

The Development of European Guide for Quality National Cancer Control Programmes

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ABSTRACT - National Cancer Control Programmes (NCCPs) are public health programmes designed to reduce cancer incidence and mortality and improve the quality of life of cancer patients. Europe continues to be characterised by unacceptable inequalities in the fight against cancer both between and within Member States (MSs) and therefore the development and adoption of high quality NCCP is of key importance for every MS. In order to help MSs to develop high quality NCCPs, the European Guide for Quality NCCPs (Guide) was prepared. The booklet is the first and only document of its kind in Europe. The process of the developing the Guide, its objectives and its structured content are described in this article. There were three methodological tasks related to NCCPs: conducting a survey on existing NCCPs in the MSs, Norway and Iceland; developing the Guide and selecting indicators applicable to monitoring of NCCP. The Guide is structured in three strands: cancer prevention, integrated care and support functions within the health system. The Guide is a living document. MSs, patients, organisations, scientific and professional communities can periodically make suggestions for improvement and further development of the Guide.

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KLJUČNE BESEDE: rak, programi, vodiči, zdravstveni sistemi

POVZETEK - Nacionalni programi za obvladovanje raka (NPOR) so javni zdravstveni programi, katerih namen je zmanjšati pojavnost raka in umrljivost za rakom ter izboljšati kakovost življenja bolnikov z rakom. Evropo še vedno zaznamujejo nesprejemljive neenakosti na področju obvladovanja raka, tako med državami članicami, kot znotraj njih, zato sta priprava in implementacija kvalitetnega NPOR ključnega pomena za vsako državo. Da bi državam pomagali razviti kvalitetne NPOR, je bil pripravljen Evropski vodič za pripravo kvalitetnih NPOR (Vodič). Knjižica je prvi in edinstven tovrstni dokument v Evropi. V tem članku je opisan postopek razvoja Vodiča, njegovi cilji in strukturirane vsebine. Vzpostavljeni so bili trije metodološki pristopi: izvedba vprašalnika o vsebinah obstoječih NPOR v državah članicah, na Norveškem in v Islandiji; priprava Vodiča samega ter izbira kazalnikov, ki se uporabljajo za spremljanje NPOR. Vodič je sestavljen iz treh sklopov - preprečevanje raka, celostna oskrba in podporne funkcije v zdravstvenem sistemu. Vodič je živ dokument. Države članice, bolniki, organizacije, znanstvene in strokovne skupnosti lahko dajejo predloge za stalno izboljševanje vsebin vodiča.

1 Introduction

Cancer management is one of the most complex segments of disease management in the healthcare sector. Healthcare systems can only respond to cancer needs of the population through appropriate planning and implementation. National Cancer Control Programmes (NCCPs) are a systematic response to this important challenge and represent the best that a health system can do for its citizens.

The World Health Organisation (WHO) defines NCCPs as public health programmes that aim to reduce cancer incidence and mortality and improve quality of life

of cancer patients, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment and alleviation, making best use of available resources (WHO, 2002). They are useful tools to support targeted and organised efforts by health systems to address the multiple challenges posed by cancer epidemics and their complexity (Albreht et al., 2009). Over the past 25 years, cancer programmes have been gradually introduced in many countries around the world. However, European Union (EU), which is home to the most advanced, consolidated and well-funded national health systems in the world, has produced the most innovative and groundbreaking initiatives in the field of NCCPs (Albreht et al., 2013). The experience of countries with long tradition of cancer plans and cancer programmes, e.g. France, England and Norway paved the way for the EU-wide discussion on the need to establish national or regional cancer programmes, plans or strategies in all European Member States (MSs) (INCA, 2014; National Health Service, 2014; Norwegian Ministry of Health, 2013). This paper presents the work that builds on the experience of the development of NCCPs, a process initiated by WHO and subsequently followed by several countries.

The European Parliament and the Council drew attention to the increasing burden of cancer in Europe and called on European Commission (EC) to take strong action to support MSs in the fight against cancer (European Parliament, 2008; Council of the EU, 2008). In 2009, the EU recommended that its MSs develop NCCPs or Strategies by 2013 (EU Commission, 2009). To support its MSs, EC launched European Partnership for the Action Against Cancer Joint Action (EPAAC JA), the largest project in the field of cancer to date, with 36 associated partners from across Europe and 100 collaborating partners from around the world (Radoš Krnel et al., 2013). Concentrating on NCCPs was a key priority for EC in developing the outlines of the EPAAC JA.

Here we present the first and only document of this kind in Europe, named European Guide for Quality National Cancer Control Programmes (Guide), which is intended to serve as a concise outline for policy makers who want to understand the basics of cancer control policy (Albreht et al., 2015). The aim of this paper is to describe the process of developing the Guide, its objectives, the extensive joint work of the European MSs during its development, and its structured content.

2 Development of NCCPS within the EPAAC JA

The Slovenian National Institute of Public Health, which continued the work on cancer control in the EU during its presidency of European Council in 2008 (Coleman et al., 2008; Coebergh&Albreht, 2008; Albreht&Pribaković Brinovec, 2009), led the EPAAC JA project, which, in cooperation with the MSs, prepared the basic aspects that should include high quality NCCPs (Jelenc et al., 2012). There were three main tasks related to NCCPs in the EPAAC JA: conducting a survey of existing NCCPs in all MSs, Norway and Iceland; developing the Guide and selecting indicators for monitoring an NCCP.

3 Process of developing the European guide for quality national cancer control programmes

The EPAAC JA process of preparing the Guide was carried out in three newly established groups. The Core Working Group on NCCPs (CWG on NCCPs) acted as the focus group for the core work on the development of the Guide. It was composed of experts in the field of cancer programmes from Belgium, Ireland, Italy, Malta, the Netherlands, Spain and Slovenia. The group dealt with the preparation of background documents, surveys and analyses.

Representatives from MSs, Iceland and Norway as well as from WHO Regional Office for Europe, European Regional and Local Health Authorities (EUREGHA) and the European Observatory on Health Systems and Policies (Observatory) formed the second group called Working Group on NCCPs (WG on NCCPs). The WG on NCCPs reviewed and completed the information produced by the CWG on NCCPs and co-chaired by the EC and Slovenia.

The Steering Committee was the third group and consisted of representatives from the EC, WG on NCCPs, the EPAAC JA Steering Committee, and the International Agency for Research on Cancer (IARC), the Observatory, the European Cancer Patient Coalition (ECPC) and industry, as well as independent experts. The group reviewed all the work and adopted the final decisions by consensus (Radoš Krnel et al., 2013).

The work on the Guide consisted of three rounds of consultation, the elaboration by experts and the revision of the chapters of the interim draft. The process took place in three types of methodological approaches: face-to-face consultations within the CWG on NCCPs, drafting of chapters by the members of the CWG on NCCPs, reformulation and rewriting of the chapters by the editorial and technical work of the consultant team. Work on the Guide started in 2011, when the survey on the characteristics of NCCPs in the EU was conducted. All European MSs, Iceland and Norway were invited to actively participate in the survey and respond to it. The survey was prepared by the CWG on NCCPs and approved by WG on NCCPs under EPAAC JA. The analysis of the programmes was based on the compliance with NCCPs guidelines of WHO, the inclusion of structural and process indicators and the self-assessment carried out by the MSs. The responses provided input for the comprehensive overview and assessment of the situation in the EU, Iceland and Norway regarding the availability of cancer programmes/documents and their content. They helped to identify both the similarities and differences between countries. There were fewer differences in the chapters that would normally serve as the basis for such a document, particularly in the epidemiological situation, priorities, development of screening programmes and provision of cancer-specific clinical services. On the other hand, we found significant discrepancies in palliative care, psycho-oncological services and the economics of cancer, Health Technology Assessment (HTA) and the role of primary care in dealing with cancer patients. The results of the survey were published in the report entitled

National Cancer Control Programmes: Analysis of Primary Data from Questionnaires (Report) which is available online (Gorgojo et al., 2012). The Report, which describes the state of NCCPs in the EU, has been revised in several rounds by the representatives of WG, Steering Committee and MS. It was an essential tool for the preparation of the Guide and for the selection of the respective indicators, as it showed the strengths and weaknesses of the existing NCCPs.

4 Structure and objectives of the guide

The working groups agreed that the Guide is divided into ten thematic chapters (Albreht et al., 2015) grouped into three main strands; cancer prevention, integrated care and support functions within the healthcare system:

- Cancer prevention:
 - Primary prevention and health promotion
 - Cancer screening and early detection
- Integrated care:
 - Diagnosis and treatment
 - Psychosocial oncological care
 - Survival and rehabilitation
 - Death support and palliative care
- Supporting functions within the health system:
 - Governance and financing
 - Cancer resources
 - Cancer data and information
 - Research

The structure is based on the presentation of best practices from MSs with a long tradition of producing NCCPs and on the guidelines previously produced by WHO (WHO, 2002; Howard, 2008). The main objective of the Guide is to provide a description of the cancer control services that can be provided by national health systems and to propose a list of indicators that countries can consider in order to improve the monitoring and evaluation of their programmes. The aim of the Guide is also to promote some convergence in national approaches to NCCP planning, to improve the ability of policy analysts, to compare programmes within and across European borders and to support a common understanding of cancer planning among EU policy makers. All this will in turn facilitate cooperation across borders (Albreht et al., 2015).

5 Discussion and conclusions

This Guide, which is one of the main outputs of the EPAAC JA, is a unique tool for administrators and policy makers in the health system who wish to improve or implement their NCCP or develop a new one. On the other hand, the Guide contains

a set of structural, process and outcome indicators that countries can consider in order to improve the monitoring and evaluation of their ongoing programmes. The prepared Guide includes the guidance previously provided by WHO. In addition, our work presents the elements resulting from the semi-structured survey conducted in the EU MSs, Iceland and Norway. The results are now an integral part of the structure of the Guide.

The Guide is available both in printed form at the National Institute of Public Health in Ljubljana and in electronic form (Albreht et al., 2015). The text is not intended to be a rigid template, but rather a flexible guide for public health professionals, cancer experts and policy makers in health care who wish to adapt to the basics of cancer control policy and help them to select the elements to be include in a programme. Indeed, the Guide cannot be prescriptive, as this would require aligning health systems in MSs. Moreover, the group of programme elements described in the Guide should not necessarily be implemented as a whole, as national policies must always be adapted to the national organisation of the health system, its resources and priorities (Albreht et al., 2015).

The Guide for Quality National Cancer Control Programmes has been prepared within the framework of the EPAAC JA. The results of the survey on NCCPs in Europe published in the report entitled “National Cancer Control Programmes: Analyses of Primary Data from Questionnaires” served as a basis for the preparation of the Guide. Indeed, the report showed the diversity of approaches used in NCCPs in the European MSs, Norway and Iceland. It highlighted at least two important shortcomings – firstly, the wide variation in the treatment of the standard chapters of these programmes in different countries and, secondly, the fact that certain issues are either overlooked or marginalised despite their importance for patients and cancer survivors. It was felt that there was a lack of guideliness that would provide the desired basic structure of a good and well-organized cancer programme. As an advantage of the methodology described, we can mention the cooperation and sense of involvement of all European MSs, Norway and Iceland; consequently, they consider the developed Guide as their work and they apply it. The EPAAC JA offered the opportunity to participate in the extensive work of various European countries and develop the Guide, which is still the first and unique document of its kind in Europe. In fact, the results of a global analysis of NCCPs were published in 2018 (Romero et al., 2018), and a year later the checklist of key elements that an NCCP should contain was published. However, this is not a guide but an article (Oar et al., 2019).

The main purpose of the Guide was to provide a flexible template that emphasises the importance of completeness of all cancer treatment and cancer management efforts at both the individual and system level. The present Guide allows MSs to study its planned content in detail and develop all its elements accordingly, without forgetting their own national organisation of the health care system, its priorities and available resources.

We would like to see the Guide as a living document, so that MSs, patients, patient organizations, scientific and professional communities and cancer advocates throu-

ghout the EU can periodically make suggestions for improving and developing the Guide. An updated version of the Guide will probably be produced as part of one of the future European cancer projects.

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Razvoj Evropskega vodiča za pripravo kvalitetnih nacionalnih programov za obvladovanje raka

Obvladovanje raka je eden najbolj zapletenih segmentov obvladovanja bolezni v zdravstvu. Zdravstveni sistemi se lahko odzovejo na potrebe prebivalstva na področju raka le z ustreznim načrtovanjem. Nacionalni programi za obvladovanje raka (NPOR) so sistematičen odziv na ta pomemben izziv in predstavljajo najboljše, kar lahko zdravstveni sistemi naredijo za svoje državljane na področju raka. V prispevku predstavljamo prvi in edinstven dokument v Evropi, imenovan Evropski vodič za pripravo kvalitetnih nacionalnih programov za obvladovanje raka (Vodič), ki naj bi služil kot vodilo oblikovalcem politik na področju obvladovanja raka, ki želijo razumeti osnove obvladovanja raka (Albreht idr., 2015).

Svetovna zdravstvena organizacija (SZO) opredeljuje NPOR kot javnozdravstvene programe, namenjene zmanjšanju pojavnosti raka in smrtnosti za rakom ter izboljšanju kakovosti življenja bolnikov z rakom, s sistematičnim izvajanjem strategij za preprečevanje, zgodnje odkrivanje, diagnozo, zdravljenje in paliativo z najboljšim izkoriščanjem razpoložljivih virov (WHO, 2002).

NPOR so koristno orodje pri podpori organiziranih prizadevanj zdravstvenih sistemov kot odzivu na številne izzive, ki jih predstavlja epidemija raka in njegova zapletenost (Albreht idr., 2009). V zadnjih 25 letih so v številnih državah po vsem svetu postopoma začeli pripravljati programe za boj proti raku. Vendar je Evropska unija (EU), v kateri so doma najnaprednejši in dobro financirani nacionalni zdravstveni sistemi na svetu, ustvarila najinovativnejše in pionirske pobude na področju NPOR (Albreht idr., 2013). Izkušnje držav z dolgoletno tradicijo programov za raka, npr. Francija, Anglija in Norveška, so utrle pot razpravi v EU o potrebi po vzpostavitvi nacionalnih ali regionalnih programov, načrtov ali strategij za boj proti raku v vseh evropskih državah (INCA, 2014; National Health Service, 2014; Norwegian Ministry of Health, 2013). V tem prispevku so predstavljene priprave programov za obvladovanje raka, ki jih je prva začela SZO, sledilo pa ji je več držav. Razen priporočil SZO smo v Vodič vključili elemente, ki izhajajo iz vprašalnika, izvedenega v državah članicah EU, v Islandiji in na Norveškem.

Evropski parlament in Svet sta že leta 2008 opozorila na naraščajoče breme raka v Evropi in pozvala Evropsko komisijo (EK), naj odločno ukrepa pri podpori državam članicam v boju proti raku (European Parliament, 2008; Council of the EU, 2008). Leta 2009 je EK državam članicam priporočila, naj do leta 2013 razvijejo NPOR ali strategije (EU Commission, 2009). Z namenom pomoči državam je EK sofinansirala

projekt skupnega ukrepanja Evropsko partnerstvo za boj proti raku (angl. *European Partnership for the Action Against Cancer Joint Action - EPAAC JA*), največji evropski projekt na področju raka. V projektu EPAAC JA je sodelovalo 36 pridruženih partnerjev iz vse Evrope in kar 100 sodelujočih partnerjev iz celega sveta (Radoš Krnel idr., 2013). Osredotočenost na NPOR je bila prednostna naloga EK pri pripravi osnutka EPAAC JA. Namen tega članka je opisati metodologijo razvoja Vodiča, njegove cilje, obsežno skupno delo evropskih držav članic med njegovo pripravo in strukturirane vsebine.

Slovenski Nacionalni inštitut za javno zdravje (NIJZ), ki je nadaljeval delo na področju obvladovanja raka v EU, ki se je začelo med predsedovanjem Slovenije Evropskemu svetu leta 2008 (Coleman idr., 2008; Coebergh & Albreht, 2008; Albreht & Pribaković Brinovec, 2009), je prevzel vodenje projekta EPAAC JA. Skupaj z državami članicami je pripravil nabor osnovnih elementov, ki jih morajo vključevati visoko kakovostni NPOR (Jelenc idr., 2012). EPAAC JA je združeval tri pomembne naloge, povezane z NPOR: izvedbo vprašalnika oz. raziskave o obstoječih NPOR v državah članicah, na Norveškem in v Islandiji; razvoj Vodiča in izbiro kazalnikov, ki se uporabljajo za spremljanje NPOR. Postopek priprave Vodiča v okviru EPAAC JA je potekal v treh na novo ustanovljenih delovnih skupinah. Glavna delovna skupina (GDS) za NPOR je delovala kot osrednja skupina, odgovorna za delo pri razvoju Vodiča. Sestavljali so jo strokovnjaki s področja programov za raka iz Belgije, Irske, Italije, Malte, Nizozemske, Španije in Slovenije. Skupina se je ukvarjala s pripravo osnovnih dokumentov, vprašalnikov in analiz. Predstavniki držav članic, Islandije in Norveške ter regijskega urada SZO za Evropo, predstavniki Evropskih regionalnih in lokalnih zdravstvenih organov (EUREGHA) in Evropskega observatorija za zdravstvene sisteme in politike (Observatorij) so oblikovali drugo delovno skupino z imenom Delovna skupina za NPOR (DSNPOR). Skupina je pregledovala in dopolnjevala informacije, ki jih je pripravila GDS. Usmerjevalni odbor (UO) je bil tretja delovna skupina. Sestavljali so ga predstavniki EK, DSNPOR, usmerjevalnega odbora projekta EPAAC JA in Mednarodne agencije za raziskave s področja raka (angl. *International Agency for the Research on Cancer-IARC*), Evropske koalicije bolnikov z rakom in industrije, pa tudi neodvisnih strokovnjakov. Skupina je pregledovala vse delo in sprejemala končne odločitve (Radoš Krnel idr., 2013).

Delo na Vodiču je obsegalo tri kroge posvetovanj, strokovno izdelavo in pregled osnutkov poglavij. Vzpostavljenih je bilo več metodoloških pristopov, kot so osebna posvetovanja v okviru GDS, priprave osnutkov ter usklajevanja poglavij z uredniškim in s strokovnim delom svetovalnega tima. Delo na Vodiču se je začelo leta 2011, ko je bila izvedena raziskava o značilnostih NPOR v EU (Gorgojo idr., 2012). Vse evropske države članice, Islandija in Norveška so bile povabljene, da aktivno sodelujejo in odgovorijo na vprašalnik. Raziskavo je pripravila GDS, odobrila jo je DSNPOR. Analiza programov je temeljila na njihovi skladnosti s smernicami SZO, vključevanju strukturnih in procesnih kazalcev ter samoocenjevanju držav članic. Odgovori so prispevali k celovitemu pregledu in oceni razmer v EU, v Islandiji in na Norveškem glede razpoložljivosti programov oz. dokumentov o raku in njihove vsebine. Odgovori so pripomogli k prepoznavnosti skupnih točk in razlik med državami. Manj razlik je bilo

na področjih, ki ponavadi služijo kot podlaga za NPOR, kot so epidemiološka situacija, prednostne naloge, razvoj presejalnih programov ter zagotavljanje zdravstvenih storitev. Po drugi strani smo se seznanili s pomembnimi neskladji na področju paliativne oskrbe, psiho-onkoloških storitev in ekonomike raka, ocenjevanja zdravstvenih tehnologij (angl. Health Technology Assessment-HTA) in primarne oskrbe pri zdravljenju bolnikov z rakom. Rezultati raziskave so bili objavljeni v poročilu z naslovom »NPOR: Analiza primarnih podatkov iz vprašalnikov« (Poročilo), ki je na voljo tudi na spletu (Gorgojo idr., 2012). Poročilo je opisalo stanje NPOR v EU in je predstavljalo bistveno orodje za pripravo Vodiča.

Vodič je sestavljen iz desetih tematskih poglavij (Albreht idr., 2015), ki so razvrščene v tri ključne sklope - preprečevanje raka, celostna oskrba in podporne funkcije v zdravstvenem sistemu:

I. Preprečevanje raka: a) primarna preventiva in krepitev zdravja, b) presejanje in zgodnje odkrivanje raka

II. Integrirana oskrba: a) diagnoza in zdravljenje, b) psihosocialna onkološka oskrba, c) preživetje in rehabilitacija, d) konec življenjske dobe in paliativna oskrba

III. Podporne funkcije v zdravstvenem sistemu: a) upravljanje in financiranje, b) viri, c) podatki in informacije o raku, d) raziskave.

Struktura Vodiča temelji na predstavitvi dobrih praks držav članic z dolgoletno tradicijo NPOR, pa tudi na smernicah, ki jih je pripravila SZO (WHO, 2002; Howard, 2008). Glavni cilj Vodiča je zagotoviti opis storitev za nadzor raka, ki naj bi jih nudili nacionalni zdravstveni sistemi, in predlagati seznam kazalnikov, ki jih države lahko upoštevajo, da bi izboljšale spremljanje in oceno svojih programov. Cilj Vodiča je tudi spodbuditi določeno zблиževanje nacionalnih pristopov pri načrtovanju NPOR za lažjo primerjavo programov znotraj EU. Vse to bi namreč olajšalo čezmejno sodelovanje (Albreht idr., 2015).

Vodič, ki je eden ključnih izdelkov EPAAC JA je edinstveno orodje za upravljalce zdravstvenih sistemov in oblikovalce politike, ki želijo izboljšati svoj NPOR ali razviti novega. Po drugi strani pa je v Vodiču navedena vrsta kazalnikov, ki so pomagajo državam pri spremljanju in oceni svojih trenutnih programov. Vodič je na voljo v tiskani različici na NIJZ v Ljubljani in v elektronski različici (Albreht idr., 2015). Besedilo ne stremi k togi predlogi, ampak je prilagodljiv vodič za zdravstvene delavce, strokovnjake za raka in oblikovalce politik v zdravstvu. Vodič predstavlja pomoč državam, ne more pa biti predpisujoč, saj bi to pomenilo usklajevanje zdravstvenih sistemov v državah članicah. Poleg tega pa ni nujno, da se skupine programskih elementov, opisanih v Vodiču, izvajajo v celoti, saj morajo biti nacionalne politike vedno prilagojene zdravstvenemu sistemu v posamezni državi, njegovim virom in prednostnim nalogam (Albreht idr., 2015).

Pričujoči Vodič je bil pripravljen v okviru projekta EPAAC JA. Rezultati raziskave o NPOR v Evropi, ki so bili objavljeni v poročilu z naslovom »NPOR: analize primarnih podatkov iz vprašalnikov«, so bili uporabljeni kot osnova za pripravo Vodiča (Gorgojo idr., 2012). Dejansko je poročilo pokazalo raznolikost pristopov, ki se uporabljajo v NPOR v evropskih državah, na Norveškem in v Islandiji. Kot prednost

metodologije pri nastanku Vodiča lahko navedemo sodelovanje in občutek vključenosti vseh evropskih držav članic, Norveške in Islandije, zaradi česar imajo nastali Vodič za svoj izdelek in ga posledično uporabljajo. Projekt EPAAC JA je torej ponudil priložnost za združitev moči evropskih držav na področju raka in razvoj Vodiča, ki je še vedno prvi in edinstven tovrstni dokument v Evropi. Kasneje je skupina tujih avtorjev opravila analizo NCCP na globalnem nivoju, ki je bila objavljena leta 2018 (Romero in sod., 2018), leto kasneje pa je bil objavljen nekakšen kontrolni seznam ključnih elementov, ki naj bi jih vseboval NCCP; objavljen je v obliki članka (Oar et al., 2019). Evropski vodič, ki ga predstavljamo, omogoča državam, da lahko natančno preučijo predvideno vsebino in ustrezno razvijejo vse njene elemente, ne da bi pri tem pozabile na lastno organizacijo zdravstvenega sistema, na prednostne naloge in razpoložljive vire. Vodič je zamišljen kot živ dokument. Države, pacienti, organizacije pacientov, znanstvene in strokovne skupnosti po vsej EU so vabljeni k posredovanju predlogov za njegovo izboljšanje. Posodobljena verzija Vodiča bo verjetno pripravljena v enem izmed prihodnjih evropskih projektov s področja raka.

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