and various other national initiatives was provided in order to review the key steps and some prerequisites of such programmes (designation of centres, funding models, etc.) in light of existing European initiatives. Attendees agreed that a European programme should be kept as simple as national initiatives, with short timelines. Increased difficulties of working across national borders should be compensated by increased added value. Collaboration across clinical research networks should focus on conducting trials that cannot be performed on an individual basis (in rare cancers, for example) to achieve a critical mass of patients and new therapies for unmet medical needs. The idea of opening up

existing national networks to collaboration with other countries across Europe was viewed as particularly attractive. It was decided that the expansion process would be pursued in a stepwise way, with an initial assessment of the feasibility of linking the British and French programmes.

The lead organisations of both programmes and a pharmaceutical company met in April 2013 to review in detail each programme's operational steps in order to assess the feasibility of a coordinated process using both networks. The designation of the specialist centres and criteria used were not reviewed at this stage, since the purpose was to make use of the existing organisational framework to coordinate the programmes rather than to harmonise their procedures. Nevertheless, the pharmaceutical company stressed that designation of centres was key to the company's decision to give access to its drugs, and that this procedure increases the visibility and quality of the centres. The main conclusion of this meeting was that it appears feasible, despite some discrepancies in the respective procedures, to coordinate both programmes and launch joint calls for proposals across the British and French networks that would lead to transnational, multi-centre studies. The main discrepancies included the level of company involvement in the project selection and the funding process. The study of the key paperwork related to both programmes (Memorandum of Understanding, agreements and call documents) subsequently confirmed the feasibility of working across both programmes.

Another coordination option arose during the meeting: opening pre-selected studies submitted by the British centres in the Alliance programme to the French CLIP² cooperation and vice versa. This pragmatic option would somehow help answer the next key question before implementation: what should be the focus of the joint British/French programme, and what should remain within the remit of national programmes? In other words, what is highly relevant at European level and would have the highest impact for the European patients? This question will be addressed with the designated centres.

The readiness of other countries to enter into a coordination process in early phase clinical research is being explored in parallel. The approach is to open the CLIP² programme to collaboration with designated centres in other countries. One essential milestone, however, will be to define a common way to assess excellence in order to establish a strong base for this transnational networking. Benchmarking criteria used in existing designation processes may help differentiate between elements for assessing science (early phase trials are very different from late stage, for example), local aspects and core capacities. Defining a common set of criteria for quality assurance, however, should not result in erasing each centre's specificities; indeed, the network's value depends on the complementarities between the centres. As seen in the national examples,

the overall quality/scientific level in early phase trials and molecular biology tests is expected to increase globally.

If this new coordination initiative succeeds at European level, patient-centred organisation of clinical cancer research would be spurred, with a high impact on health care. This is much needed at a time when the economic burden of cancer in the European Union has been estimated to exceed €124 billion (16).

Notwithstanding the success of the above, which can only be evaluated well beyond EPAAC timelines, one of the key lessons to be drawn is that cancer research coordination at a European level could be based on the coordination or expansion of existing, successful, national initiatives. However, the preliminary steps, consisting of the identification of national programmes of interest and of the right stakeholders (programme owners), need to be organised. It is an extremely tedious process, as experienced during EPAAC, even for a dedicated team. The role of the European Commission is certainly to be explored in view of this new coordination path.

Pilot project 2: A European platform for cancer outcomes Research

Individuals responsible for the conceptualisation and development of the pilot project: Maria Ferrantini³, Silvia Paradisi³, Paolo Baili⁴, Milena Sant⁴, Riccardo Capocaccia³

Building a European platform for cancer outcomes research

Another key priority to emerge from the broad and inclusive consultation carried out under EPAAC was the concept of building a European platform for cancer outcomes research, a need indicated in approximately 35% of the responses to the questionnaires (see Table 7.1). This innovative concept was further developed and its rationale strengthened thanks to the exchange of information and discussions held during the Research Forum (2 July 2012, Brussels) and the follow-up workshop organised by INCa (18–19 October 2012, Paris) with representatives of major European projects focused on cancer research and cancer epidemiology as well as funding organisations.

The ultimate aim of outcomes research is to understand the end results of particular health care practices and interventions both on individual patients and populations. To this end, the specific objectives of outcomes research are to describe, interpret, and predict the impact of interventions and also other factors on ‘final’ outcomes of importance to decision-makers. These outcomes comprise not only survival and disease-free survival, but also patient quality

³ Istituto Superiore di Sanità; Rome, Italy

⁴ National Cancer Institute, Milan, Italy

of life, perceptions and satisfaction related to health care, and the economics of interventions such as cost-effectiveness, cost-utility, and comparative effectiveness (17).

In the era of translational medicine, cancer outcomes research can well be considered an integral part of translational research, aimed at integrating early (i.e., basic/pre-clinical), translational, clinical, and late (clinical) translational research in order to speed up the application of novel products, tools and approaches in health care systems (18).

Currently, despite the development and validation of outcome measures in the context of the health services research area, standardised tools or methodologies for assessing the impact of interventions and other factors (socioeconomic, organisational, technological, and behavioural) on final cancer outcomes are not applied at a pan-European level. This fact is a major obstacle to the decision-making process, impeding the full and objective evaluation of new agents and strategies for cancer prevention, diagnosis/early detection, treatment and palliation, both in terms of benefit for the patients and of cost-effectiveness. Likewise, it means that cancer research in Europe is impaired in defining a research agenda intended to generate better scientific products and information, and as a consequence, in achieving the ultimate objective of optimising the quality of cancer care through an evidence-based decision-making process. The advent and explosion of personalised cancer medicine has added another facet to the need to urgently address this gap. (19)

Opportunities, challenges, unmet needs and options

Building a platform for cancer outcomes research in Europe should take advantage of numerous opportunities that exist to fill the existing gaps and to find solutions for meeting today's most urgent needs.

In Europe, initiatives have focused on the following:

- Promoting collaboration between cancer registries to improve the quality, comparability and availability of cancer incidence data, including defining data collection standards and providing training for cancer registry personnel and promoting the use of cancer registries in cancer control, health care planning and research (European Network of Cancer Registries, ENCR);
- Collecting detailed clinical information not usually available to population-based registries through high-resolution studies aimed at describing and comparing patterns of care between countries and regions (EUROCARE), and interpreting differences between countries in terms of survival (EUROCARE and International Cancer Benchmarking Partnership);

- Improving the use of cancer registries in European countries, information exchange and benchmarking of best practices, and strengthening the infrastructure for population-based cancer registries in Europe (EUROCOURSE);
- Creating a platform for joint translational cancer research between clinical registries as well as a network of comprehensive and standardised databases, to link the clinical registries with bio-repositories, and set up an infrastructure for large-scale, cross-national studies (EurocanPlatform);
- Prospectively collecting data on physical and psychosocial outcomes in cohorts of survivors, in addition to clinical characteristics at diagnosis (PROFILES);
- Supporting European countries in rationalising and harmonising the development of comparable and coherent patient registries, thus enabling cross-border exchange and analyses of data for public health and research purposes (PARENT);
- Benchmarking comprehensive cancer care and producing best practice examples to contribute to improving the quality of interdisciplinary patient treatment (BenchCan, an exclusive accreditation programme developed by the Organisation of European Cancer Institutes [OECI]).

All the above-mentioned projects contribute to the acquisition of knowledge and complementary expertise as well as to the development of tools and model systems that together will prove invaluable to the implementation of a cancer outcomes research platform in Europe. However, major challenges remain as the oncology discipline evolves. Clinical records, the major source of information for cancer registries, will need to greatly improve in terms of completeness of recorded information and also to deal with the challenges of molecular medicine (pending the definition and endorsement of internationally recognised systems of classifying tumours by specific markers and of categorising individual therapies), increasing prevalence and survivorship (pending the achievement of an international agreement on the variables to be used and their consistent recording for all cancer patients). Based on these considerations, potentiating the activities associated to clinical recording clearly emerges as an urgent need.

The potential of outcomes research to improve cancer care delivery relies on the following prerequisites: (a) defining sound, feasible and decision-relevant final outcome measures; (b) providing evidence in terms of causal linkage about the effect of interventions on those outcomes; and (c) translating findings into information potentially capable of influencing decision-makers.

Therefore, the main challenges for the development of a European platform for outcomes research can be summarised as follows:

- Organising the process of collection, aggregation, linking and analysis of data within and between quality-assured patient registries and population-based registries in the different European countries, with particular attention to assuring quality and comparability of data, pending the definition and endorsement of a harmonised procedure codes across Europe (see Chapter 6 for the differences in the type of data collected by different institutions).
- Defining outcome indicators and evaluating them in relation to the introduction of new treatments (refer to Chapter 6 of this book for the sources of different cancer indicators);
- Facilitating, through European law, the protection of patients' data (i.e., epidemiologic research on cancer patient outcomes) while ensuring maintenance of the current high standards of data protection and confidentiality;
- Agreeing on the cancer types to be used in a pilot phase; and
- Identifying the most appropriate funding model/instrument.

With regard to data collection and analysis, outcomes research can be thought of as involving an information cycle that includes collecting data about health care practices and patient/population-level outcomes, analysing those data, and reporting on the findings. For this reason, the development of a cancer outcomes research platform, although an independent initiative, would greatly benefit from a functional and operational link to the European Cancer Information System (ECIS) proposed by the EPAAC team focused on cancer data and information and described in Chapter 6 of this book, with the aim of collecting and analysing population-based data (not only on cancer survival but also on stage and treatment) in a centralised way across Europe, offering open access to the resulting databases.

The above-mentioned challenges are perhaps best captured as pending, operational needs which have emerged through the course of EPAAC:

- Harmonising and standardising cancer data collection methodology (including quality control), as well as data linkage and sharing for use in outcomes research;
- Collecting information on the impact of diagnostic tools, treatment and intensity of follow-up on outcome in terms of effectiveness (i.e., effects on population-based patient cohorts) and based on the definition of outcome indicators, in order to overcome the lack of information in current

database, reduce differences in clinical treatment patterns, and evaluate the effectiveness of treatments recommended by guidelines;

- Developing consensus coding and categorising cancer stage at diagnosis, with consistent stage recording for transmission to registries, in order to increase the quality of stage-specific treatments;
- Optimising collection of data on quality of life and functional status of survivors, through a cross-disciplinary approach and integration of the different data sources;
- Integrating population-based cancer registry data with clinical data derived from clinical sets and biobanks to explain the differences in survival across areas and over time; and
- Promoting the methodology and professional training concerning cancer outcomes research among the interested professionals.

Implementing a distributed European platform for cancer outcomes research will require integrating the existing knowledge, expertise, tools, and model systems in a coordinated effort to develop common approaches and protocols for addressing the key issues identified. The strategy and methodology envisaged for implementing this initiative will be based on the following steps, as defined during a meeting held on 4–5 April 2013 in Valencia, Spain:

- Identifying study questions/pilot areas of study which should include
 - definition of outcome indicators,
 - evaluation of outcome indicators in relation to the introduction of new treatments for selected cancers,
 - sustainability and outcomes of personalised oncology in terms of cost-effectiveness and survival and quality of life, respectively,
 - diachronic evaluation of changes in survival for advanced stage disease,
 - selecting cancer types;
- Identifying centres that have the necessary expertise and know-how for the purpose;
- Developing common methodologies and protocols to address the selected questions;
- Identifying funding organisations willing to commit in the establishment of a European platform for cancer outcomes research; and
- Verifying the interest of the European Commission of committing in this endeavour.

The participants in the discussion on this pilot project agreed on the importance of high resolution studies that, as highlighted by the EURO CARE analyses, can shed light on the reasons for differences in survival by comparing patterns of care between countries and adherence to standard cancer care (20). High resolution studies are carried out using data from population-based cancer registries on a sample basis, involving the collection and analysis of detailed information on diagnostic, therapeutic and follow-up procedures that are not usually routinely collected by cancer registries (21,22). Therefore, high resolution studies are highly valuable for evaluating the dissemination and the impact of new treatments in population-based set of patients, as well as the frequency of and variation in adherence to standard care. Ultimately, high resolution studies are important to improving health care practices.

The ultimate aim is to test the feasibility of obtaining multi-centre outcomes research measures based on a commonly standardised methodology. To this regard, it is worth mentioning a very recent study showing the practical feasibility of generating evidence about drug use and cost-effectiveness in oncology practice (23).

Potential impact

Based on all the above considerations, the development of a European platform for cancer outcomes research is expected to have a major impact on research, policies, clinical practice, health care outcomes, and health economics in the oncology area. An additional advantage would be that institutions funding cancer research could assess their return on investment through the monitoring and assessment of the outputs and the impact of their research projects.

Ultimately, a European platform for outcomes research would aim to create a system for assessing the dissemination and effects in clinical practice of health procedures of proven efficacy or of new treatments, on samples of unselected patients and in the general population. The platform would address both patient outcomes and macroeconomic aspects, providing benchmark studies for addressing inequalities in access to care and in the quality of care, and for identifying evidence-based measures to overcome the differences in cancer patients' survival across countries. Coordination at the European level in this area would therefore bring high value to both patients and health policymakers. In addition, a cancer outcomes research platform for Europe would help to align cancer research efforts between and even within countries. Finally, it would also promote collaboration within the scientific community through data and knowledge exchange, informing a coordinated health research agenda in Europe.

Pilot project 3: A European knowledge hub for epidemiology and public health research on cancer: research coordination and knowledge sharing

Individuals responsible for the conceptualisation and development of the pilot project: Rosana Peiró^{5, 6}, Carlos Segovia⁷, Dolores Salas⁵, Teresa Corral⁶, Ana Molina⁵, Juana Ferrús⁵, Jose Antonio López-Guerrero⁸

Why we need coordinated cancer epidemiology and public health research

It is a widely accepted that too little is being done to prevent cancer even though prevention and public health policies remain the only serious option for controlling its long-term impact (24). Many international reports advocate the wisdom of prevention, but prevention policies developed at a European level have not been very effective (25). This is partly explained by the fact that less than 4% of the overall annual global research budget is spent on epidemiologic and public health research, with only a negligible contribution from the private sector (26).

A number of factors point to the need to strengthen research in cancer epidemiology and public health as a way to enhance critical mass in these fields. First of all, cancer determinants are increasing on a global scale: large corporations are expanding their marketing of rich caloric foods; urban development is mediated by private motorised transport demands; and environmental risks (for instance pollution or use of chemicals) are increasingly widespread on an international scale, regardless of geographic location, cultural sensitivity to environmental protection, socioeconomic development or environmental policy.

Moreover, cancer is a multi-causal disease; some of its risk factors are interrelated, and it is accepted that many are also related to other diseases. Although progress is being made to unravel the complex interactions between genetic background, metabolic features and exogenous risk factors, this methodology is quite difficult, requiring enormous population samples. Yet, this knowledge is also crucial for understanding the mechanics of cancer, for developing specific prevention policies and for evaluating the impact of these policies in reducing cancer and other diseases that benefit from similar policies. In the context of the ongoing financial crisis, it is more important than ever to make the best use of resources, preventing what we know how to prevent in order to emerge from the recession with stronger and more sustainable health systems (27,28). Thus, strong epidemiologic research across borders is important, but the systematic

⁵ Centre for Public Health Research; Valencia, Spain

⁶ CIBERESP, Spain

⁷ Institute of Health Carlos III; Madrid, Spain

⁸ Valencian Institute of Oncology Foundation; Valencia, Spain

and standardised collection of biological samples in population based biobanks or centralised biological resources have proven to be very demanding (2).

In addition, there are enormous differences in research capacities across Europe, both between countries and between disciplines. With regard to epidemiology and public health, budgetary allocations to cancer prevention research are in decline when compared to clinical, molecular or genetic research, further contributing to the weakness of this type of cancer research and the low critical mass at a national and European level.

Our team identified cancer epidemiology and public health as an important area to target in coordination efforts, and cross-border research networks emerged as the best vehicle to achieve this goal. By ramping up the promotion, funding and support for these networks at a national and European level, we can identify new possibilities for prevention, early detection, diagnosis and treatment, finding solutions to pending challenges in cancer management (29). Networks have the potential to boost research capacity by connecting specialised research groups in cancer epidemiology and by including less experienced research groups in large European studies. Sharing the knowledge gained with the population – essentially including them as a node in the network approach – also helps in getting population support on board and advocacy for evidence-based prevention policies.

Existing networks in epidemiology and public health research

There has been some experience in cancer research networks in the USA (30), but less evidence of this type of cooperation is found in Europe. Exceptions include the Nordic Cancer Union, which funds strategic projects and collaborative cancer research within these countries. In addition, there are well-known, successful networks dedicated to cancer at a national level, such as the National Cancer Research Institute in England, the Italian Alliance Against Cancer or the Spanish Network for Cancer Research, among others. The European Screening Network, or EURO COURSE, has also served to foster collaborative research.

In epidemiologic and public health research, there is little experience in networking, probably due to the low budget assigned to this kind of research and to the small number of groups working on it. One of the few exceptions is found in Spain, among the health research structures known as Biomedical Research Centre Networks (CIBERs). These virtual networks of research groups in specific scientific fields include one the Biomedical Research Centre Network for Epidemiology and Public Health (CIBERESP). Its main objective is to promote collaborative research, encouraging links between different research groups to achieve higher social impact and more effectively contribute

to addressing health problems. CIBERs require proven excellence in research in the relevant scientific field, measured primarily by the quality of scientific publications and the research conducted by each group. It must be underlined that the principle behind the CIBER is synergy, given that the interaction between research groups produces better results than individual contributions (31). CIBERESP was the network behind a large cancer research project conducted with the participation of almost 20 groups around Spain.

This pilot experience in Spain inspired a proposal put forward in EPAAC for coordinating efforts in the cancer epidemiology and public health research in the European context. The first ideas were presented at an EPAAC workshop in Paris (October 2012), where participants expressed their enthusiastic support. During the Second Research Forum in Valencia (April 2013), a formal kick-off for the proposal was organised with a group of about 20 European researchers in cancer epidemiology, and in-depth discussions brought to light some key coordination issues (32) and helped chart a path forward in the implementation of a knowledge hub in cancer epidemiology and public health research.

Building a knowledge hub by cancer research groups in epidemiology and public health

The aim of this pilot project is to create and connect a network of high-quality research groups working on cancer epidemiology and public health.

In the short term, the knowledge hub would map the capabilities and needs of human resources for epidemiologic research on cancer by identifying research groups and Member States with strengths and weaknesses in this field. In the medium- to long-term, a network structured around the knowledge hub will enable Member States to collaborate using their own funding on a selected number of cancer epidemiology research projects. Finally, in collaboration with other stakeholders, the knowledge hub will eventually promote and contribute to the process of developing a common cancer epidemiology and public health research agenda in Europe.

The function of the knowledge hub is to emerge as a platform for knowledge transfer and exchange. It will focus on facilitating networks of researchers to plan joint research initiatives of common interest. These networks would be able to identify fundraising opportunities for multi-Member State, high impact research initiatives (e.g., large cohort studies on the environmental factors linked to cancer, inequalities in exposures between European countries, or social innovation as a tool for public health interventions). A crucial issue is the way in which they could link up with large projects in a highly stable and scientifically productive network such as the European Prospective Investigation into Cancer and Nutrition (EPIC), among others. Moreover, the hub will

support the improvement and evolution of better research practices to benefit the European research community by (a) leading initiatives focused on research quality enhancement; (b) identifying and developing infrastructures and tools for research to be used in a more efficient way between Member States; (c) cooperating with other European organisations to address common priorities; and (d) disseminating new developments in cancer prevention to citizens' and patients' organisations.

Some of the aims of this alliance would consist of the following:

- Interlinking or sharing databases, that is, getting the best out of existing efforts;
- Facilitating database complementarity;
- Promoting the function of knowledge brokerage with the production of scientific advice for evidence-based policy;
- Proposing a call for tenders of European Commission grants;
- Proposing a range of research topics – with emphasis on European collaborative research programmes with European added value; and
- Proposing consistent guidelines for epidemiologic and public health research on a pan-European level.

The knowledge hub would determine its own governance structure, including principles and rules of procedure. It would have at least two basic pillars, one representing overall governance and funding, and the other covering scientific issues and research performance. A fund for a secretariat is one of the minimum requirements at this first stage.

The principle purpose of the knowledge hub would be cancer epidemiology research coordination at the European level. In the short-term, this could be achieved by promoting the coordination of research projects between Member States, using the same methodology in the development of large population studies and measurement of differences in exposures in Europe, or by sharing the same general objective by implementing the specific objectives according to the availability of resources and capabilities between research groups in Member States. The funds will be obtained from both Member States and the European Commission. On the one hand, the research groups will apply for competitive funds to their own national research agencies, and on the other the European Commission will fund the coordination task for both the development of the research proposal and the project management.

An externally conducted evaluation and identification process for 'high-quality research groups' in Europe working on cancer-related projects in epidemiology

needs to be established. A straightforward application and approval process is preferred to maximise the number of interested research groups, which may be either research groups belonging to public research institutions or other types of organisations. At the same time, the simplified process will allow newcomers to become involved in the field, making the knowledge hub a dynamic structure that invites innovation.

The knowledge hub could contribute to mapping research funding at an EU level, averting unnecessary duplication (here, a note of caution should be introduced, as not all duplication is negative), identifying gaps and determining the main actors in the field. The coordination of epidemiology and public health research at the EU level would be impossible without this research funding information system, and such a resource would be invaluable to policymakers. An online system could potentially work, although an incentive is needed for people to provide this information. Funding agencies should be approached with this idea, as they are the stakeholders who will provide this information and use the system. A potential hurdle is the fact that many countries do not have a specific category/budget line for epidemiologic and public health research within national programmes.

In conclusion, a European initiative for epidemiologic and public health research should be structured on three levels: (a) a scientific agenda with a common research programme for a limited time period with a peer-review evaluation, (b) an information system with the scientific community providing information to funding organisations on what is needed, and (c) collaboration and links with other stakeholders involved in cancer epidemiology research, such as patients' organisations.

Conclusions

EPAAC aimed to build on lessons learned from previous coordination initiatives and especially on the recommendations from the Eurocan+Plus project (2), the largest and most important consultation on the future of coordination efforts in cancer research in Europe to date. In order to adopt an innovative approach to the problem, we set out to focus efforts on areas where coordination would deliver high returns to the patient/citizen; involve all the stakeholders in cancer research; build consensus on principles for coordination (common principles and priorities, shared values); create a 'win-win' situation for all stakeholders (designing coordination methodologies that bring added value to all); and deliver added value to previous coordination efforts. We tried to create a forum where funders and other stakeholders could join efforts for a higher purpose, creating the building blocks of consensus and shared values between Member States

on which the European Commission may eventually bring complementary support in the form of mechanisms and/or finances for long-term collaboration. This kind of forum, already promoted by the Eurocan+Plus study, has proven a highly valuable opportunity to exchange information and best practice and to discuss future joint orientations in cancer research, including epidemiology and population health, areas that have not been prioritised highly by DG Research in recent years. We firmly believe that such a forum would be worth pursuing after the conclusion of EPAAC, along with continued focus on implementing the coordination initiatives described here.

It was clear from the start that no single methodology could be applied for coordination of all areas of cancer research between all countries. Our challenge was thus to tailor coordination methodologies to the specific research topics at hand and to the needs and wishes of the interested parties, using consensual principles for coordination to guide the way and lessons learned from previous or current coordination initiatives at national and European level to help conceive novel and pragmatic solutions.

While the limited timeframe and budget rendered the initial goal (coordination of one third of all cancer research in Europe by 2013) unattainable, three areas of cancer research which are highly relevant for coordination from a patient/population health perspective have been elaborated in pilot projects aimed at pooling efforts, expertise and resources between countries. The pilot projects are the first step towards European coordination in these areas, and institutional support, both at national and European level, may be crucial for the long-term extension and continuation of these initiatives.

While it may be impossible to 'copy and paste' methodologies from one problem in cancer research to another, the three pilot projects may serve as inspiration for coordination of other pertinent areas in cancer research, and possibly even in other chronic disease research.

Successful European coordination of cancer research should be pursued where a strong scientific rationale for coordination exists, and where there are anticipated high benefits to patients and citizens. Involvement of the scientific community from the outset is crucial for the identification and elaboration of areas for coordination, and biomedical science, public health, funders and patients must sit at the same table in this process. Only with such a collaborative approach to priority-setting can a strategic innovation and research agenda be developed and implemented at a European level.

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Chapter 8

From ‘on paper’ to ‘into action’: development of National Cancer Control Programmes in the EU

Tit Albreht,^a Marjetka Jelenc,^a Lydia Gorgojo^{b,c}

Main messages

- Work in EPAAC has brought most Member States within reach of achieving the European Commission’s objective of having an integrated cancer plan by 2013 (with functional plans in 23 of the EU-27 Member States).
- Member States have readily participated in Partnership efforts to compare and describe the elements of the plans.
- Crucial work remains in identifying common indicators for plan evaluation and developing guidance for the development of high-quality NCCPs.

Introduction

As any health policymaker knows, management of cancer is inherently complex, requiring multifaceted and simultaneous interventions in interlinked components of the health system. Only through adequate planning can health systems begin to respond to population needs by preventing, detecting and treating this disease as quickly and effectively as possible.

National cancer control programmes (NCCPs) are a logical response to this important challenge. They are defined by the World Health Organization (WHO) as ‘public health programmes designed to reduce cancer incidence and mortality and improve quality of life of cancer patients, through the systematic

^aNational Institute of Public Health of the Republic of Slovenia; Ljubljana, Slovenia; ^bEuropean Observatory on Health Systems and Policies, Brussels, Belgium; ^cInternational Vaccination Centre, Sanidad Exterior, Valencia, Spain

and equitable implementation of evidence-based strategies for the prevention, early detection, diagnosis, treatment and palliation, making the best use of available resources' (1).

The past 20 years have seen the gradual uptake of these programmes all over the globe; the European Union, home to the most consolidated, advanced, and well-funded national health systems in the world, has also produced the most innovative and pioneering of these initiatives. However, innovation in individual Member States cannot mask the endemic inequalities within the European Union as a whole. Indeed, such innovation often brings them into relief. These inequalities are inconsistent with the values laid out in the Treaty of Lisbon and in the Charter of Fundamental Rights of the European Union, and they are also a threat to the social and economic foundation of the EU.

Because cancer represents a major source of health inequity in the EU, fostering and disseminating innovations to improve cancer control in Europe becomes imperative. This gauntlet was picked up by the European Partnership Action Against Cancer (EPAAC), whose objectives included the ambitious – and, according to some, impossible – aim of establishing an NCCP in all Member States by the end of the Partnership in 2013 (COM[2009] 291/4). The key to achieving this goal was not to mandate the development of a national cancer plan, but to engage all countries in the task of defining what elements should be included in such a plan, irrespective of the arrangements for health care provision that are unique to each country.

The Slovenian National Institute of Public Health, which had already led work on cancer control in the EU during the country's Presidency of the European Council in 2008, led the efforts to promote NCCPs in Europe under the EPAAC banner, comparing existing NCCPs and working collaboratively with Member States to comb the contents for clues on the most essential aspects that any high-quality NCCP should include. At the time of going to press, we were drawing up the first EU guidelines for the development of NCCPs in the European region. These guidelines are informed by the best practices in use in the most innovative Member States and legitimised by the explicit endorsement of Member State representatives and the European Commission. The guidelines are not yet complete, but the seemingly insurmountable goal of having an NCCP in every country by 2013 is now within reach.

We hope that this chapter sheds light on the vital importance of NCCPs and how EPAAC has helped in structuring future work on national cancer plan development.

Pulling the threads of cancer control together: National cancer control programmes within European health systems

The history of NCCPs

In 1995, the Chief Medical Officers of England and Wales were responsible for the first attempt to prepare a comprehensive national cancer policy, a precursor to the national plan that would follow five years later. The so called Calman-Hine report was not a detailed plan, but a policy framework setting out overarching goals: that all cancer patients should have access to a uniformly high quality of care in their community or hospital to ensure the maximum possible cure rates and best quality of life. Furthermore, it was stated that care should be provided as close to the patient's home as was compatible with high-quality, safe and effective treatment (2).

A few years later, the first comprehensive national cancer plans were developed in Denmark, England and France. In 2000, the Danish National Board of Health published the *National Cancer Plan – status and proposals for initiatives in relation to cancer treatment*, a comprehensive plan covering complete cancer control (3). Five years later, its sequel was released (4), making Denmark the first European country to develop a follow-up plan. In England, the first National Cancer Plan focused on prevention, development and implementation of service guidance, access to diagnosis and care, research, equipment, and human resources (5). Its update, known as the Cancer Reform Strategy, was published in 2007. Across the Channel, the French NCCP was published in 2002 with the full support of President Chirac, who defined cancer as a high political priority. The plan was similar to its counterparts in Denmark and the United Kingdom, but it also established the Institut National du Cancer (INCa) to oversee implementation in 2005.

The Danish, English and French national cancer plans shared many characteristics, even if each also reflected their own national context. They were comprehensive, included evaluation mechanisms to track effectiveness, and all adopted a five-year timeframe to initiate the required changes. They also led the way for the majority of European Member States, which subsequently began implementation of their own plans. In some countries with decentralised systems, the responsibilities for health care planning were entrusted to sub-national levels, for example in Spain, where regional plans were framed and guided by a national strategy. On the other hand, countries such as Finland addressed important cancer policy issues within their existing health care management schemes, obtaining good survival outcomes (6).

Today, there is still no internationally adopted common format for NCCPs, nor a commonly accepted framework for adoption. Consequently, the scope of cancer plans has always varied significantly between countries. The first comprehensive analysis of NCCPs in Europe was published in 2009, confirming the increasing adoption of these plans (19 out of the 31 countries studied at the time), but also the significant differences existing between them. Even more worrying was the fact that in many cases, elements crucial to the efficacy of the plans, including financing, resource allocation and basic mechanisms for governance, were missing or inadequate (7).

The state of the art: applying the WHO template for health systems to cancer control

Specific goals of each NCCP vary by country, depending on what cancer services are already in place, how these are linked, how efficient they are and how responsibilities are shared among stakeholders. Thus, countries with strong traditions in central planning, such as France, include among the aims of their NCCP the concentration of all decision-making, financing, coordination and planning under one body. Decentralised countries such as Spain or Italy, on the other hand, devote their energies to setting national, minimum standards and interregional harmonisation mechanisms that regional health authorities support and enforce in their territories. Countries with few preventive health services (e.g., screening), such as Bulgaria, Lithuania and the Czech Republic, aim to establish these, while other countries pursue homogeneous quality standards among existing services and increased equity and accessibility for citizens wishing to make use of them. Significant investments in cancer research may be out of reach for some countries, so increasing coverage of national cancer registries may be a more feasible priority.

Given the lack of available tools to guide the formulation and analysis of NCCPs, the WHO template for health systems, with its four main framework functions, provided an important guide for us, serving to standardise the approach to setting up and consequently evaluating NCCPs in the EU. This template covers governance/stewardship, resource generation, financing and service provision, linking related activities to overall health system goals: better population health, responsiveness and fair financial contribution (Figure 8.1).

For cancer control, stewardship challenges are marked by the complexity of the disease, characterised by different aetiologies and a number of important determinants. Because cancer can be caused by behaviours (e.g., smoking), environment (e.g., radiation), infectious diseases (e.g., HPV) or genetic predisposition, cancer policy must encompass a wide range of government actions, from tobacco control and occupational safety to population-based

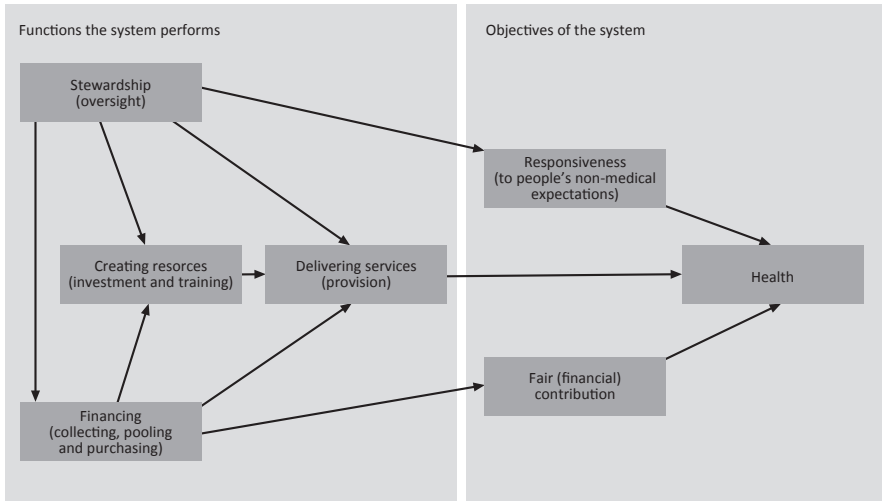


Figure 8.1 Health system functions and goals

Source: (8)

vaccination and screening services in primary care. Moreover, many risk factors are concentrated on the lowest rungs of the socioeconomic ladder, so tackling the causes of cancer also requires specific public health measures to address the social determinants of health. This can only be achieved through an intersectoral approach that acts beyond the strict borders of the health system, including in health education and communication, labour, housing, environment, agriculture, industry and social services (9,10).

Likewise, the resource-intensive nature of this mostly chronic disease will present challenges both in securing sufficient resources and in distributing them wisely. Health professionals are lacking across all countries and in a number of specialties, but certain specialists required for effective cancer care, such as radiologists, are among the groups with the most gaping deficits between need and availability. Diagnostic equipment and innovative treatments are the biggest drivers of increased costs, so the generation of these technological resources in a way that balances financial protection for citizens and incentives for industry to spur development is a major issue (11).

In financing cancer control activities, problems begin with general constraints on health systems stemming from the financial crisis, but they also go much deeper. Cancer is no longer considered an acute pathology ending in cure or death; it is chronic and may require years of treatment and palliation, not to mention follow-up checks and investigations or treatment for recurrence. Many prevention policies advocated by public health experts, such as tobacco or alcohol control, are backed up by solid scientific evidence documenting their cost-effectiveness, but for other equally important policies, such as programmes

to tackle poor diet or lack of physical activity, there is less evidence to guide policy (and therefore investments). High-quality, population-based screening programmes, meanwhile, can save considerable money by reducing treatment costs, but opportunistic, inconsistent procedures have much less potential to save lives because they drain resources from other areas. Research is the source of virtually all scientific and policy breakthroughs, but it constitutes another major cost to the system (12).

Cancer service delivery, in turn, has special challenges in terms of ensuring quick diagnosis and referral to specialists, providing multidisciplinary care, and guaranteeing a consistent and continuous care pathway for patients who may come from diverse sources within the health services portfolio (13). Service delivery will inevitably reflect the difficulties encountered in financing, resource generation and oversight, which may be manifested in a sub-optimal distribution of expensive equipment or specialists, long wait lists for screening or treatment, inconsistent quality within or between centres, and poor communication between different caretakers or levels of services.

Thus, all levels and areas of the health system must work together to ensure a comprehensive policy response to cancer, and it's clear that a single instrument capable of coordinating the entire range of cancer-related activities is as necessary as it is difficult to achieve. Needless to say, not all NCCPs are created equal. However, they are conceived to provide essential cancer services to the population, reduce fragmentation among them, increase efficiency and ensure coherence among programme elements, in line with the current and projected needs of patients and the general population.

Once the key issues in cancer control programmes are raised at the level of the European Union, important transnational aspects need to be taken into account. In the first place, there is the aim to produce an added value to the European citizen. As we are trying to reduce differences across the different Member States, our aim is to provide comparable services across the Union. Benchmarking provided from a standardised typology to approach policy, such as an integrated policy framework for cancer control, has the potential to be a powerful instrument in reducing differences. Analysing best practices and disseminating them to all Member States has also been an important part of our work at EPAAC.

Joining forces through EPAAC to promote NCCP development

The challenge

EPAAC was launched with the ultimate goal of promoting the development of effective NCCPs in Member States, but this challenge had to be dealt with in a way that took into account the peculiarities of the EU as a political and social institution. On the one hand, EU activities had to focus on maintaining the high standard of the best NCCPs in the region by developing a standardised format for NCCPs, but on the other, Member States with heterogeneous health system arrangements and capacities had to be able to shape their plan according to their specific circumstances. A pan-European national cancer control programme is not only politically untenable, but also practically unfeasible.

Thus, our aim was to standardise not the final product, but rather the approach taken to develop NCCPs, according to a common framework endorsed by all major stakeholders, including experts along the continuum of cancer policy as well as national ministries, patients and other stakeholders. We used the WHO health system template as a rough guide, but our main aim was to develop a conceptual framework which was specific to NCCPs, including all the necessary ingredients for an effective programme. At the time of going to press, a special task was still underway within the Joint Action to elaborate these guidelines, which will serve as a blueprint for Member States in their preparation of an NCCP that includes all the necessary aspects. Moreover, the guidelines will provide a framework to ease cross-country and EU-level comparisons and analyses.

Step one: Assessing the panorama in Europe

The first key activity was a survey of NCCPs in Member States. A questionnaire was developed by the Commission and the coordination team at the National Institute of Public Health of the Republic of Slovenia, in order to serve as the framework for assessing the current state of the art in each country. The questionnaire was circulated to the representatives of all European Union Member States, Iceland and Norway and then collected and analysed by the coordination team and Core Working Group in cooperation with independent consultants.

The survey followed the structure of the WHO guidelines for NCCP development, including all the key ingredients in the process. Given that the Commission's recommendation on development of integrated cancer plans had been made in 2009, with the formal obligation for NCCPs to be developed by

2013, there was considerable interest in seeing how far the process had moved towards the finalisation of the plans at the time of the survey in 2011.

Participation was quite high: of 29 surveys distributed, 26 were collected by the initial deadline, and the rest followed soon after. A preliminary report was formulated, providing some basic insight into the plans:

- All but 5 participating countries had some sort of a NCCP by spring/summer 2011.
- Even in terms of the name, there was significant diversity among Member States. NCCPs were usually denominated *National Cancer Plan*, but also *National Cancer Strategy*, *National Cancer Plan and Strategy*, *National Cancer Prevention and Control Programme*, or other formulations and even their combinations.
- Processes necessary for the preparation of NCCPs triggered many other activities related to cancer control, involving a variety of national stakeholders. One positive note was that NCCP development helped to support those aspects of cancer care that had previously been neglected or underdeveloped – in particular palliative care, rehabilitation and survivorship, economic assessment and health technology assessment.

A preliminary report was circulated to Member States at the first EPAAC Open Forum in Madrid in June 2011, and countries were given three opportunities to amend or correct the data provided by their health authority representatives, as interpreted by the EPAAC team. Because a number of countries were still developing their NCCP at the time of the survey, the revision process also provided a unique opportunity to learn from other countries' experiences using the concise results of an objective survey. Survey results were collated into two groups of tables: one summarizing all the elements of each NCCP by country, and another comparing all countries' programmes by specific aspects of the plan. After incorporating all revisions and pertinent comments, we closed the report for further changes following the Steering Committee meeting in Berlin in March 2012. The text was then adopted by the Steering Committee in Athens in September 2012.

The final report on NCCPs in Europe, validated by all MS, reflects the diversity and the dynamism of these activities in Europe. Most of the currently valid NCCPs have been completed since 2010. Particularly for countries that had no prior NCCP, this suggests that the EU Recommendation contributed to the successful development of a plan (Figure 8.2). In fact, survey respondents from both Greece and Cyprus explicitly mentioned the importance of the Communication on Action Against Cancer in helping their health systems to overcome the barriers that had been impeding NCCP formulation.

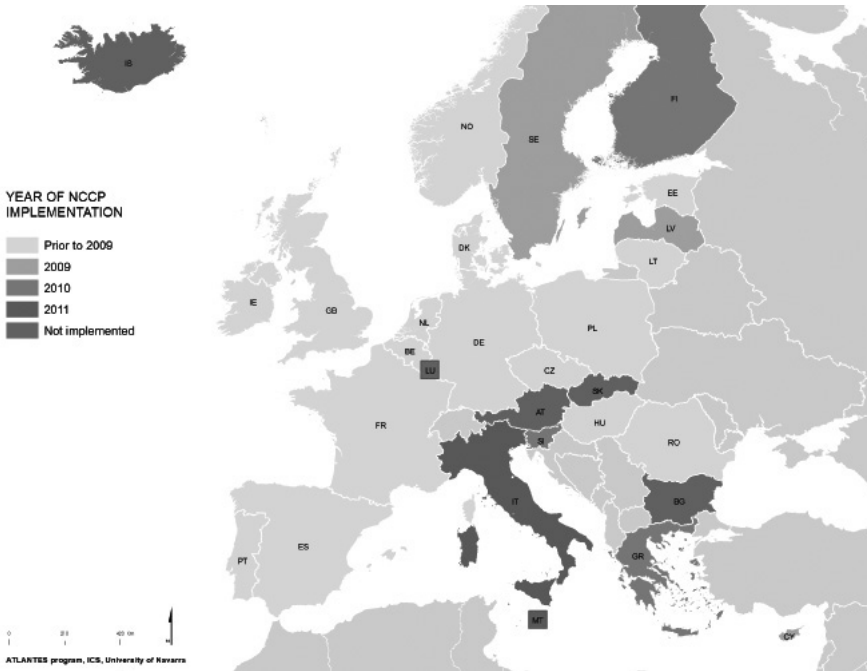


Figure 8.2 European NCCPs implemented before and after European Commission Communication on Action Against Cancer

Adapted from: (14)

The full report on survey results, available online (14), covers a range of aspects having to do not only with the specific contents of the NCCPs, but also their goals and indicators, their budget and capacity, the methodology used to develop them, and the strengths and weaknesses perceived by planners. Below, we reproduce just a few of these results to illustrate the differences in NCCP content and organisational structures among Member States, as well as the need for continued European support in developing plans and guidance in devising common indicators. The specific and practical impact these NCCPs have had on the key parameters of cancer control will have to be monitored over the next years.

NCCP content

National programmes are quite diverse, with mechanisms subject to different contextual factors including resource availability, systems capacity, organisation of services, geography, epidemiology and past experience in cancer policy. However, most countries do include basic prevention and control activities (Table 8.1). Patient empowerment and social support for families is offered in Belgium, Denmark, Germany, Hungary, Malta, the Netherlands, Spain,

Table 8.1 General elements of NCCPs

Country	Cancer Prevention	Control Activities	Supportive functions					
	Health promotion/ primary prevention	Secondary prevention (screening)	integrated care, incl. organisation	Palliative/ psycho-oncological care	Research, registries	Training	Quality control	Others
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Data management; paediatric cancer care; geriatric cancer care; rare tumours; improved insurance coverage; Comprehensive Cancer Centre
Cyprus	Yes	Yes	No	Yes	Yes	N/A	N/A	
Czech Republic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Cost control and HTA; international cooperation and harmonisation in EU and WHO partnership; network of oncocentres; equity
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Support for relatives of cancer patients
England	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Information and choice; quality of life and patient experience; reducing inequalities; autonomy, accountability and democratic legitimacy; commissioning and levers
Estonia	Yes	Yes	Yes	Yes	No	No	No	
Finland	Yes	Yes	Yes	No	Yes	Yes	No	Human resources; communication
France	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Equal access
Germany	No	Yes	Yes	Yes	Yes	Yes	Yes	Comments: For the next phase, it must be determined whether there is a need to take action in additional areas in order to combat cancer (particularly in relation to primary prevention, cancer research, environmental, occupational and consumer-oriented cancer protection)
Greece	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Hungary	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Patient empowerment; Epidemiology; Paediatric oncology
Ireland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Health inequalities; licensing and accreditation; information

Table 8.1 contd

Country	Cancer Prevention	Control Activities	Supportive functions					
	Health promotion/ primary prevention	Secondary prevention (screening)	integrated care, incl. organisation	Palliative/ psycho-oncological care	Research, registries	Training	Quality control	Others
Italy	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Epidemiology; cancer in elderly people; cancer in childhood; rare tumours; health technology; information and communication; rehabilitation
Latvia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Lithuania	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Malta	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Patient empowerment
Netherlands	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The plan included 150 different activities
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Long-term effects of cancer treatment
Poland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Hereditary factors programme for families; quality control in diagnosis and treatment of malignant neoplasm in children; replacement of equipment for treatment
Portugal	Yes	Yes	Yes	No	Yes	Yes	Yes	Report on the oncology and psycho-oncology national capacity; legislation on the maximum waiting time for treatments; best practices
Romania	Yes	Yes	Yes	Yes	Yes	N/A	Yes	
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	No	
Spain	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Paediatric and adolescent care; quality of life
Sweden	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Improved system for second opinion; patient empowerment . . . (list non-inclusive)

*Poland: Research performed outside the oncology program; N/A: not available

Sweden and England, while specific provisions to address inequalities exist in the Czech Republic, France, Ireland, Spain and England. Cost control mechanisms and HTA were explicitly included in the NCCPs of the Czech Republic and England.

Organisational differences

Countries that have devolved health care competencies to a regional level face special challenges. Approaches in Germany, Italy, Spain and the United Kingdom very strongly depend on the specific organisation of the federal state. In the case of the United Kingdom, this has led to the formation of completely independent structures for each of the constituent countries. On the other hand, in Italy, where regions enjoy a high level of autonomy in organising their own health systems, the NCCP adopted in 2010 provides important national guidance that helps to equalise certain aspects between regions, despite the decentralised nature of the health system and the persistent fragmentation characterising service provision. In particular, the Italian NCCP ensures a minimum of health structures and patient rights, not only with respect to treatment but also patients' involvement and participation in care decisions.

The organisational differences are reflected in the implementation structures and responsibilities outlined in the plans (Table 8.2); decentralised countries like Spain and Italy could not develop a single implementation structure, and only a few countries could concentrate all responsibility under one body.

Difficulties for Member States in developing NCCPs

Over the course of our work in the Partnership, we were able to learn firsthand of the difficulties that some Member States have faced on the road to developing national cancer control programmes (Table 8.3). As with other policy documents, NCCPs require wide political consensus because they touch upon all levels of health care as well as a range of other sectors. They require significant mobilisation of resources to coordinate an extensive range of services and activities related to cancer, many of which are beyond the remit of the Ministry of Health. This often represents a particular challenge in smaller countries, where limited human resources pose a challenge to complex tasks such as the preparation of an NCCP. Moreover, there can be a problem of securing all the relevant expertise needed to prepare such a comprehensive document.

The first major difficulty lay in the speed required in order to follow the Commission's Communication on NCCP development at the start of the Partnership, which only allowed five years for a plan to come to fruition. As long as this period may seem, it is short not only in terms of the preparatory

Table 8.2 Structures for implementation and accountability in NCCPs

Country	Implementation structure included in plan?	Responsibility
Belgium	N/A	Ministry of Health (Federal Public Service of Public Health, Food Chain Safety and Environment) - National Institute of Health and Disability Insurance - Regional and Community authorities
Cyprus	Yes	The National Cancer Committee is an established body with terms of reference to develop an action plan and implement the strategy within five years
Czech Rep	No	Ministry of Health
Denmark	A detailed implementation structure has been formulated following the completion of the plan	The National Board of Health and 'Task Force on the implementation of cancer policies'
England	Yes	Department of Health, the NHS Commissioning Board and the Public Health Service An Implementation Advisory Group
Estonia	Yes	National Institute for Health Development with Health Insurance Fund and NGOs
Finland	Mostly.	University Hospital Districts
France	Yes	The National Cancer Institute
Germany	Under development	Recommendations from 2011 and 2012 for most but not all objectives of the German National Cancer Plan were adopted. Currently the Federal Ministry of Health and the stakeholders are in the process of developing an implementation strategy. There is no single organisation responsible for its implementation. However, the Federal Ministry of Health has the overall responsibility in coordinating the activities of the Cancer Plan.
Greece	N/A	Ministry of Health and Social Solidarity in collaboration with various bodies, governmental and non-governmental.
Hungary	No	The Ministry of National Resources - State Secretariat for Healthcare National Institute of Oncology National Public Health and Medical Officers' Service
Ireland	No	Health Service Executive; National Cancer Registry of Ireland; Health Information and Quality Authority
Italy	No	Regional local governments

Table 8.2 contd

Country	Implementation structure included in plan?	Responsibility
Latvia	Detailed information on activities, predictive results and funding are shown by years.	Line ministries, municipalities, social partners and non-governmental institutions; Ministry of Health
Lithuania	No	Ministry of Health, Universities, Hospitals, GP, Health Education and Diseases Prevention Centre under the Ministry of Health, National Health Insurance Fund
Malta	Yes	Steering committee of the Strategy and Sustainability Division
Netherlands	Yes	All partners
Norway	No	Each responsible provider of health care is responsible for his part in the implementation.
Poland	Yes	Ministry of Health and Cancer Control Council
Portugal	Yes	NCOD and Regional Health Administrations
Romania	Yes	Cancer Commission at de Ministry of Health
Slovenia	Yes	Ministry of Health. It nominated the special board to monitor the implementation and assess the indicators and reports
Spain	No	Regional Health Authorities
Sweden	Yes	Ministry of Health, National Board of Health and Welfare, regional and local health care providers

process, but also with regard to the consultative and political process, in which a high degree of consensus needs to be achieved. The latter has certainly been a problem in Bulgaria and Slovakia. These two Member States could not achieve the requisite political agreement (Bulgaria) or provide adequate resources (Slovakia) for an NCCP to be set up by 2011. The good news is that Bulgaria was able to begin NCCP development in mid-2012, which suggests that it may be able to meet the deadline posed by the Recommendation.

Another challenge for Member States has been to secure the human and financial resources needed to implement their plans. As a diverse community, the European Union needs to take into account some potential limiting factors, such as the different levels of economic development, health care infrastructures and professional expertise. Member State capacity to purchase and incorporate health technology into the service portfolio also varies widely, depending on several factors, for example, the leverage different countries have in negotiating

Table 8.3 Challenges in NCCP development and Member State responses

Country	Methodological challenges	Political challenges	Overcoming challenges (comments)
Belgium	Short planning process; establishing specific needs-based measures	Regional vs. federal competencies to be decided	Indicators developed after plan was complete; round tables and discussions with experts and stakeholders; interministerial conferences
Cyprus	Every stakeholder wanted to emphasize his own issue, therefore, there were some disagreements and lengthy discussions	No	The Ministry of Health was the coordinator and we have strictly followed the EU recommendations
Czech Republic	No	No	
Denmark	Short planning process; professional disagreements, lack of evidence	Timing; content	Round table talks with stakeholders; broad and deep involvement to give a solid and nuanced basis for defending the decisions and content of the plan in political discussions
England	No	No	
Estonia	No	No	
Finland	No	No	
France	No	Yes; the national cancer plan is an inter-ministerial presidential plan	Having strict time table including validation by the Elysée cabinet of the President
Germany	Devolved structure of the German health care system	Devolved Structure of the German health care system	Involvement of relevant stakeholders
Greece	No	Not all stakeholders were happy with the development/ implementation of a national cancer plan	Discussions and consultations, and by referring to the 2009 Communication on Action against Cancer

Table 8.3 cont'd

Country	Methodological challenges	Political challenges	Overcoming challenges (comments)
Hungary	No	No	
Ireland	No	No	
Italy	No	Regional vs. federal competencies to be decided	Guidance approach was followed rather than prescriptive operational edicts
Latvia	No	Global financial crisis	Priority setting
Lithuania	Yes	No	Round tables discussion, working groups, meetings with patients and other organisations
Malta	Long political clearance period;	Same	Detailed economic evaluations were presented to political leaders to justify screening and vaccination programmes.
Netherlands	Political, financial context and resource availability Yes. It was difficult to get all medical specialists in oncology on board	Yes, different interests	Methodological challenges: Not overcome. Looking for a solution. Political challenges: The partners have to deal with their own interests within a collaborative and comprehensive way. They formed a steering committee with the partners and were the plan was discussed.
Norway	No	No	Comment: Starting from the report in 2005, a national strategy was implemented at regional level. The previous report identified areas of action and resource demanding.

Table 8.3 cont'd

Country	Methodological challenges	Political challenges	Overcoming challenges (comments)
Poland	Initial lack of monitoring system for screening tests are invited women in specific age group (screening tests for cervical cancer - women between age 25–59, a survey carried out every 3 years; screening tests for breast cancer (women between age 50–69 years, survey carried out every 2 years). Because of that managers were able to obtain information about women who took part in the screening tests. Two-year delay in publication of national cancer registry data	Scepticism among politicians on benefits of preventive approach	Establishment of full monitoring system for screening
Portugal	Yes	Yes	Establishing priorities Organising the existing health structures to ensure the implementation of the NCS Creating of National Coordination of Oncological Diseases to ensure political will
Romania	Evaluating resources. Quality guidelines.	Mostly regarding the lack of resources in the health system	Not entirely overcome
Slovenia	No	No	
Spain	No	No	
Sweden	Yes	No	

N/A: not available

prices with the health technology industry (economy of scale, strength of national pharmaceutical industry); the administrative procedures for the uptake of new treatments; and population density and urbanisation (which influence the optimal distribution of expensive equipment). These resource limitations must also be understood within the current context of European health systems, which are under considerable strain due to the ongoing financial crisis. Health systems are very vulnerable to budget cuts in times of economic contraction (15,16), and NCCPs require substantial resources that may be difficult to secure if national revenues are in decline.

Thirdly, NCCP development represents a challenge in the sense of agreeing to map *all* relevant services pertaining to cancer care. This goes far beyond the boundaries of health care as such, involving many different services and sectors. Cancer control requires close collaboration between different professional areas and expertise, as well as the participation of civil society. This is a point that depends heavily on a particular country's traditions and experiences and cannot always be easily achieved in the short term. Indeed, many Member States have not yet successfully resolved this challenge, indicating a clear area that could benefit from European guidelines or support in the future.

In that sense, it needs to be stressed that there are very good examples of close collaboration in producing an NCCP. Most notably, Malta recently developed its NCCP jointly with INCa, which provided a number of important synergies and enabled a very useful knowledge transfer to be carried out (17). The result is not only an achievement for an important internationally relevant institution but also a fruitful learning experience for a smaller MS. In such cases, collaboration between experts is of particular importance, providing a smaller environment with the richness of experience from an institution with a longstanding tradition in the field.

Evaluation and indicators: a clear area requiring EU support

One of the shortcomings identified in several NCCPs through the survey was the lack of an adequate ongoing evaluation process, supported by relevant indicators (Table 8.4). In many cases there was simply no stable evaluation process set up, or it was outlined for the final evaluation of the plan close to or after its expiration. Of course, in order for the plan to be adequately monitored, there is a need to carry out a solid evaluation based on a series of indicators that provide objective measurement of progress against the proposed objectives.

Articulating EU support for NCCP development: next steps

Despite the different responses, it is clear that all Member States are facing

Table 8.4 Evaluation processes and indicators for NCCFPs

Country	Final evaluation envisaged?	How will the evaluation be carried out?		Indicators be used for the evaluation
		structure	process	
Belgium	Yes	N/A	N/A	N/A
Cyprus	Yes	✓	Information not available yet	
Czech Rep	Yes	✓	N/A	
Denmark	Yes	✓	Have not been formulated; Estimates on patient flow/times and survival rates for specific cancer forms are being evaluated and followed up on by The National Board of Health/Task force on implementation of cancer policies on an ongoing basis	
England	Yes	✓	Not yet determined	
Estonia	Yes	✓	1. Incidence 2. Survival (five-years relative survival) 3. Quality of life 4. Mortality	
Finland	Yes	✓	Included in plan	

Table 8.4 cont'd

Country	Final evaluation envisaged?	How will the evaluation be carried out?			Indicators be used for the evaluation
		structure	process	outcome	
France	Yes	other			Responsibility for evaluation of the Cancer Plan 2009 2013 falls to the High Council of Public Healthcare and the Evaluation Agency for Research and Higher Education, for measures in the Research axis. They may also call on external service providers selected on the basis of an invitation to tender. Two evaluations have been scheduled: an interim evaluation at the end of 2011 and another at the end of the plan in 2013. The summary reports from the evaluation will be sent to the French President and the Ministries concerned.
Germany	Under discussion	Under discussion			Plan is envisaged to span several years, with interim evaluations carried out periodically.
Greece	Yes	✓	✓	✓	Not yet specified
Hungary	Yes			✓	Health status - Demographic and socioeconomic factors Life expectancy; standardised death rates; cancer incidence; prevalence of cancer; incidence of cancers related to the sex; Healthy Life Years (HLY) at birth, by gender and healthy life expectancy at age 65, by gender. Determinants of health: smoking, total alcohol consumption etc. Health interventions: health services - breast cancer screening coverage; cervical cancer screening coverage; hospital beds; physicians employed; medical technologies (CT/MRI); hospital inpatient discharges, limited diagnoses; general practitioner (GP) utilisation; expenditures on health; survival rates breast, cervical cancer.
Ireland	No (interim)	✓	✓	✓	Nineteen policy indicators are listed in the strategy for evaluation of outcomes at a later stage. Monitoring and review of implementation process is ongoing, focusing on the 55 recommendations in the strategy and on the specific actions identified each year in the Service Plan

Table 8.4 cont'd

Country	Final evaluation envisaged?	How will the evaluation be carried out?		Indicators be used for the evaluation
		structure	process	
Italy	Yes	✓	✓	Structure and methodology are left to a subsequent ministerial decision
Latvia	Yes	✓	✓	There are 20 indicators following from programme goals. Ministry of Health prepares programme's implementation progress report in 2013 and 2016.
Lithuania	Yes	✓	✓	Increase the number of cancer cases diagnosed early
Malta	Yes	✓	✓	Trends in incidence, mortality and survival for all cancers and for specific cancer sites and types (Quantitative) and patients' and carers' satisfaction and assessment of services (qualitative).
Netherlands	Yes	✓	✓	
Norway	No (periodic)			There is a planned interim report
Poland	Yes		✓	The main indicators are: population screening tests; geographical allocation of medical equipment, infrastructure, personnel; number of training courses.
Portugal	Yes		✓	
Romania	Yes	✓	✓	Indicators for all activities: cancer registry, prevention and treatment
Slovenia	Yes	✓	✓	Indicators are prepared in action plans, which are prepared for each year. Indicators will be used for final evaluation, but the indicators are not defined in the plan

Table 8.4 cont'd

Country	Final evaluation envisaged?	How will the evaluation be carried out?			Indicators be used for the evaluation
		structure	process	outcome	
Spain	Yes	✓	✓	✓	Incidence and mortality. Process indicators related to screening programme, resources devoted to cancer care and audit of clinical practice with indicators for breast and colorectal cancer.
Sweden	Yes	✓	✓	✓	

N/A: not available

similar challenges in terms of the cancer burden and the need to formulate sustainable, effective and responsive policies for patients and citizens. The EPAAC initiative is based on the belief that shared experiences can strengthen both cancer services and the political will to tackle this dire public health threat. While our main aim was to improve cancer policy and services in Europe, a complementary aim was to raise the profile of cancer on the European political agenda through the close participation of national stakeholders, experts, leaders, patients and citizens. The report on the survey results was enormously useful as a way to engage national and regional health authorities in the analysis of the plans, compelling a thorough self-assessment as well as a frank comparison of how individual countries' NCCPs compared to their neighbours'.

Moreover, the development of the report led to the suggestion – put forward by the Core Working Group and later implemented – of collecting links to all available NCCPs onto one website (www.epaac.eu/national-cancer-plans). For the first time ever, then, Member States, researchers and citizens can easily and comprehensively compare all NCCPs using the primary sources, in an exercise of transparency and benchmarking.

Monitoring NCCPs in Europe: development of indicators

It is important to closely link the evaluation process to the objectives of the NCCP, regardless of how ambitious they are. In the context of the EU, there are clear advantages to using at least some of the same indicators for all countries, as this would facilitate comparison and benchmarking. However, our survey results show considerable variations among identified indicators, revealing an area where EU support could clearly add value to the efforts of individual Member States.

The Joint Action had included the development of NCCP monitoring indicators as one of its objectives. This would not be work *de novo* but would rather build on informed and evidence-based selection of indicators, which had been developed on relevant international projects, especially EUROCHIP. This would provide for validity and stability and enable Member States to use the existing data and thus the existing body of knowledge in the field for the preparation of these indicators. Most important, such an approach would not result in the need for major revision of health information systems in Member States or incur any other type of additional costs.

European guide for high quality NCCPs

At the time of writing, intensive work was underway to prepare a blueprint for future work on NCCPs in Member States. We have been able to draw up a list

of the essential ingredients for a high-quality NCCP that will be dealt with in the document that emerges from the consultation process:

- Governance
- Cancer data and information
- Psychosocial care
- Palliative and end-of-life care
- Resources, infrastructure, technology, drugs and cancer-specific expenditure
- Survivorship and rehabilitation
- Early detection and screening
- Cancer prevention and health promotion
- Research

This structure should also provide Member States with the background for the elements of a national cancer control plan. By covering all the dimensions of cancer control in a structured consensus document, we aim to promote a certain degree of convergence of national cancer plans across the EU.

The key concepts outlined above will be complemented by another element essential to any monitoring and evaluation exercise: indicators. Our survey showed a frequent lack of these in monitoring the implementation and progress of NCCPs. Even less has been done to measure the impact of the activities that were set up, organised and coordinated by the NCCP.

The impact of effective NCCPs

Cancer management is one of the most important and complex tasks involved in the medical care of chronic diseases. Its complexity, vast use of resources and interactions with other sectors of social services and society at large require meticulous, flexible and dynamic planning.

Policymakers need to take into account the retrospective experiences of health systems and the prospective needs of patients in the light of two important variables that have evolved rapidly over the last decades: cancer epidemiology and advances in health technology. The ongoing demographic transition, characterised by rapid ageing of the population and increased survival for many cancers, translate to a much larger population that is living or will be diagnosed with this disease: the prevalent pool. Cancer patients and survivors have greater needs for self-care, rehabilitation and reintegration into fully normal everyday life. Likewise, advances in health technology are becoming increasingly difficult

to manage, entailing specific challenges associated with the following policy measures:

- Transparent policies related to health technology assessment
- Establishment of clear mechanisms to introduce innovative technologies and phase out obsolete ones
- Better international exchange of practices and experiences to expedite the formulation of policies already established elsewhere in response to similar issues

Changing priorities in health policy are also pushing cancer further up the agenda. Increasing cancer prevalence, combined with greater attention to patient rights, means that patients need to be made part of all the relevant steps in cancer control and the decision-making process about future developments.

NCCPs, therefore, are really an irreplaceable instrument; they constitute the only framework for cancer policy capable of fostering the participation, collaboration and synergies necessary for effective control of the disease. In essence, NCCPs are the primary instrument of a process with the following complementary and supporting objectives:

- Better structuring of cancer control management and of all its key elements
- Making cancer care and its management more transparent
- Increasing the involvement of all stakeholders
- Justifying and promoting the integration of new models of care and elements of cancer management

The benefits to health systems and governments are numerous. First of all, an effective NCCP provides for clear management, oversight and integration of a wide range of health system activities, making it easier for health systems to respond to patients' and citizens' needs. This has important positive repercussions well beyond the strict area of cancer control: efficient use of resources; accumulation of experience that can be applied to other disease areas; and generally, greater legitimacy, trust and support for the health system from a citizen perspective.

For citizens and patients, too, effective NCCPs are of vital importance. Although not all citizens may know what an NCCP is, it is likely that they or their loved ones have battled cancer. European citizens are characterised by the great value they attach to the universal health care model, one that provides all citizens with equal opportunity to access investigation, treatment and care when a medical calamity strikes. Given the potential consequences associated with cancer, the sense that the health system is capable of responding

to patients' needs is perhaps the only source of comfort that patients have in the immediate aftermath of a cancer diagnosis.

Discussion

Cooperation with Member States

Surveys always pose a challenge because of low response rates and delays, but we were pleasantly surprised and encouraged by the high response rates and the volume of open-ended answers to questions on NCCPs. Feedback from Member States was written in most cases, and the need to contact the correspondents again was quite infrequent. This meant that processing the information obtained from the questionnaires was relatively straightforward, both for the initial survey and for the subsequent quality checks and reviews. Indeed, more challenges arose in the interpretation of the responses (contextual explanations, qualifications added to the answers to some of the more closed questions) than in ensuring participation.

The motivation expressed by some Member States, as we describe in more detail below, also materialised in the form of their participation in the Core Working Group. This group was actively involved in revising the results of the survey, both from the point of view of their own countries as well as from a broader context, although it should be added that in cases where respondents had to divide their working time between cancer and other policy issues, the enthusiasm with the project was somewhat tempered. In any case, the help of the group was instrumental in finalising the report.

A more complex issue had to do with the specificity of the United Kingdom situation. We only interacted with the Department of Health in London, which in turn is actually responsible only for the English Cancer Plan and has no authority to comment or represent other United Kingdom countries. This had to be clarified at a later stage, and representatives from Northern Ireland, Scotland and Wales were contacted in order to obtain further information about their respective cancer plans.

High level of motivation in developing answers to all questions

Throughout the process, we were pleased to see a very high level of motivation and commitment to complete the task of answering all questions related to the survey. There was support for the respondents both from the coordination team as well as from the analytical group preparing the draft report. Through the synergetic cooperation from the extended team, we managed to get the most updated data about NCCPs in Member States by the spring of 2011. As a cross-

sectional instrument, the survey was limited to that particular time, although respondents were also asked to comment on the current state of affairs, not including potential reflections about the revision of the existing NCCP. This had not been a serious problem as most NCCPs were quite recent and had not undergone revision at the time of the survey.

A difficult process of developing indicators

Similar exercises in the past have shown that agreeing on a common set of indicators very often represents a particular challenge at the international level. This is due to a number of factors, although two stand out as the most decisive. On the one hand, there is a lack of consensus within the medical or health discipline on which indicators to choose. On the other, harmonisation efforts usually reveal a need for more data and an extended list of indicators. Even in times with less financial restrictions and hardship than we are experiencing at present, it is difficult to justify important additional investments into pure transfer of data or, even more difficult, into expanding data sets with an additional costing structure. Apart from these two factors, harmonisation processes may also be very time-consuming, requiring an intense use of human resources. Last but not least, there have been several important EU and other international projects that have already generated indicator sets (e.g., EUROCHIP) and valuable national experience, such as the one of the French National Cancer Plan, mobilising considerable resources, so it seems inappropriate to repeat the process simply in order to obtain a few more indicators.

Facing austerity measures

Austerity measures represent an important challenge to the further development of health care systems, in particular for advances in research and uptake of new therapies. Investments in health care tend to be large and to require a long-term perspective; reducing these investments will have negative repercussions on quality of care in the present, but also in the long run, as research is allowed to stagnate and innovative processes are excluded from the system due to cost. Cancer care is particularly vulnerable in the face of austerity policies because it requires high inputs of all resources, including specialised health professionals, different types of health technologies and mechanisms to integrate care with other services and sectors. Failure to follow up on the scientific and technological advances in cancer can seriously hamper the improving trends we are seeing in terms of reduced mortality and extended survival for many cancers. Furthermore, failure to incorporate innovations into the care continuum may also affect the quality of life of cancer patients and all the populations at risk, as it is clearly related to success in early diagnosis and effective treatment

of cancer. An additional point of concern is the potential for increasing the socioeconomic differences in all aspects of cancer control. This issue will be addressed in the next Joint Action on cancer. Finally, austerity measures are likely to have the most negative impact on cancer control by reducing timely access to care, because restrictive fiscal policies lead to reduction in the health workforce, reduced hours and restriction of services.

Monitoring and further work and development of this field

Work done on studying the developments in NCCPs in EU Member States has been extensive so far, giving us important information about the developments in this field. Likewise, the European guidelines on the development of NCCPs that will emerge from EPAAC, combined with the set of selected indicators that will allow for efficient monitoring of the implementation of NCCPs, are valuable additions to the corpus of tools available to European policymakers on the issue of cancer.

However, all this is by no means sufficient to sustain the magnitude of improvements obtained over the last 5–7 years. Work on NCCPs should ideally be taken up by one of the professional institutions at the EU level in order to secure an adequate level of oversight for future developments and ensure that ongoing work upgrading and developing cancer policy instruments is not sidelined. Structuring cancer control contributes to the rational use of all the resources required for its functioning. One of the goals in this respect would be to foster the convergence of cancer control and care policies across the EU; however, this issue has strongly political overtones that go beyond the scope of simply generating the adequate tools to carry out the convergence process. Because the Joint Action is owned by Member States, these countries are charged with identifying the key institution at the EU level that would be competent enough to take charge of this important task.

EPAAC: Adding value through a European approach

Involvement of all Member States: Working Group on national cancer control programmes

Full participation by Member States in this initiative has been essential for two main reasons: the European Commission's communication on the introduction of national cancer control programmes and the different solutions to cancer policy across the Union, which could realistically be mapped only through a combined effort of all Member States. There is obviously a great added value in the direct exchange of information and in interaction with governmental

representatives (as opposed to studies carried out strictly among the academic community). EPAAC was able to catalyse this participation by setting up a Working Group on NCCPs. The main missions of this Working Group included analysis of the current state of NCCP development across the EU, developing a joint approach to the future development of NCCPs and setting up a mechanism to monitor the quality of these future developments.

Forming a multilevel working structure in order to optimise workflow

This type of approach provided us with a clear multi-level structure (Figure 8.3):

- Operational team at the National Institute of Public Health of the Republic of Slovenia, working on day-to-day activities and developments related to the NCCPs;
- Core Working Group, meeting 3–4 times a year for in-depth discussions on the current deliverables in production and on the path for the next outputs;
- Working Group on NCCPs, serving as a sounding board and forum for all relevant issues related to NCCP policies in Member States;
- Steering Committee of EPAAC, a managerial and strategic level body taking decisions relevant to health policy in Member States.

This structure provided a productive environment for all stages of the process and will continue serving the activities outlined until the end of the Joint Action.



Figure 8.3 EPAAC working structure on NCCPs

Integrating outcomes into the regular and routine practices in Member States through a dynamic consensual process

Providing an adequate framework and deciding on the most appropriate international template for the structure of NCCPs is just one step in the process to better cancer policy in Europe. The next is the formulation of a consensus among health system stakeholders that the development of an NCCP is a normal and routine part of the health policy planning process. At least a year before an NCCP expires, there should be activities in place to ensure the preparation of a new one. Our survey showed that this process may last much longer, at least for initial plans, but of course that depends strongly on the political will and the broader consensus around the key points relevant to the plan. It is to be expected that, as with any kind of mid- and long-term work, a national institution will be designated to develop the national cancer plan and monitor its implementation. It would be impossible to prescribe a single institution that would carry out this role in all Member States. In some countries, the position of the Ministry of Health has a strong, centralised structure that justifies its role as the ultimate leader for NCCP work. Elsewhere, a tertiary cancer centre or public health institution may be more appropriate. However, our findings suggest that as of today, this function has too rarely been defined with clarity at the time of NCCP preparation.

Achievements of the process and the road to their further development

We believe that the biggest achievement through our EPAAC work has been in enhancing the exchange of experiences and approaches across the EU, Iceland and Norway. Notwithstanding the present activities, cancer has topped the health policy agenda for quite a few years, due both to the death toll and its huge requirements for human and material investments. The organisational structure of our work has provided for a multi-level approach, starting from the Core Working Group, which functioned as a small, operational, flexible group of experts, capable of reaching sound conclusions on a relatively short-term basis through a process of professional deliberations. The second level was the level of the Working Group on NCCPs, which served as the main policy forum with Member States and as an effective sounding board for the feedback and modifications of the documents previously discussed and prepared by the Core Working Group. Finally, the Advisory Board, with its supervisory role, provided for the necessary guidance and reflection.

In addition, several Member States contributed actively to the process of identifying the key issues and messages from this process for the future.

Their work on the report arising from the NCCP survey, as well as the initial activities on the preparation of guidelines for NCCPs and indicators for their monitoring, has given a great boost to efforts to complete these last two tasks by 2014. Both are useful instruments that could prove to be a useful legacy. More important, these instruments could be used both at the European Union level as well as nationally.

Looking to the future

Securing the outcomes of EPAAC – work on the NCCPs, survey, guides and indicators

The next Joint Action should continue the work on national cancer control programmes. A consistent, sustainable setting must be provided to preserve the achievements of the present work. Our EPAAC project on NCCPs is not only related to reporting, but also to the integration of different policies, a task closely related with all aspects of cancer. We have tried to establish NCCPs on a conceptual level as a continuous professional task, primarily serving Member States, leaving the broader dimensions of the work (such as comparability of NCCPs and benchmarking on professional, equity, financial and other grounds) with a secondary role.

Future surveys: Comparing the developments and the implementation of guidelines

The survey of national cancer control programmes has provided a great deal of information about the current state of these programmes in European Member States. There was an important dimension related to raising awareness on how countries formulated their NCCP as well as what elements were included. It would be very important to repeat similar surveys in the future as they would provide a continued insight into the developments in the Member States regarding cancer control planning. However, NCCPs are not only an important challenge for health policymakers in terms of planning but also with regard to implementation. Thus, the possibility to use our proposed guidelines for high-quality NCCPs to monitor future work and updates on the implementation of NCCPs is of potentially great value.

The implementation process may reveal shortcomings in specific aspects included in the NCCP during its preparation, particularly with regard to patient empowerment and financial sustainability. The involvement of patients and their interests in all processes related to cancer control needs to be carefully planned and managed. Patient experiences, patient empowerment and shared

decision-making with patients should be dimensions that are incorporated in all processes so seamlessly that patient involvement is taken for granted in all plans. Likewise, the economic and financial backbone for NCCPs is another important aspect. Plans must be seen as serious policy documents, binding their owners and all the involved stakeholders with clear means to carry out their respective missions and clear accountability mechanisms to promote effectiveness. In short, all resources and all processes need to be ensured and supported.

Future surveys of NCCPs should provide an important overview of the situation in Member States while at the same time facilitating cross-country comparisons. These studies have two important benefits: one is in elucidating the drawbacks and shortcomings of NCCPs in some MS, while the other is in benchmarking and seeking to improve the overall level of NCCPs through the exchange of best practices. This process will require the involvement of qualified experts, either through ad hoc projects or with a more stable structure capable of such periodic assessments; the latter possibility would also help to promote present and future work on NCCPs.

Integrating indicators into regular reporting systems in Member States – work with Eurostat

The idea of producing a list of indicators has been proposed in order to provide for the ongoing assessment of the implementation process and the objective evaluation of the targets set out by the NCCP. This should be supported by a list of readily available indicators that do not represent an additional burden of data collection and harmonisation of definitions. Indicators should be primarily drawn from those already used for other reporting purposes, and only a subset should be selected to support the monitoring and the evaluation of NCCPs. In any case, continued work with Eurostat is warranted, both on the list of indicators as well as for their consistency. Apart from that, Eurostat's experience in regulating indicators should also be very useful in preparing the formal framework for reporting for Member States.

Conclusions

Our activities on NCCPs represent the culmination of the EPAAC experience, bringing together two of the qualities that endow the EU with a certain exceptionalism: innovation and cooperation. The first, of course, is rooted in the excellence that Member States pursue on an individual basis in order to provide their citizens the best possible health care. However, the possibility to exchange best practices, benchmark across national borders, learn from (and teach) neighbouring countries . . . no other region in the world can boast

the potential brimming in Europe, which is a direct reflection of the second concept – cooperation.

As the financial crisis continues, putting neighbours at odds with each other, it is important to remember that the key to Europe's potential – in cancer as in all areas – does not reside in its differences, but in its diversity. While the former concept connotes separateness, disagreement and fragmentation, the latter suggests that although we are all characterised by our own idiosyncrasies and individuality, we are bound together by common values and a shared vision for the future. Together, united in diversity, as the European motto proclaims, we can realise that vision in cancer control for the benefit of all European citizens.

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Chapter 9

Summary and conclusions: the European Partnership for Action Against Cancer . . . Just the beginning

Jose M. Martin-Moreno,^{a,b} Tit Albreht,^c Sandra Radoš Krnel^c

Main messages

- The European Partnership for Action Against Cancer has illustrated the tremendous potential that a collaborative approach has in the response to common challenges.
- Given the heavy – and rising – burden that cancer imposes on European health systems and citizens, it is important to continue supporting the projects begun during the Partnership as part of a broader effort to control cancer at a Member State and European level.

The European Partnership for Action Against Cancer was launched to mobilise the European cancer community to coordinate its actions in cancer control, and in this regard, it was a round success. The EPAAC project leaders enlisted the help and participation of a wide range of stakeholders, including European and national policymakers, health professionals, researchers, patient groups and citizens. Together, they organised flash mobs, started a school for screening management training, developed European networks in cancer care, initiated pilot projects to coordinate research, designed the structure of a future cancer

^a University of Valencia; Valencia, Spain; ^b University Clinical Hospital; Valencia, Spain; ^c National Institute of Public Health of the Republic of Slovenia; Ljubljana, Slovenia

information system, launched a health promotion game on social media, and came within reach of achieving a National Cancer Control Programme in all Member States.

The momentum created by this initiative, then, has been very encouraging, but as reflected in the chapters of this book, the trajectory of its energy is not yet complete. In recounting their efforts to improve different facets of European cancer control, the authors have also had to acknowledge the many challenges that hinder their work. Health advocates must overcome a number of obstacles endemic to concerted European action in any field: balancing the agendas and priorities of individual countries, organisations and collectives; coordinating investments coherently; creating the regulatory mechanisms at a European and Member State level to facilitate cross-border cooperation; overcoming cultural and linguistic barriers; addressing the socioeconomic inequality between and within Member States; and mobilising financial, technological, informational, physical and human resources towards a common goal. Challenges specific to the field of cancer must also be faced: the heavy and rising disease burden; the encompassing nature of comprehensive policy, both within and outside the health system; the wide gap between population need and availability of resources; the fragmentation of data; the long induction period necessary to measure progress; the high costs of research innovation; and the variety of different cancers that exist, each requiring a specific and specialised response. The integrated cancer care community must deal with all of these challenges to some degree, while at the same time motivating policymakers with the incredible progress that can be made and calibrating the expectations of patients and citizens so that miracles are not expected.

Were the stakes not so high, perhaps these problems would be better left untouched. However, much hangs in the balance in European cancer control – enough to justify strong commitment from policymakers in the EU, Member States and elsewhere towards meeting the challenges head on. Compelling reasons exist to scale up European cooperation and investments in this vital area, for patients and citizens, but also for Member States and the EU as a whole.

First of all, it is important to remember that progress – no matter how incremental or incomplete – is measured in human lives. The Europe Against Cancer programme did not fully reach its goal of reducing cancer deaths by 15% by the year 2000, but it was still credited with saving nearly 100,000 lives (1). In the expanded EU-28, where considerable inequalities remain especially between newer and older Member States, millions of patients' lives depend on the principles of European solidarity being translated into action. An illustrative example is the case of cervical cancer, which is easily preventable

through a simple, low-cost screening procedure using technology dating back to the 1940s. Since that time, population-based screening programmes and preventive interventions have led to a sharp decrease in incidence and mortality. In the older Member States of the EU-12, just 2 out of every 100,000 women died of this disease in 2010. However, this figure was four times as high in the EU-15 (2), pointing to a clear need for the type of programmes described in Chapter 4, which aim to strengthen capacity so that individual countries are better able to address the health needs of their populations. If the European Union is to fulfil its stated commitment to equality within its borders, it cannot ignore its essential contribution to improving cancer-related health services in all Member States.

The fact is that Member States are stronger together and – at least in the case of cancer control – they have the means to construct a project that is more than the sum of its parts. Indeed, the fact is that few individual countries are in a position to address the enormity of the cancer burden on their own. Particularly in eastern Europe, there is relatively little tradition or experience in health promotion or cancer prevention, whereas in the southern Member States (and elsewhere), budget shortfalls stemming from the financial crisis have made it difficult to improve or even maintain services. Small countries cannot realistically address the needs of patients with rare cancers, while large countries struggle to provide equal access and high quality cancer services to all of their citizens. These problems are added on to deeper issues, having to do with the strength and quality of health systems, governance mechanisms, decision-making processes, payment systems and other aspects crucial to adequate health service provision. However, even those on the forefront of cancer control have much to gain, for example, if a European Cancer Information System (ECIS) like the one described in Chapter 6 is finally constructed. The access to cancer data from all over Europe would enhance cancer research potential exponentially, helping investigators understand the mechanisms of cancer genesis and how to best address them in European settings.

These innovations also strengthen the EU as a whole, making it competitive on a global level in terms of research development and private investments. European universities and research institutions are the cradle of new advances in prevention, epidemiology, screening and care, while European health technology industries have produced some of the most important advances in cancer diagnostics and treatments in the past decades. By creating the regulatory and funding conditions that enable those innovations to make an impact throughout the region and beyond, European institutions have an important role to play in supporting Europe's position on the vanguard of scientific development.

EPAAC represents a praiseworthy step in that direction, but the goals put forward by the Commission – namely a 15% reduction in cancer incidence by 2020 – will require the necessary time, resources and support, not only from European bodies, but also from Member States, to come to fruition. Below, we summarise and review the activities described in the preceding chapters of this book, drawing lessons that can be applied to cancer control and beyond, and calling for continued commitment to build on the successful work done so far.

Examples of innovation and cooperation in European cancer control

The revitalization of cancer prevention in Europe

The Association of European Cancer Leagues (ECL) has successfully relaunched the European Week Against Cancer, engaging young people on the subject of cancer prevention in novel ways, including through social media, flash mobs and youth competitions. The Commission's continued support for this annual campaign, as well as its contributions to cancer prevention through research grants, health protection regulations and cancer control policies, can help national health systems to efficiently and effectively reduce the cancer burden.

Taking a simplified view, the keys to preventing cancer are common sense: *don't smoke, drink in moderation, eat well and exercise. Avoid sunburn and exposure to toxic substances; take advantage of available screening programmes.* These kinds of messages are at the core of the European Code Against Cancer¹ (3), a set of straightforward tips that empower individuals to prevent cancer through behavioural changes and participation in public health programmes. In cancer prevention, however, the principal challenges do not lie in understanding how to prevent cancer, but in bridging the implementation gap to apply existing knowledge to health promotion campaigns in ways that change people's behaviour, making them proactive agents of their own health.

ECL understands that attitudes about health are formed early, so part of their efforts in health promotion from within the Partnership were focused on using a proven vehicle (the European Week Against Cancer) to communicate cancer prevention messages to young people. This population is typically considered hard to reach for public health communicators; young people rarely know friends or peers with cancer, and development of the disease is likely decades away, making it difficult to transmit relevance. Other challenges reside in measuring impact: it will be virtually impossible to directly link health promotion campaigns to their influence on future cancer indicators.

¹ The Code is presently undergoing its fourth revision to update each message based on current evidence.

Yet, we know that these types of campaigns, if well executed, can be effective in changing behaviour (4).

ECL tested novel approaches to communicate prevention messages to young people, using social media, youth competitions and flash mobs. Partnering with its member leagues as well as with Members of the European Parliament and others, ECL renewed the European Week Against Cancer, taking its mission to new media and new settings. In doing so, the team commissioned by the Partnership gained valuable experience and knowledge that will be applied to future action taken by ECL and its national cancer leagues.

In contributing to the results that ECL achieved, the support of the European Commission cannot be disregarded or underestimated. The European Week Against Cancer was not a new concept, but one based on the past success seen during the Europe Against Cancer programme of the 1980s and 90s. After the finalisation of that initiative, however, the momentum gained over 12 editions of the Week began to dwindle, and just 2 years later, its celebration was suspended. Nearly 10 years had to pass before EPAAC provided the missing ingredient – EU support – for its revival. Even more than the relatively modest sum of seed money, the cohesive mandate that EPAAC conferred on ECL was the decisive ingredient to the success of the initiative. Going forward, the Commission should not withdraw this vital backing.

Taking a broader view, the European Commission deserves to be fully supported in its commitment to other health promotion and prevention efforts. This field is too often the ‘poor relation’ on national health budgets, garnering only nominal investments from most national health systems, despite the fact that ‘best buy’ public health interventions can save thousands of lives at a minimal cost to the system (5). The EU can help rectify this situation by fostering epidemiologic and behavioural research; using regulatory mechanisms to limit tobacco use and alcohol consumption; creating economic levers to provide incentives to Member States that scale up their public health activities; and supporting campaigns – such as the European Week Against Cancer – that help citizens understand their own role in preventing cancer.

Cancer control 2.0

The EPAAC Dissemination team tested innovative approaches to online health communication, including through an online social gaming campaign to share the messages from the European Code Against Cancer, which attracted nearly 17,000 users. This type of campaign can easily be adapted to other areas within the field of cancer and of public health, with potential to positively change health-related behaviours all over Europe.

As recent advances in communication technology revolutionise social patterns, political movements and economic trends, so too do they have great potential to change the face of health communication – if we can find a way to amplify the reach of credible information and curtail the effect of misleading or deceptive health-related messages.

The EPAAC Dissemination team, led by experts from the Slovenian National Institute of Public Health, aimed to make online health communication from a trusted source an interactive and fun experience. After establishing an active presence on popular online social networks, including Facebook, LinkedIn and Twitter, the communications team went one step further, designing an online game for social media that drew in about 17,000 users over the four-month campaign (see Chapter 3). They applied marketing techniques (giveaways and celebrity branding) and gamification methodology to create a highly successful and innovative campaign to raise awareness on cancer prevention and the Partnership's work.

As reflected in the description of dissemination activities in Chapter 3, the field of online health communication is still nascent, and health communicators have much to learn. However, the potential for positive change is remarkable. These campaigns are generally quite low-cost and relatively modest in terms of human resource needs. A small, skilled communications team is capable of designing applications that draw in specific but large populations, such as young people, with public health messages that might otherwise be ignored. The ability to create targeted content implies that in the near future, health communication campaigns may be able to efficiently tailor health-related messages to highly specific populations, according to their interests, needs, family history and other parameters. The interactive nature of online platforms increases the potential for messages to be shared, discussed and assimilated. There is also promise for scaling up or creating new personalised preventive interventions, similar to existing online and mobile applications to quit smoking (6). These applications can reach thousands of users at a fraction of the cost of programmes that require the physical presence of health professionals and patients.

The results achieved in the Partnership's dissemination work represent only a glimpse of what could be possible in online health communication. While individual Member States and health systems explore this potential on their own, there are also strong reasons for the European Union to increase its involvement. First of all, patients with cancer and other chronic diseases could benefit from joining European-wide online communities that provide reliable information and support related to their illnesses. Patient empowerment, rooted in social and community support, could be bolstered by the dissolution of geographical boundaries, particularly in the case of rare diseases. As we saw

in Chapter 5, specific rare cancers affect very few people, but together they constitute roughly 20% of all cancer diagnoses. With modest EU support, these patients could obtain trustworthy health advice, participate in online disease management programmes and connect with other Europeans who understand and can help them deal with the problems they and their families face. Children with cancer could represent another vulnerable group that could be particularly receptive to the gamification strategies applied over the course of the Joint Action.

The European Union also represents an ‘honest broker’ in terms of managing the public-private partnerships that will inevitably emerge from developments in online communication. Today private actors in marketing have the most expertise in terms of targeting messages, designing communication campaigns and reaching specific populations. On the other hand, European universities and research institutions (including EU-led centres and organisations) have the best quality health information to share with citizens, while national health systems are the natural hosts and administrators for health information portals for citizens (7). Arguably, there is no body that is better placed than the European Union to set the ground rules that bring these diverse stakeholders together for a common cause. In promoting online health communication at a European level, the EU will also foster the incipient partnerships that make a difference in individual Member States.

Quality training for screening programme managers – is there a ripple effect?

Experts from the International Agency for Research on Cancer (IARC) and the Finnish Cancer Registry successfully launched a pilot training course for managers and coordinators of cancer screening programmes in 17 countries in the region. The positive perceptions of country delegates suggest that the establishment of a permanent European School of Screening Management could contribute to improving the quality of population-based cancer screening in countries with little experience in these programmes.

Population-based screening programmes can save tens of thousands of lives every year at a generally low cost to the health system, but lack of planning experience, combined with poor management and oversight, may lead to opportunistic screening programmes that drain resources without reporting clear benefits to citizens. At worst, low quality screening programmes may lead to inaccurate results, over-diagnosis and over-treatment, all entailing detrimental effects on the people undergoing the screening (8). Even in times of economic growth, such waste is unacceptable, widening the gap between the highest and lowest socioeconomic groups at a considerable cost to the system. During an economic

recession, the negative impact of poorly planned screening programmes comes into further relief. Despite the existence of European guidelines for breast, cervical and colorectal cancer screening (9–11), many countries in the region still lack the operational capacity to put this guidance into practice.

To tackle this problem, partners from the Finnish Cancer Registry and the International Agency for Research on Cancer (IARC) organised a pilot training course targeted to screening programme planners, managers, coordinators and other relevant staff. The network of European Schools of Screening Management (ESSM) was conceived to empower national and regional health planners with the skills and knowledge needed to implement evidence-based programmes in their home countries. Two modules, separated by a four-month interim period, covered the basics of programme planning and management and provided enough flexibility for the session leaders to create course content directly based on participants' needs. The 1:1 ratio between instructors and country delegates, as well as the primary focus on practical work, led to constructive sessions that all participants perceived positively.

Delegates from EU Member States and other countries in the region have already resumed their programme work at home. The impulse created by the ESSM has likely instilled new confidence in them, but it is too early to tell whether a short pilot course, with only about two dozen participants, will be enough to make a tangible difference in the 15 European countries that sent delegates. Indeed, the screening programme managers in many of these countries face an uphill battle in obtaining the sustainable resources needed to adequately address the health inequities associated with poorly implemented screening programmes, with many obstacles that would challenge even the most seasoned experts. Among others, these barriers may include a lack of equipment and laboratories, prohibitive payment structures to access screening, inadequate population databases to identify target populations and monitor programme effectiveness, and insufficient capacity within health care services to treat diagnosed lesions quickly and effectively.

Still, the ESSM carries a note of optimism to these settings, and to the thousands of health professionals there who want to provide the best possible care to the populations they serve. In countries with little tradition of evidence-based practice, a few influential voices may be able to plant a seed of change. Taking home the lessons learned in the training course, these managers will also help to inculcate a commitment to best practice among their own staff, creating a positive ripple effect in national programmes – if not a splash.

For the current to gain force, however, the ESSM will need to be expanded, improved, and sustained. Given the complexities involved in starting or scaling

up population-based programmes, which require coordination among thousands of disparate professionals at many different levels of the health system, there is a clear need for continuous management training. Establishing the ESSM as a permanent European programme would allow incipient screening programmes to have the professional, technical and scientific support they need to achieve tangible improvements in patient outcomes, while also fostering the expertise needed to initiate population-based programmes in countries where they do not exist. This approach has the added value of strengthening health systems development and capacity building in countries both within and outside the borders of the EU.

The ESSM pilot course was modest in scope and limited in time, and it was set within the narrow organisational framework of EPAAC (of a Joint Action rather than an action programme). However, it provides a preview of what could be possible if the EU and Member States continue the work started, giving European screening professionals the opportunity to teach and to learn from each other in a paradigm of cooperation and excellence, and offering the promise to millions of European citizens that everyone will have the same chance to confront cancer head on.

European inroads to better cancer care for all

Although the funding, management and delivery of health care services are under the remit of individual Member States, European professionals have welcomed the opportunity provided by EPAAC to explore closer cross-border collaborations on issues such as rare cancers, in which there is a clear added value from a joint approach. The European Commission has an important role in articulating international networks for better cancer treatment, with potential to improve patient outcomes and quality of life.

How to reconcile the clear Member State competencies in health care with the principles of free movement of citizens, goods and services and the clear mandate of the EU to guarantee equal access to quality health services for all Europeans? This question will likely confound European and national policymakers for some time, but in the meantime, health professionals all over the continent are devising innovative and practical ways to circumvent that debate, finding added value in collaboration with their counterparts in other Member States. A diverse group of these professionals, brought together by leaders from the University of Barcelona, the Institut National du Cancer and elsewhere, were charged with analysing how these collaborations are being developed – and how an EU perspective in health care can contribute to their consolidation.

The added European value is evident in the case of multidisciplinary cancer networks and particularly networks related to rare cancers. Both of these areas

stand out for the consensus that exists on the need to cooperate and share resources and knowledge. In the case of networks, the professionals taking part in EPAAC found that a multitude of models exist. The different typologies respond to different needs, but several common factors were found to determine the success or failure of the approach, namely, the balance between organisational innovation and network stability; monitoring and evaluation of outcomes; the role of patients; the engagement of primary care; regulatory and funding mechanisms that facilitate a network approach; the involvement of policymakers; and strong leadership. Articulating these needs with operative guidance for health system managers and policymakers is the next task, to be taken up by the integrated care community together with regional, national and European authorities.

In the case of rare cancers, the added value that a European dimension grants is even clearer. A patient with a cancer that affects 1 in 100,000 people will have little chance to get expert care in a small Member State like Malta, Luxembourg or Cyprus, whose populations are under a million. However, the critical mass afforded by the 500 million inhabitants of the European Union opens opportunities for clinicians, researchers and patients in coming to a better understanding of the tumour characteristics and the best course of treatment. The limited number of oncologists specialising in these tumours also facilitates collaborative work, making networks on rare tumours a flexible and dynamic structure to improve care for patients with neglected diseases.

Preliminary work was completed in EPAAC to lay the foundation for reference networks for rare tumours within the EU, including assessing the feasibility of drafting European clinical guidelines for their care. This endeavour would likely be impossible for any common medical condition, around which varied interests from many different areas compete for leadership and control. However, in rare cancers, the mutual recognition from all quarters that cooperation is a necessary condition for progress may be enough to generate something truly unique, valuable and – for the hundreds of thousands of patients with these diseases – potentially life-saving.

The European Union is well positioned to assume leadership – not only regional but global – in the field of rare cancers. Together, Member States and EU institutions have the resources and the collective expertise to build a stable regulatory and funding infrastructure that enables development of European reference networks for these tumours. Beyond the tangible improvements in patient outcomes and quality of life that these developments could produce, valuable inroads would be made in forging lasting, collaborative partnerships among European health professionals. In the absence of clear boundaries between the EU and its Member States in guaranteeing high quality health

care for all Europeans, these advances towards close, synergetic and mutually beneficial collaboration could shed light on how European cooperation could be articulated in other fields.

Lightning in a bottle: Harnessing the power of cancer information

The Fondazione IRCCS Istituto Nazionale dei Tumori led the Partnership's work on cancer information, mapping its sources and providers, analysing the technical and political challenges obstructing the establishment of a common platform, and proposing a roadmap for Member States and European bodies to use in the future creation of a European Cancer Information System. The eventual achievement of this ambitious goal would mark a decisive turning point in European cancer research, fostering independent research in Europe and beyond, and reporting clear benefits to citizens and patients.

Information is power, or so says the common adage. Certainly cancer information is an irreplaceable tool for many: researchers in epidemiology who try to understand the patterns of the disease burden; health system managers who must evaluate population needs; patients who seek the best possible care; and policymakers who need to evaluate the effectiveness and cost-effectiveness of measures implemented to control cancer. However, information is also a sensitive matter, subject to concerns related to privacy, ethics, quality, comparability and intellectual rights. Political and legal obstacles also limit data-sharing, as the competition for scarce resources and the lack of a legal basis for a shared system impede progress. Thus, despite (or perhaps because of) the vast amount of data on cancer being collected across Europe, the creation of a shared platform to make it available to researchers and other stakeholders has always been elusive.

With EPAAC, the goal is within our reach. Cancer data availability was mapped, and the process of harmonising cancer data has got off to a solid start. The challenges and opportunities associated with the creation of a European Cancer Information System were investigated, and a practical proposal on indicators (including incidence, mortality, survival and prevalence as well as patterns of care) was delivered to all partners.

Given the existing structures dedicated to collecting information on cancer, including national and regional cancer registries as well as European and international institutions such as EUROCARE, EUROSTAT, ENCR, IARC and others, the main tasks envisaged for an ECIS do not include data collection, but rather its organisation, management, quality control, analysis and dissemination. The expert group tasked with leading EPAAC's work on cancer information, coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori, evaluated different organisational options for carrying out these

tasks, including centralised, distributed or ad hoc structures. These approaches may be combined in different ways, depending on the task and the degree of openness or control desired for the data.

Upon the conclusion of the Partnership, the future of an ECIS – so essential realising the potential of European cancer research and cancer control – falls to the European Commission, Member States and cancer information institutions. There are compelling reasons for them to build on the valuable work started in the Partnership, beginning with the potential benefits that patients and citizens will reap from strong evidence on which to base efforts in treatment, policy, advocacy and awareness. An operative ECIS would also help to strengthen European cancer research, perhaps more than any other single measure, because it would create the conditions necessary for bottom-up innovation throughout the continent. Particularly in Member States with fewer resources, access to a repository of information on the scale of an ECIS would stimulate national research far more effectively than isolated grants awarded to established institutions of excellence. It would also allow all countries to compare the effectiveness of their national health policies to the outcomes achieved by neighbouring countries with relatively similar epidemiologic, demographic, environmental and socioeconomic conditions (e.g., Germany and Austria; the Czech Republic and Slovakia; the Netherlands and Belgium, etc.). On the other hand, countries could also gain insight into the circumstances that condition cancer indicators in distant Member States. For example, Northern Europe can better understand the advantages entailed in a Mediterranean diet, while Southern Europe could benefit from knowledge on multisectoral health initiatives implemented with success in Nordic countries.

While the potential benefits of creating an ECIS are immense, they would not be fully apparent for years. The process of constructing a shared system has now begun, but the short-term nature of the Partnership effectively precludes the possibility of finalising it through the present Joint Action. As the authors of Chapter 6 pointed out, only a long-term commitment from Member States and the European Commission, complete with a coherent regulatory structure and a sustainable source of funding, will enable the creation of an ECIS. When these prerequisites have been fulfilled, the institutions gathering, organising and analysing data will be ready to come together and design a common plan to transform cancer information into a tool that works better, faster and for more patients.

Balancing competition with cooperation to foster research innovation

The European CanCer Organisation (ECCO) coordinated EPAAC's work on cancer research, bringing together hundreds of researchers to generate practical solutions to the obstacles hindering its coordination. Every sub-field requires a tailored approach; three pilot projects were successfully launched to refine coordination strategies in early phase clinical research in personalised medicine, cancer outcomes research, and epidemiology and public health.

The European cancer research community, far from being a monolithic entity that acts in unison, is actually a diverse amalgam of cancer research programmes initiated by Member States, international organisations, public and private universities, research centres, charities and the health technology industry. The multiplicity of research agendas and funding sources – not to mention languages and cultures – has led to uneven progress in the field of cancer, with particular challenges in the translation of pioneering research results into more effective interventions for cancer prevention, diagnosis and treatment. The Eurocan+Plus project, which ran from 2005 to 2007 under the leadership of IARC (but initiated under instances of the European Parliament and funded by the European Commission), identified the main obstacles in the way of coordinating European cancer research. The next step – addressing those obstacles – has been the focus of the Partnership's work on research.

The nature of the Joint Action rendered impossible the ambitious goal of coordinating a third of the funding for cancer research in Europe by 2013, not only for reasons of time and budget, but also due to the innate difficulties involved in comprehensively mapping all sources of research funding. However, ECCO and its partners were able to make valuable progress prioritising areas for future coordination efforts through pilot projects, oriented to the establishment of platforms in some of those areas. Early phase clinical research in personalised medicine, cancer outcomes research, and epidemiology and public health were the three fields chosen for concerted action. Close, interactive collaboration with the Commission is hoped for in order to articulate these concepts more fully, although all research projects of the European Union will need to be tendered.

The first area, strongly rooted in biological and clinical research, represents an area of particular interest for academia, Member States, and pharmaceutical and health technology companies, which together invest billions of Euros in basic and clinical research every year. Industry and governments struggle to overcome the challenges keeping these innovations from patients, and there is a clear need for a joint approach. Translational strategies that optimise cooperation between academia, government and industry will be necessary to manage the complex innovation cycle and provide incentives that reward cooperative efforts.

Both the British Alliance and the French CLIP² programmes have developed the means to doing just that. Under EPAAC, the feasibility of combining these programmes and extending them to other countries was explored, with encouraging conclusions. The results of any Alliance-CLIP² collaboration will not emerge immediately, and the practical problems of expanding the programmes into other EU Member States have not been fully resolved, but participating partners are optimistic that this area of clinical research is one in which European added value can shine through.

Establishing a European platform for cancer outcomes research also emerges as a potential area for greater collaboration between Member States. This pursuit would be greatly facilitated by the creation of an ECIS that allows comparison of cancer indicators such as incidence, prevalence and survival. Such a platform would also provide the means to objectively assess the impact of interventions and other factors (socioeconomic, organisational, technological, and behavioural) on cancer outcomes as well as to evaluate the performance of health systems with regard to cancer control. The possibilities for Ministries of Health and health system managers to learn from experiences in other Member States cannot be underestimated, but the research community would also be better able to report on the inequities that undermine European guarantees to high quality health care. The capacity to compare outcomes and health system performance is fundamental to forging a common research and health services agenda in cancer, but challenges surrounding access to and availability of data will have to be resolved before this objective can be achieved.

Lastly, epidemiologic and public health research was explored as an area where further coordination would be particularly useful. Two main reasons stand out in terms of justifying a stronger European presence in the field: first of all, the quantity of epidemiologic data required to answer pending research questions; and second, the low priority given to prevention and public health in Member State budgets. Cross-border research networks, supported by data from an ECIS, emerged as the best potential vehicle to propel public health innovations and progress. These networks, organised around a European knowledge hub for epidemiologic research, could pool scarce resources and provide the structure needed to foster collaboration between European researchers, funding organisations, patients and others. However, the concept of a knowledge hub is still quite raw, with a long road ahead before the operational details of such a project come into focus.

Different lessons have crystallised during the Partnership in terms of coordinating cancer research. First of all, the challenge is enormous, and its response cannot be taken lightly. Funding bodies dedicated to cancer research have developed independently, even within Member States; diverse processes,

criteria, priorities, methodologies and goals characterise the research panorama, and there is no ‘one-size-fits-all’ solution to coordinating all areas of knowledge. Every sub-field requires a specific and tailored response, adapted to the perceived cooperation needs and the professionals and citizens that are involved. Secondly, strong commitment and support from the European Commission and other EU bodies is a *sine qua non* condition to success. Only a supranational political authority has the power to regulate data access and facilitate the coordination of public, private and non-profit organisations towards a common goal.

Yet, it is worth highlighting that progress is possible despite the challenges. The formulation of a common research agenda in cancer is still a challenge, and there are a number of prerequisites that must be met beforehand. Some of these, such as an ECIS, represent considerable challenges all by themselves. However, the European cancer research community has shown their willingness to lay the foundation for a European project that holds tremendous promise for improving the lives of Europeans. With every step, relationships are formed, trust is gained and working methodologies begin to converge. Through networking and joint projects, the features of a European cancer research community begin to penetrate national research scenarios and settings. The need – and the potential – for consolidating a European dimension to cancer research is clear.

The road ahead for Member States: translating knowledge into policy through National Cancer Control Programmes

A central goal of the Partnership was to support Member States in the development, consolidation or improvement of a National Cancer Control Programme (NCCP) by the end of EPAAC. This goal had been achieved in virtually every Member State. Having turned this important corner in the formulation of comprehensive cancer policies, Member States must now work together to produce indicators and guidelines so that diverse plans can be compared and their quality ensured.

The existence of an NCCP signifies above all that Ministries of Health and other health system authorities have made a commitment to tackle their country’s cancer burden in an organised and coherent way. Beyond that, cancer control advocates *hope* that the NCCP includes a multidisciplinary and multisectoral dimension, that it is based on evidence and on the principles of equity and fairness, that it establishes clear mechanisms for evaluation and accountability, and that it secures the long-term funding needed to provide comprehensive cancer services to everyone who needs them.

How successful have EU Member States been in designing these programmes? The work led by the Slovenian National Institute of Public Health in the Partnership was devoted to answering that question, and in the process, to

stimulating health system planners that had not consolidated their countries' NCCPs into initiating, resuming or finalising a plan.

The picture that has emerged is mosaic, reflecting the political, cultural and socioeconomic diversity of the European Union as a whole. Although a number of plans stood out for their rigour and ingenuity, there are also gaps in quality and comprehensiveness. In terms of quality, one of the key shortcomings identified in some plans was the lack of monitoring or evaluation processes to support the innovation and policy cycle. With regard to comprehensiveness, it became clear that NCCPs were constrained not only by resource limitations, but by lack of experience with planning these types of programmes.

The NCCPs also reflected the specificities of health system organisation in each country. The 29 countries that completed the survey (the EU-27 plus Norway and Iceland) encompass a wide variety of funding and organisational models, and plans have been tailored to these circumstances. Cultural aspects, such as the inclusion of patients in decision-making processes, also influenced the plans, as did the challenges entailed in reaching political consensus among all relevant stakeholders.

Great strides have been made towards meeting the Commission's goal of having an established NCCP in all Member States by the end of the Partnership, a goal which is coherent with European principles of equality – including in health care. Ultimately, though, the existence of a plan is not enough. Much work remains before uniform performance standards are met – indeed, these performance standards do not currently exist. Thus, it will be some time before NCCPs become synonymous with quality cancer services. Unfortunately, the fact is that the only published guidance that can inform the formulation of an NCCP is either out of date or out of context: The World Health Organization's *Policies and managerial guidelines* (12) were published over 10 years ago, while their six-module *Guide for effective programmes* (13) was conceived primarily to help low- and middle-income countries. Although these seminal publications are still valuable, there is an urgent need to update guidance with current health policy evidence and to adapt recommendations to a European context.

The next phases in this line of policy work have already begun: the determination of indicators to monitor NCCPs and the articulation of European guidance for their development. In the case of indicators for NCCPs, a solid evidence base already exists following international initiatives such as EUROCHIP and national programmes like the one in France. The Core Working Group will continue working to select the indicators that could be applicable in a European dimension. With regard to the formulation of a European guide for high quality NCCPs, key areas have already been outlined for future work;

they include the major vertical axes of cancer control (primary and secondary prevention, treatment and palliative care); emerging areas of special interest, such as psychosocial care and survivorship; and horizontal facets of governance, resources, research and data.

Capturing these aspects in a way that can be adapted to a wide variety of settings, circumstances and stakeholders will require a collaborative and multi-country effort, preferably led by a European institution chosen with the consensus of all Member States. Furthermore, it needs sustained support from European authorities, which must take an interest in monitoring NCCP indicators; periodically updating European guidance; and establishing the process of NCCP development, implementation and improvement as a routine task for health systems. Only when these plans become an ordinary part of health system planning can the extraordinary results they promise become a reality.

Roadmap to the future

As we write these conclusions just a few short months away from the formal end of this Partnership, it is time to retrospectively assess the activities carried out under its name. Certainly EPAAC has made a difference; the Commission's mandate was a decisive factor in securing the participation of diverse organisations, including public research institutes, regional and national health authorities, supranational bodies and private enterprises. Some of the projects described in this book, like the European School for Screening Management, had existed on paper prior to the Partnership's launch, but they needed the cohesive force of EU leadership before they could take off. Other activities, such as the collaboration on a future ECIS and the surveys assessing NCCPs or requesting feedback on priorities for European research, could have been performed outside the Joint Action, but synergies would likely have been far more difficult to obtain. As the associated and collaborating partners contributed to the initiative, so too did EPAAC help to strengthen their respective roles; the Association of European Cancer Leagues has been gratified by the new interest in their work, and the institutes that have taken a lead role in EPAAC are well placed to consolidate and expand their activities in the future.

Indeed, perhaps one of the most innovative features of the Partnership has been to put into practice – on a large scale – a relatively novel model of collaborative leadership, hinging on the empowerment of its 'collateral leaders'. Alexander and colleagues described this model, in which 'broad-based leadership supports, but does not substitute for, the leadership exercised by formally designated partnership leaders' (14). These collateral leaders are the idea generators, helping to keep the project fresh with new ideas and lines of action, while the highest

level of leadership (in this case the European Commission), supports their action by providing a framework – political, financial, regulatory or structural – that enables the sub-projects to be implemented with increased legitimacy and a formal mandate.

EPAAC has exemplified the success of this approach, yet it also raises the question of what will happen once the Partnership ends. For many of the projects described in this book, including the construction of an ECIS and the coordination of European cancer research funding, some EU structural and functional support is essential to enabling the implementation of the findings reported here. An obvious follow-up is the next Joint Action on the Development of a European Guide on Quality Improvement in Comprehensive Cancer Control (CANCON), which will again be led by the Slovenian National Institute of Public Health, following confirmation that the Commission has secured funding for another three-year collaborative project. Some foci will remain the same, such as screening and secondary prevention, survivorship issues and integration of cancer care at a regional or small country level. At the same time, new spheres of work will develop, including an examination of the role of primary and community care in cancer control. These will be supplemented by a multitude of smaller yet important topics that will be elaborated in the form of position papers.

Still, more time is needed for the consolidation of European efforts against cancer. As positive as the EPAAC experience has been, there is also a sense of unfinished business, of short-term measures against long-term problems. Perhaps, as Coleman proffers, the popular rhetoric of the ‘war’ or the ‘fight’ against cancer has convinced us that we can ‘defeat’ this disease (15); after all, wars end. Cancer, on the other hand, is a disease, and as such, it will be with Europe for the foreseeable future (if not forever). The political cycle may also be too short to allow legislators and health policy planners the luxury of implementing programmes for the benefit their grandchildren, and high-profile launches of popular programmes could be more attractive than the methodical, thankless and even tedious work necessary to see them through. The reasons to explain the contrast between the scale of the task, on the one hand, and the type and level of response, on the other, could even be physiological; the primitive fight-or-flight instinct has served humans well against immediate dangers, but it is not apt to deal with long-term threats such as cancer.

Whatever the reasons cited to justify anything less than a sustained and committed effort to addressing cancer, they do not respond to the reality of as experienced by the more than 3 million Europeans diagnosed with the disease every year (16). Upon learning of their tumours, these people embark an existential journey to survive in dignity and maintain a certain quality of life.

To succeed, and to come out stronger from the process, they often need every possible tool at their disposal, including information, multidisciplinary health services, social and psychological support, and access to innovative treatments. Sometimes even the best treatment is not enough, and then these citizens will need the care that provides them with a peaceful and dignified death. The tens of thousands of people who have not yet received a diagnosis, but who may be living with cancer, urgently need their doctors to explain how screening can help them, and the many millions of Europeans who do not have this disease need to understand how they can prevent it in order to live their lives to the fullest.

None of the needs described above exist in a vacuum; all are interconnected and dependent on each other. Information and research are the most horizontal areas of work, constituting the basis for prevention, diagnostics, treatment and policy. However, each component of cancer control is closely related to the rest. For example, screening participation rises with effective health promotion campaigns, but its impact is hampered unless diagnosis is followed by appropriate treatment (17). Thus, there is a pressing need for a comprehensive response, in the form of evidence-based programmes linked together through national cancer plans. In turn, these should be supported by pan-European regulations, structures and guidance to ensure a minimal level of coherence, if not harmonisation.

Policymakers from the EU and Member States are public servants, and as such they are faced with a myriad of different problems and demands from their constituents, their colleagues and their partners. Considering the current context of economic recession and the persistent reluctance from many Member States to embrace the full implications of the European project, an EU public health programme capable of adequately addressing the cancer burden may be impractical and even impossible. Real health equity will remain more of an aspiration than an objective, and cancer incidence may keep rising no matter what programme is put in place, as the population ages and past decisions catch up in the form of present and future illnesses. Yet, European citizens are depending on their elected representatives at a national and EU level to do whatever they can, however they can, to stave off the worst effects of a public health problem of enormous proportions. Continuing the valuable work begun during the EPAAC experience is just one more milestone in a process that will need to continue well into the future. The European Commission, through their committed funding for another Joint Action, and the Slovenian National Institute of Public Health, through their willingness to coordinate these efforts, will mark the course for the next three years, but it is essential that Member States, health professionals and citizens be actively engaged in this endeavour in order to propel European cancer control into the future.

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Index

- Adolescent behaviour 80
- Alcohol drinking, prevention & control 48, 52, 73, 151, 152, 213, 228, 247
- Breast neoplasms, prevention & control 63, 88, 99, 100, 102, 104, 105, 106, 107, 108, 111, 119, 120, 121, 136, 137, 152, 157, 158, 161, 162, 163, 164, 225, 228, 230, 250
- Cancer care 9, 19, 20, 21, 23, 24, 25, 32, 117, 118, 120, 122, 124, 125, 127, 129, 133, 134, 135, 136, 137, 142, 158, 165, 180, 181, 186, 195, 196, 199, 213, 216, 218, 226, 230, 233, 235, 243, 24, 251, 260
- Cancer outcomes research 28, 32, 117, 118, 121, 164, 165, 185, 189, 194, 195, 196, 197, 198, 199, 255, 256
- Cancer research 4, 1, 26, 29, 30, 36, 37, 38, 63, 142, 143, 145, 147, 150, 152, 154, 171, 172, 174, 179, 180, 181, 182, 183, 184, 185, 186, 187, 188, 189, 190, 191, 192, 194, 195, 196, 199, 200, 201, 202, 204, 205, 212, 218, 245, 253, 254, 255, 256, 257, 260
- Cancer strategy 36, 216
- Chronic disease, prevention & control 3, 36, 52, 62, 205, 213, 248
- Colorectal neoplasms, prevention & control 48, 49, 88, 92, 98, 100, 103, 107, 108, 111, 120, 153, 157, 158, 161, 162, 163, 164, 230, 250
- Coordination, 3, 6, 10, 20, 21, 27, 29, 30, 48, 52, 90, 93, 103, 105, 107, 108, 110, 111, 112, 123, 125, 126, 130, 134, 143, 147, 148, 149, 151, 167, 168, 171, 174, 179, 180, 181, 183, 184, 185, 186, 187, 188, 189, 190, 192, 193, 194, 199, 201, 202, 203, 204, 205, 206, 212, 215, 225, 234, 251, 255, 256, 257, 260
- Data collection 26, 150, 155, 156, 162, 195, 197, 240, 253
- Diet 35, 38, 52, 73, 80, 200, 214, 254
- Early detection of cancer 9, 10, 30, 49, 88, 89, 104, 105, 106, 109, 110, 112, 154, 184, 195, 201, 210, 232
- Environmental exposure 142, 145, 152, 153, 185, 200, 202, 212
- Gamification 61, 62, 63, 66, 67, 72, 73, 74, 75, 79, 80, 248, 249
- Health campaigns 10, 14, 15, 17, 39, 44, 47, 52, 57, 58, 63, 64, 66, 68, 70, 71, 72, 74, 75, 76, 77, 78, 79, 80, 81, 103, 105, 107, 246, 247, 248, 249, 261
- Health communication 72, 78, 247, 248, 249
- Health information systems 231
- Health planning 145, 150
- Health promotion 9,10,12, 13, 32, 35, 36, 37, 39, 41, 50, 51, 52, 53, 57, 58, 59, 61, 62, 67, 70, 72, 79, 109, 218, 219, 232, 244, 245, 246, 247, 261

- Health services 1, 2, 20, 23, 100, 104, 118, 125, 129, 143, 195, 212, 214, 221, 228, 245, 251, 256, 261
- Health system 1, 7, 11, 12, 20, 25, 31, 40, 110, 118, 121, 124, 125, 129, 130, 134, 137, 141, 151, 152, 155, 165, 170, 171, 181, 200, 209, 210, 211, 212, 213, 214, 215, 216, , 220, 225, 226, 232, 233, 238, 243, 244, 245, 246, 247, 248, 249, 251, 252, 253, 256, 257, 258, 259
- Internet 14, 36, 41, 44, 47, 59, 62, 66, 68, 73
- Knowledge hub 200, 202, 203, 204, 256
- Life style 40, 41, 62, 64, 67,73,79,80,152, 185
- Mass screening 102, 152, 153, 162
- Melanoma 63, 161, 164
- Multidisciplinary 10, 20, 21, 29, 32, 88, 92, 93, 98, 105, 106, 110,117, 121, 122, 125, 130, 133, 146, 163, 172, 214, 251, 257, 261
- National Cancer Control Programmes 9, 10, 11, 18, 25, 30, 31, 33, 109, 121, 122, 156, 181, 188, 209, 210, 211, 212, 214, 215, 216, 217, 218, 220, 221, 222, 223, 225, 226, 227, 231, 232, 233, 234, 235, 236, 237, 238, 239, 244, 257, 258, 259, 261
- Networks 3, 15, 20, 21, 24, 26, 27, 28, 51, 52, 59, 60, 62, 63, 71, 75, 88, 89, 101, 103, 105, 106, 117, 123, 124, 125, 126, 127, 128, 129, 130, 131, 132, 133, 134, 135, 136, 137, 171, 173, 186, 187, 190, 192, 193, 201, 202, 243, 248, 251, 252, 256
- Obesity 37, 38
- Outcomes 11, 20, 21, 23, 24, 26, 28, 32, 59, 61, 65, 66, 92, 98, 100, 117, 118, 120, 121, 122, 123, 127, 129, 133, 134, 135, 143, 144, 145, 147, 164, 165, 169, 179, 184, 185, 186, 189, 190, 194, 195, 196, 197, 198, 199, 227, 228, 229, 230, 238, 239, 251, 252, 254, 255, 256
- Pilot projects 30, 104, 151, 181, 182, 186, 189, 190, 191, 194, 199, 200, 202, 205, 243, 255
- Primary prevention 52, 118, 218, 219
- Quality assurance 2, 3, 18, 92, 93, 97, 98, 100, 101, 102, 103, 105, 108, 109, 110, 111, 112, 121, 136, 137, 163, 186, 191, 193
- Quality of care 121, 122, 154, 158, 183, 199, 211, 235
- Rare cancers 3, 6, 20, 24, 32, 117, 120, 123, 124, 130, 131, 132, 133, 134, 135, 136, 137, 146, 150, 159, 160, 161, 185, 192, 218, 219, 245, 251, 252
- Sarcomas 132, 133
- Skin neoplasms 44, 63, 161
- Smoking 14, 37, 38, 39, 41, 51, 52, 62, 67, 80, 151, 152, 164, 212, 213, 228, 247, 248
- Social media 14, 15, 16, 17, 35, 38, 41, 42, 43, 44, 52, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66, 71, 72, 73, 74, 78, 80, 81, 244, 246, 247, 248
- Social networking 44, 50, 59, 60
- Uterine cervical neoplasms 161, 162
- Web 2.0 59, 61

The European Commission proposed the European Partnership for Action Against Cancer (EPAAC) for the period 2009–2013 to support Member States in their efforts to tackle cancer, providing a framework for identifying and sharing information, capacity and expertise, and engaging relevant stakeholders across the European Union in a collective effort to control cancer. With activities running from early 2011 to early 2014, the EPAAC Joint Action has spanned work in the fields of cancer prevention and health promotion; health communication, screening and early diagnosis; healthcare, coordination of cancer research; cancer information and data; and National Cancer Control Programmes.

This volume describes a selection of sub-projects within the EPAAC Joint Action that represent outstanding examples of cooperation and policy-orientated innovation in the various fields covered.

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The editors

Jose M. Martin-Moreno is Professor of Preventive Medicine and Public Health at the University of Valencia, Spain; Director of the Quality Assurance Unit at the University Clinical Hospital, Valencia; and Advisor to the World Health Organization's Regional Office for Europe, Copenhagen, Denmark. **Tit Albreht** is Head of the Centre for Health System Analyses at the National Institute of Public Health of the Republic of Slovenia and Assistant Professor of Public Health at the Medical Faculty of the University of Ljubljana. **Sandra Radoš Krnel** is Head of the Research and Project Management Unit at the National Institute of Public Health of the Republic of Slovenia.

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