

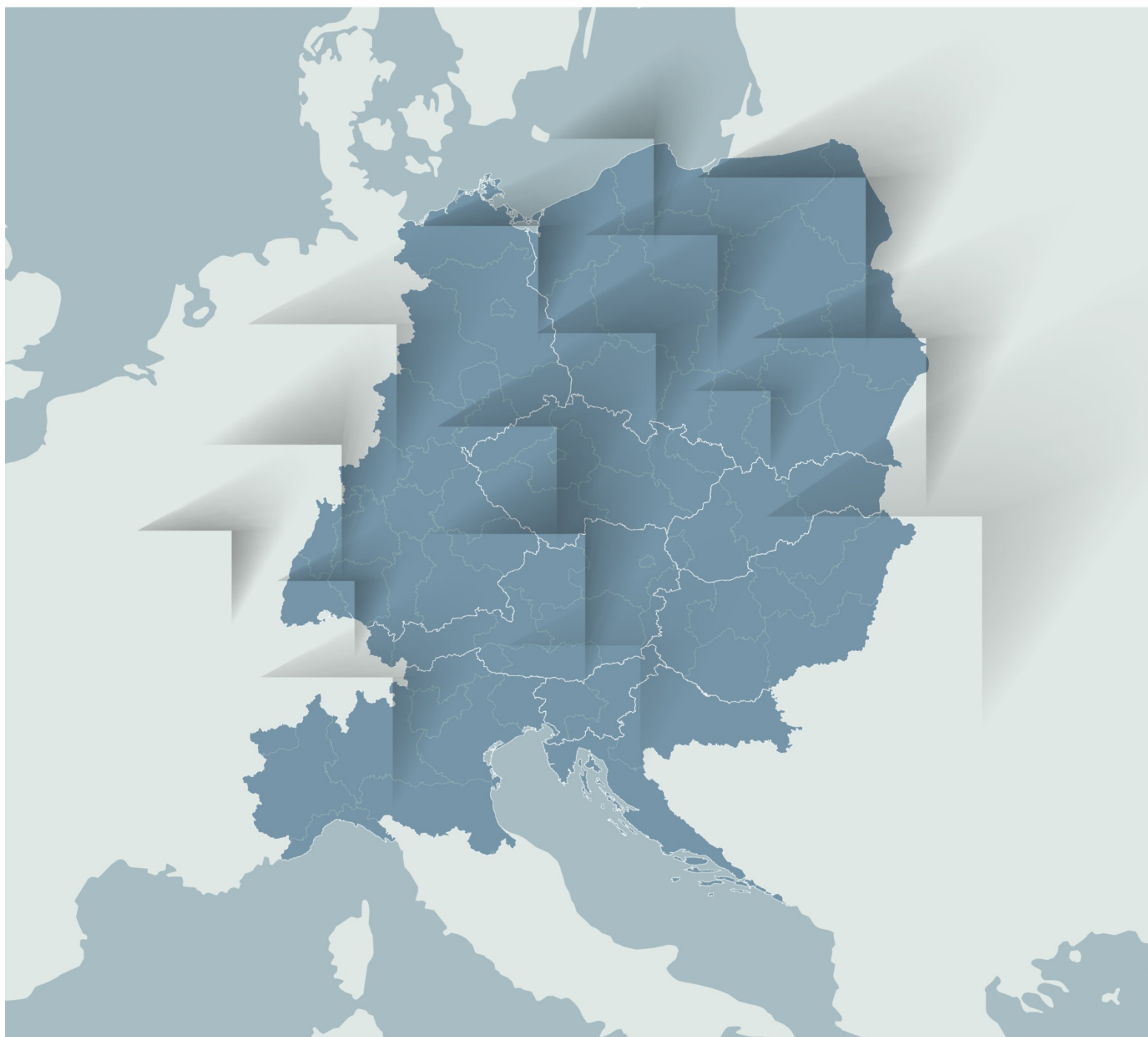
# INTENT

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Policy recommendations for adopting  
the patient-centred model and  
guidelines - Version 5

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Outline



INTENT partners are facilitating Patient Centred Cancer Care (PCCC) model in five pilot regions: Budapest (HU), Slovenia (SI), South Moravia (CZ) and the Veneto and Friuli Venezia Giulia regions (IT). Based on research, implementation guidelines for the INTENT PCCC model were developed in order to foster change within existing health care organizations (e.g. cancer care centres or cancer care networks). It is envisaged that implementing the PCCC model would have positive consequences also for broader society. With its focus on patient needs new jobs and positions are to be developed. In order to provide care in all stages of the disease new e-Health tools and various forms of Social Entrepreneurship are to be employed. At the same time, successful implementation of the PCCC model is dependent on numerous broader social circumstances outside of the sphere of influence of existing healthcare organizations and policies in the field of cancer care need to be tackled as well. Current state of these policies was detailed in the Report on policy mapping across the five pilot regions.

Hereby, Policy Recommendations for adopting the patient-centred model and guidelines before you are integrating findings from Implementation guidelines for the PCCC model and Report on policy mapping and thus summarizing them in the form of recommendations for policy makers, aiming to foster PCCC model. Policy recommendations are categorized in accordance with the Report on policy mapping in three Focus areas: Cancer Care Models, Patient Empowerment and Performance monitoring. The Fourth Focus Area (Innovation in organization of cancer care) from the report was integrated in the first two Focus Areas.

Further discussion with the project partners will provide an identification of entry points in participating Health Ministries to facilitate implementation of the policies.

## 1. Focus area 1 - Cancer care models

### 1.1. National/Regional Cancer Control Programs

- a) National Cancer Control Program (NCCP) is a crucial document for implementing Patient Centred Cancer Care. In the case of a regionalised healthcare system, Regional Plans are a point of reference.
- b) Specific national and regional contexts such as sources of financing and degree of decentralization are to be considered when developing a National Cancer Control Program to ensure its purpose, which is financing of its implementation.
- c) The adoption of additional cancer control documents is necessary at times in order to ensure the implementation of a comprehensive cancer plan.

### 1.2. Integration of care

- a) In order to foster multidisciplinary approach, that takes into account several disciplines and the medical, psychological and social needs of patients, decision makers need to reach a formal agreement about the patients' needs that the health system is going to try to satisfy through the care process in a document defining patient pathways.
- b) Multidisciplinary approach and patient pathways are shared throughout the region to guarantee equal treatment quality in the region and avoid discrepancies across the entire trajectory of cancer care.
- c) The algorithms of patient pathways are to be established for the course of specific types of cancers.
- d) Enhancing quality of life of patients in one of the primary goals of clinical patient pathways. Nutrition, rehabilitation (physical, socioeconomical), and psychological are part of the cancer care pathway.

- e) Nurses and supportive disciplines (e.g. rehabilitation, nutritionist, psycho-oncologist, palliative expert) are part of the MDTs. Volunteer patient organisation provide valuable information for patients and their relatives.
- f) Responsibility for patient's care needs to be allocated in every step of the patient pathway.
- g) Case managers are to be integrated in the care team. Case managers should be recognized and reimbursed according to their position within the organisation, education and training.
- h) Local health authorities need to make sure with patient referrals that patients receive the care in accordance with the patient pathways, regardless of whether all the necessary services are available within that local health authority. This also includes the right to be included in the clinical trials.
- i) A strategy and organisational tools are in place to guarantee that care and research are bound together, and the results of research are timely transferred to care and vice versa.
- j) Integrating ICT tools and Internet of Things and thus improving IT infrastructure is an opportunity for collaboration among stakeholders (research centres (e.g. universities), data science departments, computational centres, or private enterprises) and in this way enhance patient navigation in the healthcare system.
- k) Verbal and non verbal communication skills are very important since the preferred channel of communication for patients is one-to-one meeting with health professional. Organize/require communication training of the care team (for instance USA and Canada implemented in the MD certification the evaluation of MD communication skills; consequently, Universities implemented classes to prepare students to the examination).<sup>1</sup>

### 1.3. Cancer Care Networks

- a) Cancer Care Networks are the ideal management strategy to integrate partners. Furthermore, this strategy helps to overcome resource constraints, helps to evolve accessibility, improves efficiency, provides equal treatment quality and helps to avoid discrepancies in the region.
- b) The existing institutional connections in cancer care are to be formalized into clearly defined Comprehensive Cancer Care Network.
- c) The framework for establishing Comprehensive Cancer Care Networks CCCN are the guidelines issued by CanCon Joint Action. The model of a CCCN was successfully piloted. The guidelines are available here:  
[https://cancercontrol.eu/archived/uploads/images/Guide/pdf/CanCon\\_Guide\\_FINAL\\_Web.pdf](https://cancercontrol.eu/archived/uploads/images/Guide/pdf/CanCon_Guide_FINAL_Web.pdf).
- d) In the framework of iPAAC Joint Action, active from 2018 to 2021, there will be further piloting of CCCN in Berlin and Wrocław, the outcomes of which will feed further recommendations. Two Work Packages in the JA iPAAC directly dealing with patients' needs.<sup>2</sup>
- e) Cooperation is comprehensive and includes all stakeholders of the network: cancer related (comprehensive cancer centres, oncology clinics) and not (e.g. general hospitals, outpatient services at all levels, supportive disciplines and rehabilitation), social Entrepreneurship (e.g.

<sup>1</sup> <https://www.nejm.org/doi/full/10.1056/NEJMc1301008>

<https://www.nejm.org/doi/pdf/10.1056/NEJMp038246>

<https://jamanetwork.com/journals/jama/fullarticle/208633>

<sup>2</sup> a) JA Work Package 10 is concerned with further developing practical instruments ensuring a standardized integrated and comprehensive oncological care in all European member states which is tumour-specific and delivers all-encompassing high-quality care to all patients. iPAAC JA Work Package 8 deals with optimising the use of healthcare resources and promoting realistic and evidence-based responses to existing needs. More at <https://www.ipaac.eu/>.

- patients/caregivers and associations), General Practitioners (GPs), small and large private enterprises.
- f) An Information and Communication Technology system is in place to exchange information (e.g. patients' files) electronically among partners of the network. Patient records are kept in an electronic form.
  - g) It is advisable to install framework for sharing patient data among institutions participating in the network, as they are separate legal entities.
  - h) It is advisable that a threshold in the volume of activity is set for reimbursements. Activities can then be reshuffled according to specialization of each institution.<sup>3</sup>
  - i) If Cancer Care Networks can reduce costs, the budget surplus should stay in the Network's budget and be reinvested in amelioration projects to further implement PCCC.
  - j) Stakeholder<sup>4</sup> involvement is crucial for developing innovations in cancer care. When introducing innovation in cancer care consultation between health institutions providing health service and the payer of the service is needed. - pridružena točka
  - k) Procedures are in place to respond to patient needs (e.g. contact point that activate response to patient needs).
  - l) Home services and local health districts are to be encouraged and their services integrated with cancer care in order to provide continuity of care to cancer patients.
  - m) Network has in place screening tools to identify early signs that require intervention of supportive disciplines (e.g. distress screening, nutrition screening, etc) for patients. Psychological needs may arise in relatives, services for them should also be provided.
  - n) Equal opportunities in access to cancer care services (from screening, early detection, clinical trial enrolment, psychooncology services, rehabilitation, after care and palliative care) need to be ensured to all cancer patients.

## 2. Focus area 2 - Patient empowerment

- a) Patient orientation within the healthcare system is crucial, hence patients must be fully informed on the processes related to their access to the treatment, continuation of care and options available to them and to be able to identify specific person they refer to for additional information (case managers, oncologist, psychologist).
- b) All disciplines responding to patients' needs (e.g. psycho-oncology, nutritionist, rehabilitation specialists, including spiritual support) should be on demand and already available since the early stage of the disease (e.g. diagnosis, first treatment), including after hospital discharge. Maintaining high quality of patients' lives increases the continuation of treatment.
- c) Psycho - oncological care is an integral part of cancer care and needs to be provided in variety of forms (individual expert consultation, peer support, volunteers, help phone lines, health visitors) at all points of cancer care.
- d) Patient involvement in consulting capacity is to be encouraged by engaging patient support organisations in developing, implementing and evaluating National Cancer Control Programmes.
- e) Patient needs are to be collected and considered also in the planning processes.

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<sup>3</sup> Example of such a plan - Slovenian National Cancer Plan- is available at <http://www.dpor.si/eng/>.

<sup>4</sup> Stakeholders consist of 3 main categories: 1. Health professionals, 2. Patients and their relatives and 3. Policy makers.

- f) Programs of health literacy are to be implemented and widely promoted cancer patients, caregivers and among interested general public.
- g) Patient education programmes Implementation, promotion and monitoring of patient education programmes is needed.
- h) It is beneficial, that outpatients are able to collect health related information (access to their medical records) remotely through ICT systems (eHealth and mHealth) and transfer them to the care team while at the same time all the security standards are satisfied.
- i) Timeliness of provided cancer care is instrumental for outcomes, comprehensive cancer care management and for patients' psychosocial wellbeing.
- j) Survivorship and rehabilitation need visibility and recognition on the policy agenda.<sup>5</sup>
- k) The role of patient or caregiver advocates, patient support organisations is to be enhanced by their participation in shaping guidelines, multidisciplinary teams and representation in institutional bodies such as Scientific Boards or Patient Committees. Patient or Caregiver advocates are part of the clinical trial and Translational Research advisory board and together with other experts provide feedbacks to the board of Directors.<sup>6</sup>
- l) When planning new non-profit research projects patients' needs and patient organisations are to be included.
- m) The network, through the PE program, organizes focus groups between staff of the care team and patients on specific medical topic (e.g. breast cancer, supportive-rehabilitation services).

### 3. Focus area 3 - Performance monitoring

- a) After incorporating the recommendations it is essential to establish monitoring of the implementation in order to evaluate impacts and find further improvements if necessary. Performance assessment of comprehensive cancer care needs to be systematic and use tools for continuing quality improvement such as INTENT benchmarking tool. Existing OECI accreditation process provides such tools:  
<https://www.oeci.eu/Accreditation/Page.aspx?name=BACKGROUND>.
- b) Process of quality improvement needs to be continued. The INTENT online benchmarking tool provides this opportunity by focusing on how to improve clinical and patient outcomes, patient satisfaction, efficiency and cost effectiveness, social competencies and innovation capacity. The tool is composed from integrated new indicator sets (which were created by collecting experiences in pilot sites). Online benchmarking versions are improved by feedbacks from pilot sites. The feedback includes review from internal benchmarking teams about readiness of the tool for use and compatibility between the tool, management, and additional information systems.
- c) Cancer Control Programs need objective data to base activities on, monitor and assess the success of these activities. These objective data are often collected and presented as indicators. Some

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<sup>5</sup> Detailed overview of policy recommendation on survivorship is provided in Cancer Control Joint Action - Policy Papers. Ljubljana: National Institute of Public Health and Scientific Institute of Public health, Brussels, Belgium; 2017, p. 149-150.

<sup>6</sup> "Alliance for Clinical Trials in Oncology,"; Greene et al., 2018; "NCTN: NCI's National Clinical Trials Network," ; "Southwest Oncology Group Cancer Research Network,".

indicators can be used for performance assessment, some are important for planning health services and some indicators can be used for both purposes.

- d) When CCCNs are developing patient pathways, they need to develop performance indicators linked to them.
- e) MDT composition and activity should be monitored.
- f) Networks monitor waiting times and set maximum thresholds. Procedures are in place to act when waiting times are above set thresholds.
- g) The network has social accountability: the network communicates performance (patient outcomes, satisfaction, quality of life, research outcomes) to the patient committee that regularly meets with the board of directors or publicly.
- h) Patient quality of life is an indicator of the services provided and as such a part of the social accountability of the Network along with overall survival, treated patients, activity, etc...
- i) Network monitors quality of life in patients (thermometer distress, PROMS, PREMS, social distress) overtime and after hospital discharge (e.g. through mHealth solutions).

#### Glossary:

ICT systems - Information and communications technology systems such as eHealth and mHealth

MDT - Multidisciplinary Team

NCCP - National Cancer Control Programme is a public health programme designed to reduce the number of cancer cases and deaths and improve quality of life of cancer patients.

OECI - Organisation of European Cancer Institutes

PREMS - Patient Reported Experience Measures (Real time patient feedback)

PROMS - Patient Reported Outcome Measures