CanCon
Cancer Control Joint Action

European Guide on Quality Improvement in Comprehensive Cancer Control

Tit Albreht, Régine Kiasuwa and Marc Van den Bulcke

Co-funded by
the Health Programme
of the European Union

European Guide on Quality Improvement in Comprehensive Cancer Control

Editors: Tit Albreht, Régine Kiasuwa and Marc Van den Bulcke

Reviewers: European Observatory on Health Systems and Policies

Publishers:
National Institute of Public Health
Trubarjeva 2, 1000 Ljubljana, Slovenia
E-mail: info@nijz.si
Tel. +386 1 2441 400
www.nijz.si

and

Scientific Institute of Public health, Brussels, Belgium
E-mail: marc.vandenbulcke@wiv-isp.be
Tel. +32 2 642 5760
http://www.e-cancer.be/

ISBN: 978-961-7002-20-1
Belgium, 2017
First published 2017

Typesetting by Laterna Magica, Ghent, Belgium
Printed and bound in Belgium by Maca-Cloetens, Brussels, Belgium
Copyright © National Institute of Public Health, Slovenia

Number of Copies: 500

Price: 0,00 EUR

This publication arises from the CanCon Joint Action, which has received funding from the European Union through the Consumers, Health, Agriculture and Food Executive Agency, in the framework of the Health Programme 2008-2013. The European Commission is not responsible for the content of this publication. The sole responsibility for the publication lies with the authors and the Consumers, Health, Agriculture and Food Executive Agency is not responsible for any use that may be made of the information contained herein.

CIP – Cataloguing in Publication
National and University Library, Ljubljana, Slovenia

616-006(082)

EUROPEAN guide on quality improvement in comprehensive cancer control / [editors] Tit Albreht, Régine Kiasuwa & Marc Van den Bulcke. - Ljubljana : National Institute of Public Health ; Brussels : Scientific Institute of Public Health, 2017

ISBN 978-961-7002-20-1 (National Institute of Public Health)
1. Albreht, Tit
288720128

Contents

ACKNOWLEDGEMENTS v

LIST OF TABLES, FIGURES AND BOXES vii

LIST OF ABBREVIATIONS ix

LIST OF CONTRIBUTORS xi

FOREWORD xv

PART I

Chapter 1 Introduction 1

Tit Albreht and Marc Van den Bulcke

Chapter 2 European Guide on Quality Improvement in Comprehensive Cancer Control Context, summary recommendations and appraisal 7

Josep Maria Borrás and Mark Dobrow

PART II

Chapter 3 Methods and quality assurance process applied in the development of the Guide 29

Régine Kiasuwa, Ana Molina Barceló, Camilla Amati, Rosana Peiró Pérez, Melina Sant and Marc Van den Bulcke

Chapter 4 Cancer screening: policy recommendations on governance, organization and evaluation of cancer screening 39

Stefan Lönnberg, Mario Šekerija, Nea Malila, Tytti Sarkeala, Marcis Leja, Ondřej Májek, Marco Zappa, Eveline Heijnsdijk, Sirpa Heinävaara, Harry de Koning and Ahti Anttila

Chapter 5 Integrated cancer control: the case for comprehensive cancer care networks 77

Tit Albreht, Camilla Amati, Marco Asioli, Gianni Amunni, Ana Molina Barceló, Christine Berling, Augusto Caraceni, Keith Comiskey, Fiona Conroy, Mary Hynes, Maeve Cusack, Lois O'Connor, Daniela D'Angelo, Ladislav Dusek, Stein Kaasa, Christoph Kowalski, Yulan Lin, Antonio Federici, Fotios Loupakis, Lucio Luzzatto, Ondrej Majiek, Silvia Miccoli, Giovanni Nicoletti, Giuseppe Pasqualetti, Rosana Peiró Pérez, Alessandra Pigni, Cheti Puccetti, Elio Rossi, Milena Sant, Julien Tognetti, Annalisa Trama and Simone Wesselmann

Chapter 6 EU policy recommendations for quality improvement in cancer after-care at the community level 105

Tit Albreht, Natashka Danova, Plamen Dimitrov, Marianne Heins, Stein Kaasa, Zalika Klemenc-Ketiš, Anne Kari Knudsen, Joke Korevaar, Frede Olesen, Radivoje Pribakovi? Brinovec, François Schellevis, Inge Spronk, Mirela Strandzheva and Matej Vinko

Chapter 7 Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States 135

Tit Albreht, Josep Maria Borrás Andrés, Miriam Dalmas, Francesco De Lorenzo, Claudia Ferrari, Cora Honing, Riikka Huovinen, Stein Kaasa, Régine Kiasuwa, Anne Kari Knudsen, Winne Ko, Hilde Krogstad, Vittorio Mattioli, Ana Molina Barceló, Rosana Peiró Pérez, Graziella Pourcel, Joan Prades, Liisa Pylkkanen, Julien Tognetti, Luzia Travado, Ingrid van den Neucker, Wendy Yared

Chapter 3

Methods and quality assurance process applied in the development of the Guide

Régine Kiasuwa, Ana Molina Barceló, Camilla Amati, Rosana Peiró Pérez, Melina Sant and Marc Van den Bulcke

Introduction

Joint actions are a particular form of collaborative projects between Member States to gain expertise in domains where the responsibility largely remains at the level of each EU Member State. Consequently, coming to a common output within the context of a joint action requires a particular process coordinating and facilitating the interactions between the different partners, stakeholders and Member States. We have built on the experience gained in EPAAC, the previous Joint Action on Cancer, in which most CanCon partners already participated. As the final output of this Joint Action, CanCon, is a single Guide document, it was recognized that in addition to a general administrative and financial coordination, a dedicated team providing the general structure of the guide and monitoring its development and the structure would be important.

A specific work package led by the Belgian Cancer Centre of the Scientific Institute of Public Health was created that would be aided by the Guide coordination team to oversee the development of the CanCon Guide document. The aims of this work package is to (i) ensure coherence and quality of the guide document, (ii) provide guidance and support for collecting the material used for drafting the policy recommendations within the core sections, and (iii) support the inclusion of two cross-cutting issues within each core topic: inequalities and cancer information systems.

Guide Coordination Committee: quality assurance process applied in the development of the Guide

To maintain the quality assurance of the project, a so-called Guide Coordination Committee was installed at the start of the project. The Guide Coordination Committee represents the work package leaders, European Commission representatives, the work package 4-associated partners and two external experts (Table 3.1). The European Observatory on Health Systems and Policies assisted the Guide Coordination Committee in the development and compilation of the Guide.

Table 3.1 Composition of the Coordination Committee for the Guide

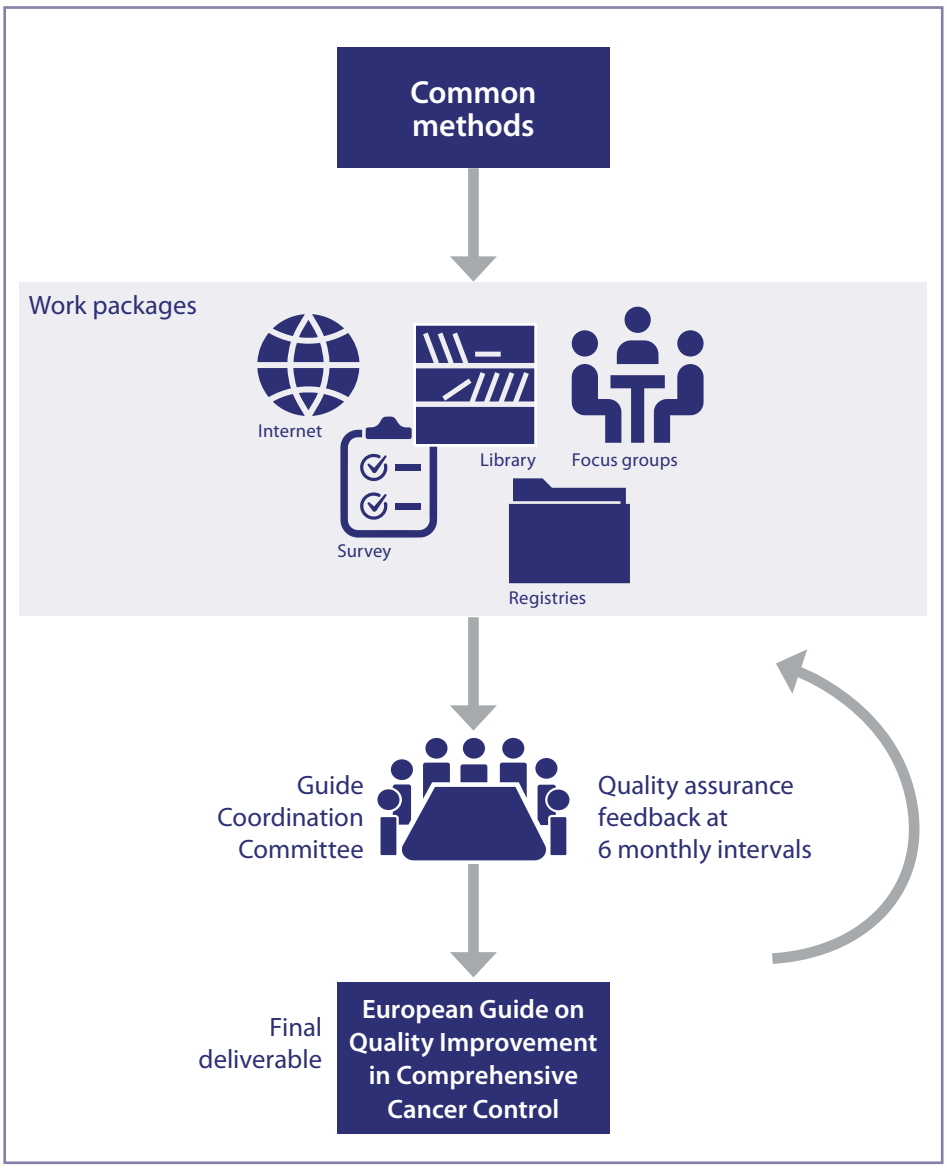
Name	Affiliation
Tit Albreht	National Institute of Public Health of Slovenia, Ljubljana, Slovenia
Camilla Amati	Istituto Nationale di Tumori, Milan, Italy
Ahti Antilla	Finnish Cancer Registry and Cancer Society of Finland, Helsinki, Finland
Christine Berling	Institut National du Cancer, Paris, France
Josep Maria Borrás	University of Barcelona, Barcelona, Spain
Miriam Dalmas	Ministry of Public Health, La Valetta, Malta
Mark Dobrow	University of Toronto, Toronto, Canada
Josep Figueras	European Observatory on Health Systems and Policies, Brussels, Belgium
Irene Glinos	European Observatory on Health Systems and Policies, Brussels, Belgium
Régine Kiasuwa	Cancer Centre, Scientific Institute of Public Health, Brussels, Belgium
Tina Lipuscek	National Institute of Public Health of Slovenia, Ljubljana, Slovenia
Lucio Luzzatto	Istituto Toscano Tumori, Firenze, Italy
Ana Molina Barceló	FISABIO, Valencia, Spain
Giovanni Nicoletti	Ministry of Public Health, Rome, Italy
Willy Palm	European Observatory on Health Systems and Policies, Brussels, Belgium
Rosana Peiró Pérez	FISABIO, Valencia, Spain and CIBER of Epidemiology and Public Health (CIBERESP), Madrid, Spain
Joan Prades	University of Barcelona, Barcelona, Spain
Graziella Purcel	Institut National du Cancer, Paris, France
Anna Rouillard	ECCO (European Cancer Organisation), Brussels, Belgium
Milena Sant	Istituto Nationale di Tumori, Milan, Italy
Holger Schunemann	McMaster University , Hamilton, Canada
Saskia Van den Bogeart	Ministry of Public Health, Brussels, Belgium
Marc Van den Bulcke	Cancer Centre, Scientific Institute of Public Health, Brussels, Belgium
Ingrid van den Neucker	ECCO (European Cancer Organisation), Brussels, Belgium
Jerica Zupan	European Commission, DG – Joint Research Centre, Brussels, Belgium

The main tasks of the Guide Coordination Committee are to

- endorse the quality assurance criteria to be applied in the development of the core chapters of the guide;
- critically assess the methodological approach in the core work packages;
- propose improvement/changes; and
- approve the final content of the core chapters.

The quality assurance process for the joint action is illustrated in Fig. 3.1. At the start, a common principle of methodology was agreed relating to the collection and use of material for drafting the policy recommendations. For this, literature reviews, surveys, expert inputs and a common evidence appraisal approach alongside incorporating contextual features of the EU health systems are considered of great important.

Fig. 3.1 The quality assurance process in development of the Guide



Through biannual meetings, the Guide Coordination Committee follows the progress of the activities and provides input and suggestions for improvement. After each round of quality assessment, a periodic quality assurance report summarizing the main achievements, potential difficulties and transverse or recurrent issues is prepared and shared with all work package teams. To support the writing teams and ensure coherence and quality, the Coordination Committee provided a glossary of terms as well as a list of existing and validated tools for appraising and judging quality of the evidence collected. A workshop dedicated to the Guide's authors has been organized to present and discuss features of using the collected material to draft policy recommendations. Experts in guidelines and policy recommendation development were invited to share practical experience and guidance tailored to the topics of the four core chapters of the Guide.

Overview of the methodology applied within the core chapters

Considering the diverse topics covered in the guide, each chapter applied a different combination of approaches to develop recommendations for the policy-makers. Overall, literature reviews, surveys, semi-structured interviews, expert opinions and discussions, evidence grading/appraisal exercises and pilot field studies are the most commonly applied methods (Table 3.2)

Table 3.2 Schematic view of the approaches applied in the core chapters

CanCon Guide methods	Literature review	Survey	Semi-structured interviews	Expert opinion	Grading or appraisal	Field or pilot study
Screening	X	X		X	X	
Integrated Cancer Control	X	X		X	X	X
Community-level Cancer Care	X	X	X	X		X
Survivorship and Rehabilitation	X	X	X	X	X	

Details on the applied methodologies can be found in each of the core chapters. Below only a brief listing of the different approaches in the respective chapters is presented.

Work package: Cancer screening

Evidence on efficacy and effectiveness of cancer screening was drawn from recent systematic reviews and European quality assurance guidelines, supplemented and updated also with conventional literature searches using PubMed. Specific literature searches were used for potential new screening programmes for prostate, lung, gastric and ovarian cancer. Rating of evidence was performed and current evidence was discussed at consensus meetings with international experts.

Status reports on the implementation of cancer screening were available from a number of surveys. Supplementary data on current implementation status of cancer screening programmes were obtained through the partners and experts.

Recommendations for the Guide chapter were drafted by the authors of the chapter and delivered for comments and review within the Working Group and the Guide Coordination Committee.

Work package: Integrated cancer control

Surveys were performed to collect information on CCCNs as a possible model of cancer care organization across Europe, collecting information from representatives of EU health authorities, cancer societies, directors of comprehensive cancer centres, cancer registry directors and from RARECAREnet. Herein, semi-structured interviews with international experts were performed.

Various literature searches were performed using peer-reviewed journals, grey literature and web sites of cancer networks, governments and relevant online databases.

Work package: Community-level cancer care

A questionnaire-based survey of experts and country informants in 32 countries was performed and international guidelines assessed. Databases and web sites were used in literature and evidence searching.

The findings of five European countries (Bulgaria, Denmark, the Netherlands, Norway and Slovenia) were included given the specific interest in participating shown by their respective ministries of health. The findings are, therefore, a result of self-inclusion and not of a systematic and structured involvement of specific countries. Also, the methodologies used in the different countries in order to substantiate some specificities of their after-care process, relationship between levels of care, and between the central and regional relationships vary greatly. Consequently, there was no overall harmonization of methodologies. In Bulgaria, the National Centre for Public Health Analyses carried out a set of structured interviews on perceptions of after-care services, in particular from the point view of the type of provider. In Denmark, a reform of after-care is in progress including plans on follow-up care for each main type of cancer. For the Netherlands, the Netherlands Institute for Health Services Research (NIVEL), carried out a series of health services research studies and measured the impact on after-care on the volume of care in a general practitioner (GP) practice. The Norwegian case described a health services intervention study where the activities of an ongoing transformation (the transfer of certain specialist services including palliative care to the community level) are outlined. The Slovene study combined a quantitative cross-sectional survey of a stratified random sample of 250 GPs practising in Slovenia, with semi-structured interviews conducted on a purposive sample of six physicians from Upper Carniola region. Good practice recommendations on after-care in GP practices were developed and tested during the study.

Work package: Survivorship and rehabilitation

Based on preliminary work on existing guidelines or plans for long-term follow-up care for cancer patients, four countries were recognized as pioneers: the United States, Canada and Australia, which follow the work achieved by the Institute of Medicine *(1)*, and the United Kingdom *(2)*. Based on these, five key areas were identified as to be investigated in the field of long-term follow-up care for cancer patients, with specific attention to four cross-cutting issues. The five key areas were

- medical follow-up, including management of late effects and tertiary prevention
- psychological support
- social rehabilitation including employment issues

- empowerment of cancer survivors
- multidisciplinary approach and coordination of care providers.

In addition, four cross-cutting issues were covered

- care for survivors of childhood cancer
- inequalities in survivorship
- cancer information and data registration
- research.

In order to collect evidence about these nine issues and to translate it into policy recommendations for EU Member States, a three-fold methodology has been used: literature reviews, a critical appraisal exercise including a deliberative process involving invited EU experts to discuss the results and their applicability in EU Member States and a survey on current status in EU Member States regarding cancer follow-up care.

Two cross-cutting issues: equity and cancer information

In the exploratory and preparatory phase of CanCon, partners recognized the importance of two themes, assumed as transversal across the Guide: equity and cancer information.

Equity in cancer was considered in CanCon a key issue to be included as a transversal topic in the Guide. Several steps have been developed in order to ensure the inclusion of the equity perspective in the Guide construction process. This task has been developed in the context of WP4, and was leaded by the Fundación para el Fomento de la Investigación Sanitaria y Biomédica (FISABIO) de la Comunitat Valenciana.

In order to provide tools that help including the equity perspective in the Guide development, some specific recommendations were provided in the Methodological Paper elaborated by WP4 paper, among other issues, theoretical models such as the social determinants of health model *(4)*, and a glossary of equity terms was presented. The cancer inequalities involve social inequalities in the prevention, incidence, prevalence, detection and treatment, survival, mortality, and burden of cancer and other cancer-related health conditions and behaviors *(5)*. The objective was to harmonize the concepts and terms used in the Guide. For example, it was recommended to use the concept "health inequalities" instead of "health inequities", because is a much more readily understandable term by the general public and the term "health inequities" does not find a direct translation in all languages. In consideration of these points, this document uses the term health-cancer inequalities with the sense of avoidable and unfair differences in health and cancer (European Commission, 2009). Some examples on social inequalities in the cancer continuum were included in the Methodological Paper in order to provide each WP leader arguments to justify the need of addressing this issue in the Guide (e.g. people living in high deprivation area participate in a lesser extent in colorectal cancer screening than people in low deprivation area *(8)*. In order to consider social determinants of health in the formulation of the issues they addressed, a PROGRESS-Plus tool (meaning place of residence, race, occupation, gender, religion, socioeconomic status, social capital, and others like age, disability, sexual orientation, discrimination, etc.) *(7)* was provided, as well as key words and MeSH Terms (eg: Socioeconomic Factors [MeSH]…) to use when a literature review was planned.

The tools for mainstreaming equity included in the Methodological Paper were used as quality standards in the revision process of the chapters. A workshop to discuss how to take equity into consideration for evidence-informed health policy-making was made, discussing concrete examples on each chapter.

At midterm, a questionnaire was sent to WP leaders in order to receive feedback on difficulties and opportunities to include equity in the process of chapter development (eg: Have you and/or your partners any difficulties/opportunities to include inequalities as a transversal issue to be described and discussed in the chapter, as CanCon required? Were the equity suggestions we made to your chapter useful for your work? Has been easy to incorporate them in your chapter development?).

Specific equity questions, based on the Equity Checklist developed by the Campbell and Cochrane Equity Methods Group *(6)* were formulated to assure that the final recommendations of the Guide were equity-oriented (e.g. which groups or settings are likely to be disadvantaged in relation to the policy recommendation?).

A second transversal issue relates to cancer information i.e. the need for presenting data able to document the effectiveness of cancer control activities and assess the applicability of results in most EU health systems.

Administrative and clinical cancer data derived from healthcare facilities, including pathology reports and pharmaceutical data, are essential for the organization of research, clinical practice and can also impact the quality of life of cancer patients physically, socially and professionally.

Cancer information is an essential tool to uncover problems and to quantify their extent in terms of public health. Over 150 European Cancer registries (CRs) in the EU intercept the main data flows generated by these sources to provide cancer basic indicators as incidence, mortality, survival and prevalence, which constitute a key tool for estimating the burden of cancer in populations.

Through linkage with additional population data (e.g. census files, costs/reimbursements for treatments, costs, household surveys, hospital and laboratory files, organized screening registries), further health indicators can be provided by CRs on quality of life, rehabilitation; heath assessment technology studies profit from good quality CRs data. Presently CRs data are available via the ECO[ref], and in the next years we can foresee the existence of a European Cancer Information system based at the EC-Joint Research Centre, hosting the "European National Cancer Registries" secretariat since 2012.

From the European Health Information Survey (EHIS), the Organisation for Economic Cooperation and Development (OECD) and EUROSTAT aggregated data on risk factors, early diagnosis, healthcare resources and socioeconomic variables can be derived. Assessment and outcome tools validated in several countries include a connection between population-based data and clinical data, e.g. EPAAC recommendations on multidisciplinary teams, the activity promoted by OECI with the EUROCANPLATFORM PROJECT and the CCC accreditation scheme.

Throughout the action, the consideration of relevant data in the methods was ensured through the promotion of databases including records of clinical decisions, outcomes, indicators, as well as of clinically-based evidences, best practices, cost-effectiveness issues, use of resources and features of different healthcare systems influencing implementation.

References

1 Hewitt M, Greenfield S, Stovall E, eds. From cancer patient to cancer survivor: lost in transition. Washington, DC, US National Academy of Sciences; 2006.

2 National Cancer Survivorship Initiative. Vision document. London, National Cancer Survivorship Initiative; 2008 (http://www.ncsi.org.uk/wp-content/uploads/NCSI-Vision-Document.pdf, accessed 15 January 2017).

3 Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. *Injury Control and Safety Promotion,* 2003;10(1–2):11–12.

4 Whitehead M, Dahlgren G. Levelling Up, Part 1: Concepts and principles for tackling social inequalities in health. Copenhagen: World Health Organization; 2006

5 Krieger N. Defining and investigating social disparities in cancer: critical issues. Cancer Causes Control. 2005 Feb;16(1):5-14

6 Welch V, Petticrew M, Tugwell P, Moher D, O'Neill J, Waters E, White H; PRISMA-Equity Bellagio group. PRISMA-Equity 2012 extension: reporting guidelines for systematic reviews with a focus on health equity. PLoS Med. 2012;9(10):e1001333

7 O'Neill J et al. Applying an equity lens to interventions using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in health. *Journal of Clinical Epidemiology,* 2014;67(1):56–64.

8 Steele RJ et al. Effect of gender, age and deprivation on key performance indicators in a FOBT-based colorectal screening programme. *Journal of Medical Screening,* 2010;17(2):68–74.

Further reading

Adams J, White M, Forman D. Are there socioeconomic gradients in stage and grade of breast cancer at diagnosis? Cross sectional analysis of UK cancer registry data. BMJ, 2004;329(7458):142.

Blinder VS et al. Return to work in low-income Latina and non-Latina white breast cancer survivors: a 3-year longitudinal study. *Cancer,* 2012;118(6):1664–1674.

Bowen S, en Zwi AB. Pathways to "evidence-informed" policy and practice: a framework for action. *Policy Forum,* 2005;2(7):600–605.

Centre for Evidence-Based Medicine. *Study designs*. Oxford, Centre for Evidence-Based Medicine; 2016 (http://www.cebm.net/index.aspx?o=1039, accessed 5 January 2017).

Guyatt GH et al. (2015). *Users' guide to the medical literature: a manual for evidence-based clinical practice,* 3rd edn. New York, McGraw-Hill Education for American Medical Association.

Herndon JE 2nd et al. Effect of socioeconomic status as measured by education level on survival in breast cancer clinical trials. *Psychooncology,* 2013;22(2):315–323.

Howick J (2011) *Resolving the paradoxes in evidence-based medicine. A philosophical inquiry.* London, Wiley-Blackwell.

Jacobs JA et al. Tools for implementing an evidence-based approach in public health practice. *Preventing Chronic Disease,* 2012;9:110324.

Langenbach MR et al. Why so late?! – delay in treatment of colorectal cancer is socially determined. *Langenbeck's Archives of Surgery,* 2010;395(8):1017–1024.

Nagelhout GE et al. Trends in socioeconomic inequalities in smoking prevalence, consumption, initiation, and cessation between 2001 and 2008 in the Netherlands. Findings from a national population survey. *BMC Public Health,* 2012;12:303.

Rychetnik L et al. Criteria for evaluating evidence on public health interventions. *Journal of Epidemiological Community Health,* 2002;56:119–127.

Rychetnik L et al. A glossary for evidence based public health. J*ournal of Epidemiology Community Health,* 2004;2004;58:538–545.