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INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Co-funded by
the Health Programme
of the European Union

Recommendations on the inclusion of Patient Pathways, Quality Indicators, PROMS, and the implementation of Comprehensive Cancer Care Networks in the updates of National Cancer Control Programmes

WP 10 - Governance of Integrated and Comprehensive Cancer Care

Task 10.2 – National Cancer Control Programmes

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Version: Date:	Final 8 December 2021

These Recommendations arise from the Innovative Partnership for Action Against Cancer Joint Action, which has received funding from the European Union through the Consumers, Health, Agriculture and Food Executive Agency of the European Commission, in the framework of the Health Programme 2014-2020. The European Commission is not responsible for the content of this recommendations. The sole responsibility for the recommendations 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. The authors are not responsible for any further and future use of the recommendations by third parties and third-party translations.

Contents

Abbreviations

CHAFEA	Consumers, Health, Agriculture and Food Executive Agency
CCCN	Comprehensive Cancer Care Network
EORTC	European Organisation for Research and Treatment of Cancer
EU	European Union
GIN	Guideline International Network
iET-QI	iPAAC evaluation tool for quality indicators
iPAAC	Innovative Partnership for Action Against Cancer
iPa^2-Guide	iPAAC Patient Pathway Guide
IRB	Internal Review Board
ICHOM	International Consortium for Health Outcomes Measurement
ISOQOL	International Society for Quality-of-Life Research
JA	Joint Action
NCCP	National Cancer Control Programme
MS	Member State
PREMS	Patient Reported Experience Measures
PROMS	Patient Reported Outcome Measures
SoS	Set of Standards
QIs	Quality Indicators
WP	Work package

Executive summary

The Recommendations on the inclusion of Patient Pathways, Quality Indicators, Patient Reported Outcome Measures (PROMS) and the implementation of Comprehenisve Cancer Care Networks (CCCNs) in the updates of National Cancer Control Programmes (NCCPs) in order to govern national oncological care were prepared in the frame of Work Package (WP) 10 - Governance of Integrated and Comprehensive Cancer Care, as part of the Innovative Partnership for Action Against Cancer Joint Action (iPAAC JA).

The work regarding WP 10 was devided into five Tasks: Task.10.1 National Cancer Control Programmes, Task 10.2 Patient Pathways, Task 10.3 Quality Indicators, Task 10.4 PROMS and Task 10.5 Implementation of CCCNs. Outcomes of all mentioned Tasks are included in the this document, entitled „Recommendations on the inclusion of Patient Pathways, Quality Indicators, PROMS, and the implementation of Comprehensive Cancer Care Networks in the updates of National Cancer Control Programmes".

The recommendations with respective performance measures that are presented in the document are intended to improve the European NCCPs which are key documents in the field of cancer control. These clear recommendations are also paving the way for the new version of the European Guide for Quality National Cancer Control Programmes which was published in 2015 in the frame of the project European Partnership for the Action Against Cancer Joint Action (EPAAC JA) and was defined as a living document.

The survey on the current European NCCPs which was prepared in collaboration with the members of the working group of Task 10.1 - NCCPs was curried out as one of the initial tasks of WP 10. All 34 countries involved in the research completed the survey. Regarding the quality, the survey was focused on some key elements that quality NCCPs or similar cancer documents should include: patient pathways, quality indicators, PROMS and implementation of CCCNs. Patient pathways and quality indicators were addressed in less than two thirds of the countries. CCCNs were implemented or partially implemented in less than two thirds of countries. PROMS were not addressed in the national nor regional cancer documents in 20 countries. These results suggested that the quality of NCCPs and/or other cancer documents should be improved with regard to the inclusion of patient pathways, quality indicators, PROMS and implementation of CCCNs in the updates of the programmes.

On the basis of an extensive research the recommendations with respective performance measures presented in this document were prepared in order to update the NCCPs and govern national oncological care, as well as to update the European Guide for Quality National Cancer Control Programmes.

1 Introduction

Innovative Partnership for Action Against Cancer Joint Action (iPAAC JA) is the third consecutive JA in the field of cancer supported and co-financed by European Commission (EC) which indicates the high level of awareness of the EC regarding this public health problem.

Since the beginning of the 21st century a number of EU Member States (MSs) have started to develop, publish and implement National Cancer Control Programmes (NCCPs) which are key documents in the field of cancer control. Health systems can respond to population needs regarding cancer only through adequate planning.

A NCCP is a public health programme designed to reduce the number of cancer cases and deaths and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies for: prevention, early detection, diagnosis, treatment, rehabilitation, palliation, research, etc. to search for innovative solutions and evaluate outcomes (WHO, 2002; Albreht et al., 2013). It is designed with the aim of making the best use of available resources.

A NCCP promotes the development of care management guidelines, places emphasis on the prevention of cancers or early detection of cancer cases so as to increase the possibility of cure and better control and faster return to pre-diagnosis life, and plan for the provision of services that will seek to offer as much comfort as possible to patients and their carers with advanced or incurable disease.

The quality of NCCPs is therefore of key importance. In the frame of European Partnership for the Action Against Cancer (EPAAC) JA the first and unique document of its type in Europe, entitled European Guide for Quality National Cancer Control Programmes (Guide) was prepared (Albreht et al., 2015). The Guide is an effective tool for health system administrators and policymakers in the field of cancer who wish to improve or implement their NCCP or to develop a new one. Furthermore, in the Guide there are series of structural, process and outcome indicators that countries may consider in order to improve the monitoring and evaluation of their current programmes. The Guide was defined as living document and will need to be supplemented.

In the frame of WP 10 – Governance of integrated and comprehensive cancer care of the iPAAC JA we reviewed and assessed the existing European NCCPs on the basis of a survey which was prepared within the working group. We found out how some important elements (Patient Pathways, Quality Indicators, Patient Reported Outcome Measures – PROMs and Implementation of Comprehensive Cancer Care Networks - CCCNs) are addressed in the existing European NCCPs.

The recommendations on how the above-mentioned elements could be included in the updates of NCCPs in order to govern national oncological care presented in this publication were developed through a consensus process within in the WP 10 working group of experts. They are paving the way for a new version of the Guide which needs to be updated.

1.1 Specific objectives of the Task 10.1

Specific objectives of the Task 10.1 were:

- To review and assess the existing European NCCPs and to find out if and how the elements of WP 10 Patient Pathways (Task 10.2), Quality Indicators (Task 10.3), Patient Reported Outcome Measures - PROMS (Task 10.4) and Implementation of Comprehensive Cancer Care Networks (Task 10.5) are already addressed,
- To develop the recommendations with performance measures through a consensus process within in the working group on how the results of tasks 10.2-10.5 could be included in the updates of NCCPs in order to govern national oncological care.

1.2 Survey on NCCPs

The work started with a survey on NCCPs which was prepared in collaboration with members of the working group of Task 10.1 NCCPs. The surveyed countries were identified, as well as the officials involved in cancer programmes in the surveyed countries who would complete the survey. A list of e-mails of potential responders was prepared as well. It was decided to send the survey to each contact person separately.

In the period from September to December 2018 the survey was sent to the following countries:

Austria, Belgium, Bulgaria, Croatia, Cyprus, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Montenegro, the Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovak Republic, Slovenia, Spain, Sweden, Turkey, England and Wales from United Kingdom. The countries had three weeks of time to respond. In cases of non-respondents the reminders and phone calls were planned.

All countries completed the survey, the response rate was 100 **%**. Based on the analysis of the completed surveys, the so called Report on the basis of the analysis of data from the survey on National Cancer Control Programmes/Cancer documents in EU (Jelenc & Albreht, 2019) was prepared.

Two countries (Belgium and Netherlands) who completed the survey did not have a NCCP, one country (Croatia) prepared a draft document. Sixteen countries reported they have a single document and sixteen countries reported that they have several documents addressing cancer. Regarding the type of the document countries reported they have programmes, plans, strategies and that they use other names or mixed terminology as well. The number and types of different cancer documents reported by countries are presented in Table 1.

Type of document	Number of countries
Programme	11
Plan	7
Strategy	5
Other or mixed terminology	9

Table 1. Number of different types of cancer documents reported by countries

Regarding the quality of the NCCPs/Cancer documents the survey was focused on some key elements that quality NCCPs/Cancer Documents should include. These are: Patient pathways, Quality indicators, Patient reported outcome measures-PROMS and the Implementation of CCCNs. Analysing the results of the survey we found out that patient pathways and quality indicators are addressed in less than two thirds of the countries

Regarding the implementation of CCCNs the situation is similar; CCCNs are implemented or partially implemented in less than two thirds of countries

Inclusion of PROMS in NCCPs is not satisfactory. In fact, in twenty countries PROMS are not addressed in the national nor regional cancer documents.

We concluded that the quality of NCCPs or other cancer documents should be improved. More attention should be payed to the inclusion of Patient pathways, Quality indicators, PROMS and Implementation of CCCNs. All these elements should be included in the updates of the NCCPs which does not cover these topics at the moment.

Literature

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2 Recommendations

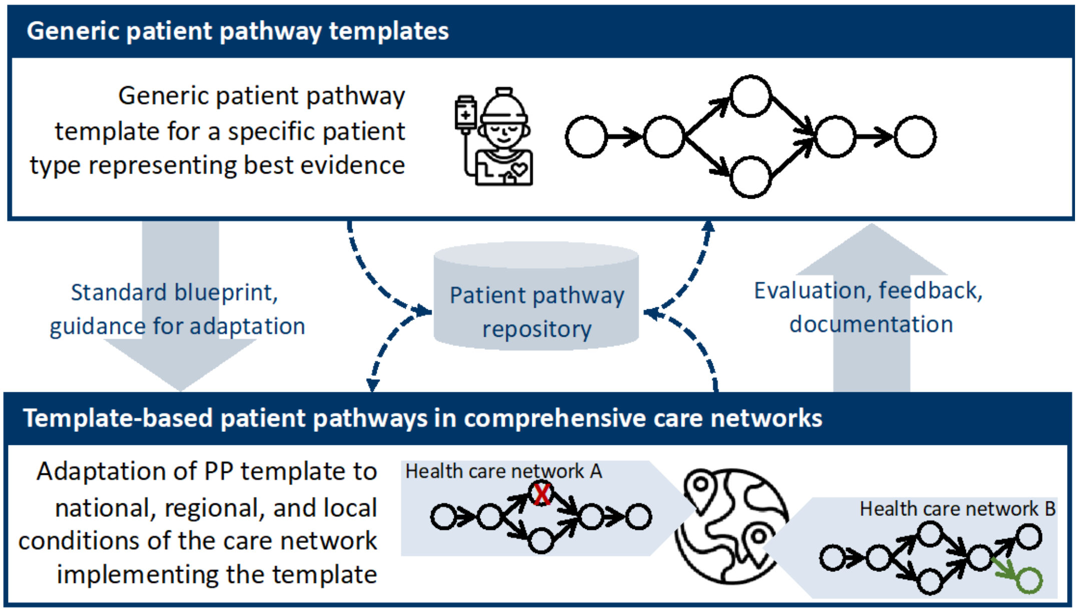
2.1 Description of the Task 10.2 Patient Pathways

In order to coordinate cancer care on the national level and to increase access to quality cancer care, the implementation of CCCNs is recommended by the European Guide on Quality Improvement in Comprehensive Cancer Control (Cancon Guide - Albreht et al., 2017). One of the CCCNs' tasks is the provision of practical support tools. In this context, comprehensive, integrated patient pathways are recognised as a valuable approach (Albreht et al., 2017). Whereas,the term patient pathway is often used with regard to optimising cancer care processes and aligning information and communication flows, there are still central elements missing. These are:

1. A common terminological basis and understanding of the patient pathway concept and
2. A methodical support for the development of patient pathways on national and network level.

In the light of these gaps, Task 10.2 (Patient Pathways) addressed the development of an agreed definition of patient pathways as well as of a method for creating and implementing patient pathways to be used in CCCNs and its units. These objectives were achieved by analysing the state of the art and practice of patient pathways (Richter & Schlieter, 2019a, Richter & Schlieter 2019b) and by applying a requirements-base, user-centred approach to develop a consolidated patient pathway framework as methodical basis for patient pathway development and implementation (Richter & Schlieter, 2020, 2021).

The patient pathway method uses a template approach, which is highlighted by the development and implementation of evidence-based patient pathway templates for defined tumour entities. Such templates function as generic frames to be adapted to the individual conditions and environments of specific CCCNs. The template-based patient pathway approach is illustrated with Figure 1.



Icons made by Freepik and srip from www.flaticon.com

Figure 1. The template-based patient pathway approach for CCCNs

2.1.1 Main results

Task 10.2 has the following main results in the realm of patient pathways:

- A **patient pathway definition** was developed and agreed by the members of WP10. The definition comprises the fundamental characteristics and scope of patient pathways as follows (Richter & Schlieter, 2019a, Richter & Schlieter, 2019b):

  > *A patient pathway is an evidence-based tool that supports the planning and management of the care process of individual patients within a group of similar patients with complex, long-term conditions. It details the phases of care, guiding the whole journey a patient takes by defining goals and milestones, and supports mutual decision-making by the patient and his/her multidisciplinary care team collaborating in a comprehensive network of care providers.*

- The iPAAC Patient Pathway Guide (short **iPa^2-Guide**) was developed and agreed upon. It is a practical handbook summarising the scientific findings within Task 10.2 and describes the creation of generic patient pathway templates and their adaptation to national, regional and local conditions of CCCNs. In the iPa^2-Guide, the roles to be involved in the development and implementation process and the phases and steps of patient pathway development and implementation are described in detail. A set of minimum requirements of patient pathway implementation in CCCNs was developed and agreed upon. Patient pathway implementation recommendations are given.

  By applying the iPa^2-Guide, **patient pathway templates for colorectal and pancreatic cancer care in CCCNs** were developed, agreed and provided. The templates were tested in two iPAAC WP10 pilot sites in Poland and Germany by adapting and implementing them.

  Links to the patient pathways templates for colorectal and pancreatic cancer:

  - https://www.ipaac.eu/res/file/outputs/wp10/patient-pathway-template-crc.pdf

  - https://www.ipaac.eu/res/file/outputs/wp10/patient-pathway-template-pancreas.pdf

- A practical **patient pathway repository and development tool** is provided by the Task 10.2 leaders[1]. It supports the development, management and provision of patient pathway templates as well as the adaptation of these templates to CCCN specifics.

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2.1.2 Recommendations with performance measures

The following recommendations should be considered on the inclusion of patient pathways in the updates of NCCPs.

1. Recommendation: Include the patient pathway definition in the NCCP documents and promote its use to establish a nationally uniform terminological basis and understanding

Performance Measure: The patient pathway definition as explicit component is included in the NCCP.

2. Recommendation: Appoint a responsible patient pathway unit on national level to strategically manage and coordinate all patient pathway related activities as well as to support CCCNs with the adaptation and implementation of patient pathways.

Performance Measure: A responsible patient pathway unit is appointed and its role is specified. The responsible patient pathway unit should be adequately funded to fulfil its tasks.

3. Recommendation: Use a sound methodological approach such as the iPa2-Guide to develop, implement, evaluate and continuously improve generic patient pathway templates for the tumour entities of interest as part of the NCCP and to adapt patient pathway templates to national conditions.

Performance Measure: Generic patient pathway templates for the tumour entities of interest are provided on national level and the development, implementation and evaluation processes on national level are defined and communicated.

4. Recommendation: Establish and maintain a national electronic patient pathway template repository to manage the development, provision, revision and adaptation of patient pathway templates for CCCNs. Try to ensure the interoperability with other national / European electronic patient pathway template repositories in oncology, to be used in CCCN.

Performance Measure: A central electronic patient pathway template repository is deployed and maintained.

5. Recommendation: CCCNs should establish a continuous patient pathway management process to monitor, evaluate and improve patient pathways by using corresponding quality and performance indicators.

Performance Measure: A continuous monitoring and evaluation process for patient pathways in CCCNs (and in relation to national patient pathway templates) on the basis of quality and performance indicators (for example: adherence to pathways, evaluation of pathways) is defined and established.

6. Recommendation: CCCNs should develop and implement their network-specific patient pathways by adapting the patient pathway templates provided on national level, whenever necessary.

Performance Measure: Number of CCCNs that adapted the patient pathway template for a tumour entity of interest.

Literature

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Richter, P. and Schlieter, H. (2021). Patient Pathways for Comprehensive Care Networks – A Development Method and Lessons from its Application in Oncology Care. In Proceedings of the 54th Hawaii International Conference on System Sciences (HICSS 2021), pages 3753-3763. URL: http://hdl.handle.net/10125/71071 (last accessed: 17.05.2021)

2.2 Descriptions of the Task 10.3 Quality Indicators

Oncological quality indicators (QIs) are measures that make the quality of the structures, processes and results of care visible. With their help, improvement potential can be identified and used in the sense of a Plan-Do-Check-Act cycle for continuous quality development. This makes them an important instrument for the management of oncological care: at the level of those providing treatment and at the level of policy makers (Follmann et al., 2020).

The European Guide on Quality improvement in Comprehensive Cancer Control (CanCon Guide) recommends that quality of care within the CCCN should be measured with quality indicators (Albreht et al., 2017).

Quality indicators should be simple, tumour specific and whenever possible evidence-based and uniform throughout the CCCN and between CCCNs. When deciding on the use of QI sets, already validated QIs that have shown that they can be applied and measured in routine oncology care should be prefered. This avoids the definition of new QIs, which are often not measurable, and at the same time ensures that the same QI sets are used in CCCNs in different MS, thus making the quality of care comparable on a broad level. (Albreht et al., 2017).

Within the framework of Task 3 of the iPAAC WP10, two tumour-specific QI sets for colorectal cancer and pancreatic cancer were developed with the help of the iET-QI methodology tool (iET-QI = “iPAAC evaluation tool for QI”). The process is described below.

2.2.1 Main results

A systematic literature review was performed with two aims. First, to identify QIs already implemented in clinical oncological practice. Second, to retrieve the description of the methodology processes used to derive these QIs.

Link: https://www.ipaac.eu/en/work-packages/wp10/ -> quality-indicators-systematic-review-evaluation-comprehensive-cancer-care-network.pdf

Since the systematic review provided only a limited number of implemented indicators with reported results, an additional search was conducted on websites of European quality assurance institutions in oncology. The search focused on colorectal and pancreatic carcinoma as the work within WP 10 concentrated on these two tumour entities to ensure synergies with other iPAAC work packages and European initiatives. Based on the results of the reported methodology in publications identified by the systematic review and the additional search on homepages of national and international quality assurance organizations, the iPAAC Evaluation Tool for Qis in oncology (iET-QI) was developed to assess the identified QIs. The methodological steps are reported according to the reporting standards for guideline-based performance measures of the Guideline International Network (GIN).

Link: https://www.ipaac.eu/en/work-packages/wp10/ -> quality-indicators-methodology-comprehensive-cancer-care-network.pdf

The iET-QI-methodology was used to create the final set of 40 QIs for the treatment and care of colorectal and pancreatic cancer. This set of indicators were implemented in two pilot CCCNs in the course of WP 10 with the aim of pilot testing the validity of the QI set for the assessment of quality of care within CCCNs.

Link: https://www.ipaac.eu/en/work-packages/wp10/ -> quality-indicators-colorectal-pancreatic-cancer-care.pdf

2.2.2 Recommendations with performance measures

The following recommendations should be considered:

1. Recommendation: Include the iET-QI (iPAAC Evaluation Tool for QIs in oncology) and the QI sets for colorectal and pancreatic cancer in the NCCP documents and promote their use to establish a consistent approach to quality measurement, benchmarking and improvement nationwide.

Performance Measure: The iET-QI instrument and the tumour-specific QI sets for colorectal and pancreatic cancer are included in the NCCP.

2. Recommendation: Apply the iET-QI tool on national level to develop further tumour-specific QI-sets and use them for quality transparency and improvement in CCCNs. Unless there is another established tumour-specific QI set already in use nationally.

Performance Measure: QI sets for the most common tumour entities are compiled using the iET QI methodology.

3. Recommendation: The QI sets are in use in the tumour-specific centres of the CCCN.

Performance Measure: Number of CCCNs that have implemented the developed QI sets.

4. Recommendation: An infrastructure for the collection of the QIs should be in place. To ensure comparability of the results, nationwide documentation solutions should be adopted.

Performance Measure: Number of CCCNs that use an electronic data documentation infrastructure for reporting the QIs.

5. Recommendation: The results of all collected Qis should be compiled and evaluated annually, if possible nationwide.

Performance Measure: There are structures in place and responsible persons appointed to prepare the reports, nationwide and/or in the CCCNs. Annual QI reports are available, nationwide and/or in the CCCN.

6. Recommendation: The results of the QIs are to be analysed annually nationwide and/or in the CCCNs (see PM 5). According to the results, measures are to be agreed upon to enable the further development, nationwide and/or in the CCCN (implementation Plan-Do-Check-Act cycle).

Performance Measure: There is a documented overview of the evaluation and the agreed upon improvement measures (if necessary), on nationwide and/or CCCN level.

Literature

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2.3 Description of the Task 10.4 Patient Reported Outcome Measures - PROMS

Strengthening the patient's voice is critical for patient-centered healthcare. Taking the patient's voice into account is not limited to the involvement of the patient in informed treatment decision making but includes collecting patient-reported experience and outcome measures in routine care. Patient-reported experience measures (PREMs) typically focus on structures and processes of care and allow for the identification of strengths and weaknesses of the care provided and the development of measures to improve care. Typically, such an approach uses comparisons of different providers ("benchmarking"). Patient-reported outcome measures (PROMs) may be used for the same purposes when implemented in routine care and can in addition be used for treatment decision making, for example, when impaired functioning is identified through a standardized quality of life instrument. If the patients have different symptoms and functioning before an intervention (typically the case), using PROMs for provider comparisons requires the collection of PROMs at least twice to identify changes that result from an intervention: before an intervention (e.g., the hospital stay) and after.

The aim of task 10.4 was to give guidance for the implementation of PROMs and PREMs in routine cancer care in CCCNs that serve the two described purposes: the use for treatment decision making and provider comparisons. A systematic literature review was conducted to identify existing multi-centric programs that are already implemented in routine cancer care in Europe that allow for both purposes. The review was limited to PROM programs that are considered the "higher hanging fruit" because they require the collection of information at least twice, before and after an intervention.

Five programs were identified that had published results at the time of literature search that revealed relevant information on existing PROM programs and gave valuable insight into issues that need to be considered when setting up such an infrastructure. Not all critical issues were addressed in these publications. To develop comprehensive recommendations, information was added from manuals on PROM implementation issued by International Society for Quality-of-Life Research (ISOQOL) and the European Organisation for Research and Treatment of Cancer (EORTC) Quality of life Group, as well as expert opinions.

The recommendations are meant to support CCCNs in implementing PROMs in routine care but are not limited to CCCNs. Instead, they may be helpful whenever PROMs are implemented in routine (cancer) care. They do not include recommendations related to necessary earlier steps, like the development and psychometric testing of PROM instruments.

2.3.1 Main results

Five programs were identified that had published results at the time of literature search that revealed relevant information on existing PROM programs and gave valuable insight into issues that need to be considered when setting up such an infrastructure. The results were published as an iPAAC report (Kowalski et al., 2019) and in a peer-reviewed journal (Scheibe et al., 2020). Not all critical issues were addressed in these publications. To develop comprehensive recommendations, information was added from manuals on PROM implementation issued by ISOQOL (ISOQOL 2015) and the EORTC Quality of life Group (Wintner et al., 2016), as well as expert opinions.

2.3.2 Recommendations with performance measures

To enable providers to better serve individual patients (e. g.: treatment of impaired quality of life) and to enable CCCNs to compare their own patient reported outcomes data with that of others (benchmarking), the task 4 working group of IPAAC JA WP 10 developed the recommendations for PROM implementation. The recommendations were deduced from the literature review undertaken by the same working group, complemented by results of existing manuals on PROM implementation issued by ISOQOL (ISOQOL, 2015) and the EORTC Quality of life Group (Wintner et al., 2016), as well as expert opinions during the discussion of previous versions of the recommendations. The recommendations are meant to support CCCNs in implementing PROMs in routine care. They do not include recommendations related to necessary earlier steps, like the development and psychometric testing of PROM instruments.

The following recommendations should be considered on the inclusion of PROMS in the updates of NCCPs:

1. Recommendation: Clarify the main objective(s) of PROM collection (screening/ monitoring vs benchmarking, or both) as well as the exact group(s) of cancer patients (e.g., kind of cancer, tumour stage and setting of care) in the NCCP. Decide if nationwide standards are needed.

Performance Measure: The NCCP contains a section on the objective of PROM collection in the MS.

2. Recommendation: Decide if and how to present PROMs to patients, providers, researchers, and the public (e.g., paper-based or integrated with the electronic health record; literal, numerical or graphical).

Performance Measure: Define the PROM audience (on national and/or CCCN level).

3. Recommendation: If nationwide standards are defined, decide which PROMs are essential and when PROM information is needed. Consider using an established international standard data set.

Performance Measure: (Only if the MS establishes nationwide standards): The NCCP contains a section on the basic dataset(s) collected. Established international standard data sets should be used.

4. Recommendation: Don’t forget the monitoring, revision, updating and future proofing of the PROM program.

Performance Measure: The NCCP contains a section on the monitoring, revision, updating and future proofing of the PROM program.

Literature

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2.4 Description of the Task 10.5 Implementation of Comprehensive Cancer Care Networks

Comprehensive Cancer Care Networks (CCCN) consist of multiple units belonging to different institutions dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation for the benefit of cancer patients and cancer survivors (Albreht et al., 2017). Within the network, the experts work together in a multidisciplinary manner in tumour-specific management groups or centres. The cooperation takes place, for example, in tumour boards and on the basis of cancer-specific patient pathways that are binding for the entire network. The objective of a CCCN is to provide comprehensive cancer care to all the people living in a certain geographic area, thus pursuing equality and the improvement of outcomes and quality (Albreht et al., 2017).

The quality of care is made transparent through quality indicators, which are used for a continuous quality improvement process. In addition to the QIs, patient-reported outcomes, as a central parameter of outcome quality, are another instrument with which the quality in the CCCN as a whole and at the level of the care providers can be measured, compared and improved.

Within the Task 10.5, a tumour-specific and a generic set of standards (SoS) for CCCNs were developed, which include the previously mentioned instruments and goals. In addition, a framework was defined to evaluate and promote the implementation of the SoS with a certification process. The overall concept was successfully implemented in pilot CCCNs in two MSs (Poland and Germany).

2.4.1 Main results

The working group has developed SoS that define which medical disciplines and professional groups are included in the CCCN and which standards for cooperation and communication must be met (including tumour boards, cooperation agreements, etc.). In addition, requirements for qualitative and quantitative expertise are specified for all specialists. Two SoS documents were prepared: a generic standard for the overall CCCN and a tumour-specific standard for centres focusing on the care of patients with colorectal cancer and pancreatic cancer. In the tumour specific SoS, the QIs developed in task 3 are included. In addition, the implementation of patient pathways (Task 2) and the integration of patient-reported outcomes (Task 4) were incorporated and have to be presented by the CCCNs.

Link to:

SoS CCCN: https://www.ipaac.eu/res/file/outputs/wp10/cccn-standard.pdf

SoS colorectal and pancreatic cancer care: https://www.ipaac.eu/res/file/outputs/wp10/cccn-standard-colorectal-pancreatic-cancer.pdf

Supporting Document for the Set of Standards for CCCNs: https://www.ipaac.eu/res/file/outputs/wp10/cccn-standard-supporting-document.pdf

In addition to the SoS, a framework was developed and agreed, which summarises the requirements that have to be fulfilled for a certification of CCCNs. This includes, among other things, the definition of the competences and division of power in the certification system into legislative, executive and judicative branch. As well as the definition of the documents that have to be submitted for certification, specifications for the auditor selection, organisation and their qualification and how the decision to award of the certificate shall be taken.

Link to European Framework for the certification of CCCNs in the course of iPAAC: https://www.ipaac.eu/res/file/outputs/wp10/cccn-certification-european-framework.pdf

All of the deliverables mentioned above (SoS, QI, PRO, Framework) have been successfully implemented in two pilot CCCN sites in two member states.

An accompanying external evaluation has assessed the implementation process, lessons learned and best practices as well as the feasibility of rolling-out the CCCN concept.

Link to: https://www.ipaac.eu/en/work-packages/wp10/ -> Results Pilot sites

For tumour-entities that are not yet addressed in iPAAC JA, you can contact the WP 10 leader Dr Simone Wesselman.

2.4.2 Recommendations with performance measures

The following recommendations should be considered:

1. Recommendation: The Comprehensive Cancer Care Network (CCCN) concept should be used for the organisation and management of oncological care in the NCCP, if applicable.

Performance Measure: CCCNs are designated nationwide and addressed in the NCCP.

2. Recommendation: CCCNs are adequately funded to fulfil their healthcare and research tasks.

Performance Measure: Transparent financing of CCCNs.

3. Recommendation: CCCNs should be organised in a binding and transparent manner and provide access to high-quality oncological care and innovation for all patients. CCCN members should have proven, tumour-specific qualitative and quantitative expertise.

Performance Measure: The Sets of Standards are applied for the designation of CCCNs.

4. Recommendation: The designation of CCCNs is done through an independent and accountable process.

Performance Measure: The contents of the European Framework for the certification of CCCNs in the course of iPAAC are applied.

5. Recommendation: CCCNs are used to evaluate the quality of oncological care nationwide. In the process, evaluations and the positioning of the networks compared to others nationally and internationally (anonymised, if small number of networks exist nationally) as well as between treatment partners within a network are to be prepared annually (please, see also Task 3).

Performance Measure: The annual reports on the quality of care in CCCNs are prepared using the QI sets (please, see Task 3) and other key performance indicators.

Literature

Albreht, T., Amati, C., Angelastro, A., Asioli, M., Amunni, G., Barcelo, A. M., Berling, C., Caraceni, A., Colamesta, V., Comiskey, K., Conroy, F., Hynes, M., Cusack, M., O'Connor, L., D'Angelo, D., Dusek, L., Kaasa, S., Kowalski, C., Lin, Y., Federici, A., Loupakis, F., La Torre, G., Luzzatto, L., Majiek, O., Nicoletti, G., Pasqualetti, G., Perez, R. P., Pigni, A., Puccetti, C., Rossi, E., Sant, M., Tognetti, J., Trama, A., and Wesselmann, S. (2017). Integrated cancer control: The case for comprehensive cancer care networks (CCCN). In Albreht, T., Kiasuwa, R., and Van der Bulcke, M., editors, European Guide on Quality Improvement in Comprehensive Cancer Control, pages 77–103. Ljubljana: National Institute of Public Health; Brussels: Scientific Institute of Public Health.

3 Conclusion

The review and assessment of the existing European NCCPs on the basis of a survey which was prepared in the frame of WP 10 - Governance of Integrated and Comprehensive Cancer Care working group, as part of the iPAAC JA showed that some important elements (Patient Pathways, Quality Indicators, Patient Reported Outcome Measures – PROMs and Implementation of Comprehensive Cancer Care Networks - CCCNs) are not adequately addressed.

In order to better govern the national oncological care in Europe the Recommendations on the inclusion of patient pathways, quality Indicators, PROMs, and the implementation of CCCNs in the updates of National Cancer Control Programmes with the respective performance measures were prepared.

These clear recommendations with performance measures are also paving the way for the new version of the European Guide for Quality National Cancer Control Programmes which was published in the frame of the EPAAC JA in 2015 and defined as a living document; it needs to be updated.