Interreg
CENTRAL EUROPE

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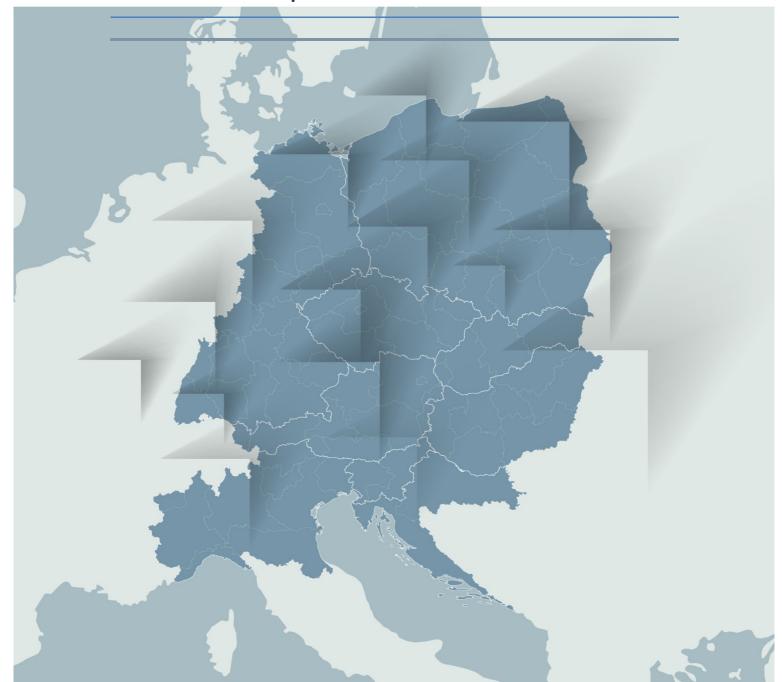# A Patient Centered Cancer Care Model and Implementation guidelines in the Central Europe.

Table of Contents

Introduction

Cancer is a leading cause of death in the EU; however, how we experience cancer is changing from an acute condition to one where survival rates are improving. People with cancer are living longer and in some cases it can be managed as a chronic illness. That said, survival usually decreases with age, although to different degrees depending on cancer type and region. The need for change in CE is challenging because public services in the newer EU Member States are still experiencing the impact of the 2007-2009 crises including static health care budgets, growing demand for care from ageing populations & a shortage of available staff. This also translates into disparities in access to & quality of care.

The shift in 'what cancer is' requires a more patient-centered approach to care. This approach should deliver more equitable access to care, harmonised and coherent care pathways, policy incentives for performance improvement and openness to more relevant and affordable innovations. This mirrors evidence that the acute hospital model is costly and economically unsustainable in its present form and that current and emerging innovations will accelerate the capacity to transfer more services to local communities. In similar terms, the drive for economies of scale and scope in high-technology investment will result in a much greater concentration of specialist services such as oncology care in regional tertiary centres.

Scope

The present document aims to describe a [Patient Centered Cancer Care (PCCC) model](#) that was developed during the completion of WP1 of the INTENT project in five regions of the central Europe (i.e Jihovychod-CZ06, Friuli Venezia Giulia-ITH4, Veneto-ITH3, Zahodna Slovenjia-SI02 and Közép-Magyarország-HU10).

The document contains two parts:

1. The PCCC model, which is made of recommendations aiming to increase the patient centeredness in the existing cancer care models in the public health organizations of the Central Europe. These recommendations can be also applied to the private sector.
2. The implementation guidelines, which is a SWOT (Strength, Weaknesses, Opportunities and Threats) analysis of each section of the PCCC model and a guided analysis which provide hints on how to overcome Weaknesses or Threats by leveraging Strengths and Opportunities of the organizations.

Both parts are general enough to be applied to all centres of the 5 regions and are complemented by WP2 deliverables (e.g. PCCC indicators), which all together will make possible implementation of WP3. In particular, the benchmarking tool by using PCCC indicators will provide centres useful information to then use the implementation guidelines herein described to improve the PCCC in the existing cancer care models.

Our main focus during completion of WP1 was the public health sector; however, we believe that our recommendations and tools are also valuable for health private enterprises.

Approach

The deliverable, described herein, was created through a step-wise approach, which included:

- Description of existing cancer care models according to different stakeholders (general managers, medical directors, physicians, nurses, patient association representatives), (DT1.1.2);
- Description of the health care organization and policies in the 5 regions, particularly on the PCCC (D.T1.1.1);
- Collection of patients' and caregivers' expectations (DT1.2.1)

The completion of these deliverables provided good practices and suggestions to develop recommendations on how to improve patient centeredness in the existing cancer model of care.

A Patient Centered Cancer Care model (PCCC) in Central Europe

Patient Centered Cancer Care

"What is Patient centerness for you?" this was one of the very first questions that INTENT partners asked during the development and realization of the INTENT project. Probably, the right answer is "It depends" -; Patient Centerness is individual-specific by definition; it depends on the (multi)cultural environment and on the health system in place in each area/region [1-6]. In order to define what PCCC means among INTENT partners, we undertook a 3-step consensus building exercise –awareness, agreement, choice -[1]. By these means, we agreed that PATIENT CARE – within the INTENT project – is:

- Improving patients' active role in care and research
  Key words: Active involvement, health literacy, decision-making, education and empowerment, patient safety, communication, psychological and social impact
- Improving health gain, including quality of life
  Key words: MDTs, quality of life, continuity of care, measurements, public disclosure of results, patient oriented research, rehabilitation (physical, psychological, social, nutritional, sexual)
- Actively contributing to organizational learning and continuous improvement in this fieldPCC in our project finally aims to modify current practices by defining an innovative and shared model of care

We also defined 10key dimensions that further define PCCC from a patient and an organization perspective and an 11th transverse one (i.e. co-design of strategies and services) (table 1). The dimensions have been investigated in the previous stages of WP1 (i.e. describing current cancer care models or collecting patients' and caregivers' expectations). For the purposes of the present deliverable, we decided to group the 11 dimensions and definitions in a radar-like graph with 6 axes, 5 out of 6 belong to the dimensions of the PCCC that we agreed on, and the 6th axis, which is the research. Although, research was not included in the initial definition of PCCC, we all felt that it must be included in its broader meaning (i.e. from innovative treatments, through translational research, to the continuous search for improvement) (Figure 1). These6 axes will be the sections of the PCCC model of care. Despite we organized the PCCC model in 6 sections, each section is tightly dependent on the others; for example, axis 1 (Patient Centered Culture) is strategic for all the other sections, axis 2 (Information, Communication, Education) is necessary for the Shared Decision Making. Likewise, in the implementation guidelines, strengths of one axis can be the answer for weaknesses in a different axis.
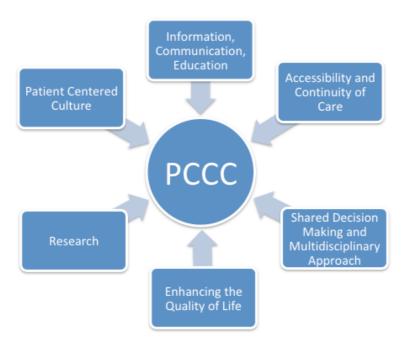
Figure 1: Graphical view of PCCC dimensions of the INTENT project.

Patient's perspective	Healthcare Organization's perspective
1. Information, communication, education[a]	6. Commitment to PCCC of leadership and management[f]
2. Continuity of care[b]	7. Patient centered culture[g]
3. Shared decision making[c]	8. Multidisciplinary approach and Continuity of care at all levels[h]
4. Accessibility (Easy access to care and services)[d]	9. Patient Safety as a key priority[i]
5. Physical and emotional support[e]	10. Enhancing the quality of life[l]

Co-design of strategies and services[m]

Table 1: the 11 PCCC dimensions of the INTENT project after conducting the Delphi exercise on PCCC.

[a] Information provided to the patient is tailored to patient's information needs, preferences [1], health literacy, etc. Empathic and exhaustive communication is promoted; professionals welcomes the participation of family, friends, and caregivers [2]. Educational activities are designed to improve patients' health behaviors and/or health status [3].

[b] Health care is provided on a continuing basis from the initial contact, following the patient through all phases of medical care (MESH). Additional info: After-discharge services are coordinated and integrated. Information regarding access to clinical, social, physical and financial support is provided on a continuing basis [3].

[c] Clinician and patients work together to make decisions and select tests, treatments and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values [4]. Alternative definition: Active involvement of and collaboration with the patient regarding decisions related to the patient's health while taking into account the patient's preference for involvement [1]. Shared decision making should be based on the best-available evidences coupled with patient preferences [2].

[d] Facilitation of timely access to healthcare tailored to the patient's needs [1].This includes: logistics, architectural aspects, administrative services, (e.g.: The appointment-making process is easy, clinic wait times are minimized, the services efficient [2])etc.

[e] Physical support: A set of behavior that ensures physical support for the patient (e.g.pain management, assistance with daily living needs) Emotional support: Recognition of the patient's emotional state and a set of behavior that ensures emotional support for the patient [1]

[f] The leadership is responsible and devoted to assure PCCC at all levels. There are specific policies and procedures designed according to PCCC standards and best practices; leaders and managers continuously evaluate their implementation.

[g] Beliefs and values shared by all members of the organization (MESH) reflect PCCC principles.

[h] specialities from many disciplines, supported by wide array of technical facilities in various services, cooperate to provide optimal treatment [5]; when treatments are not available in place, patients receive ad adequate continuity of care plan. The referral to other institutes is efficient.

[i] The organization should incorporate policies, protocols and processes to ensure the implementation of practices that, based on evidence, have been shown to protect the patient from preventable harm [6]

[l] The organization has specific strategies in place to promote and enhance the quality of life and wellbeing of patients, i.e. Using patient reported outcome measures (PROMS).

[m] Active involvement of patients and patients' representatives in planning and monitoring of the strategic plan of the center and of care in general (e.g. involvement in the definition of policies, strategies and improvement plans.)

1. Patient Centered Culture (including Commitment to PCCC of leadership and management/Co-design of strategies and services).

Definition: The Patient Centered Culture is the main pillar of a PCCC model, and it identifies the commitment of all the stakeholders to place patients at the centre of care. The leadership is responsible and devoted to assure PCCC at all levels. There are specific policies and procedures designed according to PCCC standards and best practices; leaders and managers continuously evaluate their implementation. Beliefs and values reflect PCCC principles and are shared by all members of the organization. Co-design of strategies implies an active and regular involvement of patients and patients' representatives in planning and monitoring of the strategic plan of the centre and of care in general (e.g. regular participation to the director board, involvement in the definition of policies, strategies and improvement plans).

Recommendations

Network is the key organizational answer

1. To overcome resource constrains and improve efficiency, the realization of cancer care networks is the ideal management strategy.
2. Cooperation is comprehensive and includes all stakeholders of the network: cancer related (comprehensive cancer centres, oncology clinics) and not (e.g. general hospitals, services on the territory, supportive disciplines and rehabilitation), social Entrepreneurship (e.g. patients/caregivers and associations), General Practitioners (GPs), small and large private enterprises.
3. Network goals are:
   a. Harmonization of treatments, quality and outcomes across the region.
   b. Integration of all phases of cancer intervention (primary prevention, secondary preventions – e.g. screenings – diagnosis, treatment, supportive disciplines, palliative care and survivorship – e.g. social programs, transition to adult life, back to work). For instance supportive disciplines/rehabilitation programs are present since the early phases of treatments, or palliative care accompanies late phases of treatments. Tools (psychological distress, nutritional screenings are in place to monitor regularly patient outcomes.
   c. Collaboration with non-public parties. Cancer Network seeks the collaboration with Social entrepreneurship initiatives: in several regions, patientand/or caregiver associations help patients and their caregivers in logistics(transport to and from the hospital), psychological support (e.g. listening groups, organizing meetings with psychologists), rehabilitation (e.g. lymph drainage, gentle strength training), and information on cancer and socio-economic aspects (insurance issue, school in the hospital). In its broader meaning, social entrepreneurship also includes the private sector (e.g. small-medium-large enterprises), with which collaborate for research projects aiming to improve patient outcomes/experience (e.g. better personalization of treatment through real time dosage of chemotherapeutic drugs or molecular genetics, assisted mobility of patients within the hospital) [7-9]. To be noted that laws regulating collaboration

with no-profit and profit entrepreneurship differ from region to region or from country to country, and they ultimately impact on the capability of Cancer Networks to undertake specific programs.

Cancer Care Network requirements *(for extensive description of Cancer Care Network in Europe please refer to the CanCon and iPAAC WP10 initiatives):*

4. The Network shares the strategic plan among stakeholders (e.g. cancer centres, oncology clinics, local services, general practitioners, hospitals, social services): coordination/integration/communication among stakeholders is one of the primary objectives.

5. The Network centrally monitors PCC indicators. Monitoring is centralized, regularly performed and harmonized through the geographical area that pertains the cancer care network. An ICT system is implemented in the area and used by all partners; data are either automatically transferred centrally or uploaded by partners. Performance indicators include such as overall survival, patient satisfaction, quality assessment reports and clinical trials activities are the most monitored; however, patient quality of life, accessibility to services and care, MDTs activity should also be implemented.

6. Multidisciplinary care and Clinical pathways are the most important pillars for the harmonization of cancer care; activity of Multidisciplinary teams and application of clinical pathways are monitored thought out the region.

7. Network undertakes periodically an internal/external quality assurance program to guarantee continuous improvement.

8. Cancer specific competences are based on activity volumes of each partner of the Network in order to guarantee best possible outcomes. Similarly, handling of anti cancer drugs or costly technologies are concentrated to one centre. Duplication of services and technologies are avoided to maximize economy of scale. The Network continuously seeks for improvement also through research and improvement projects aiming to improve outcome, increase performance and reduce inefficiencies.

9. Central body of the network includes patient representatives. Patient organizations are represented in the body, which governs the implementation of the network (Oversight committee), they participate during the designing and implementation of the network (e.g. clinical pathways). Patient organizations help to succeed in preventive, healing, and rehabilitation activities. Patient associations and the health care providers jointly organize training events on socio-economic-management topics in order to foster education and networking among all parties [10].

10. Network regularly collects feedbacks from patients and implement them in improvement plans. Typically, patients envision them selves as providers of feedbacks in an anonymous way; indeed, only 5% of patients are members of patient associations). Therefore effective tools must be in place to collect these feedbacks concerning PCC in all its aspects (patient centred culture, information, accessibility and continuity of care, shared decision making, quality of life, research). These tools must also take into account multicultural shift that we are experiencing in the Central Europe and Europe as a whole.

11. The network allocates budget to implement PCC. PCC indicators (e.g satisfaction questionnaire, quality of life – PROMs -, patient drop-outs, waiting times, etc…) are key performance indicators and are used during budget consultation. Budget for PCC implementation is assigned to single health care provider/clinical units to implement specific projects concerning PCCC.

12. The Network publishes improvement plans, which include PCC, with measurable deliverables and with a projected timeline (e.g. 5 years). The Network establishes accountability for each task. Upon completion of the projected timeline, Networks evaluates accomplished tasks with anonymous SWOT analysis among all stakeholders [11], collect feedbacks to set new improvement plans, and publishes (on the web) results.

13. Network maps the activities of patient/caregiver associations acting within its own geographical area and advertise them to patients: for instance, listing them on the website [12], and advertising them within the hospital premises (e.g. association leaflets in the outpatient clinics, in the welcome desk, in the patient library or in recreational areas). If national association exists, Network redirects patient coming from other regions to the national associations in order to find the closest branch to patient's house.

14. Network advertises research/project collaborations with profit enterprises and publicly advertises them to foster new activities [13].

As a final note, be advised that the former recommendations can apply as well to cancer centre that are not embodied in a cancer care network.

2. Communication, Information and Education

Definition: Information provided to the patient is tailored to patient's information needs, culture, preferences [1], health literacy, etc. Empathic and exhaustive communication is promoted; professionals welcomes the participation of family, friends, and caregivers [2]. Educational activities are designed to improve patients' health behaviours and/or health status [3]

Communication/information/education are part of the therapeutic process. The communication must take in account the engagement of the patient. The ultimate goal of an effective communication should be a shared therapeutic plan between patients and doctors.

Recommendations

This axis includes all possible communication flows (e.g. from the doctor to the patients/caregivers, from the patients/caregivers to the doctor/network, and from the network to the patients/caregivers/the public) and for all different subjects (disease and more general health related topics, organization related topics) to ultimately foster patients'/public involvement and empowerment.

Communication among patient/caregiver, the care team, general practitioners on disease related topics (e.g. diagnosis, treatment, recurrence, long term survivorship and end of life).

- Patient should be asked whether he/she wants his/her caregiver to be involved during visits and discussions. Patient defines who is the caregiver. Care team has a tailored communication to caregivers (about care and coping with the situation).
- Good communication requires:
  - Timing: time dedicated to first visits, or diagnosis communication, is extended than regular time slots. Patient information is dependent on the moment during the clinical pathway: right info at the right moment;
  - Awareness: patients and caregivers are informed to whom they can rely on during the different phases of the disease;
  - Skills of the care team: despite the topic and the moment (during treatment or after discharge), patients and caregivers always prefer to receive information by person with healthcare professionals. This requires that members of the care team have a formal training (e.g. role playing) on how to communicate and soft skills, such as emotional intelligence, active listening, considering patients' believes, needs, and feelings to eventually create a physical and emotional setting [14, 15].
- General practitioners (GP) are one of the stakeholders involved in the communication on disease related topics. The cancer care team inform the GPs with written information addressing their patient diagnosis/therapy/treatments/follow-ups and rehabilitation

needs in a comprehensive and effective format. GPs and the cancer care team share phone contacts when discussion of specific cases is required.

- Information collected during patient-caregiver interview are very important to define personalized care; likewise after discharge, patients and caregivers can provide remotely information to the care team (e.g. PROMs or portable devices to monitor vital signs).

Communication among patients/caregivers, the public and the network:

- Patients and caregivers provide perceived evaluation of quality of services. These info are valuable tools to plan service improvements. In order to achieve this, satisfaction questionnaires should be tailored to collect patients' needs and feedbacks to specific topics (e.g. communication skills of the care team). Patient's committee also are a way to report patients voice

- The website (of the network) contains: the strategic program [16], the list of participants of the oversight committee [17], and information on the Clinical pathways [17, 18].

- The network provides information (including description and contacts) to patients and caregivers on patients associations active within its own premises. Network uses different channels of information: web, social media, leaflets to be distributed in the waiting rooms or patient library.

- The network provides patient education (PE) program. PE provides information on different topics: from prevention "how can I prevent that my loved ones get cancer as well?", through comprehension of the disease/diagnosis "what is it happening?", to impact "what is going to happen?". PE staff prepares communication material tailored to expert patients or patients with low literacy and foreigners (including cultural mediators). Patients' and caregivers' informative needs should be regularly investigated (e.g. during the collection of satisfaction questionnaire)

- The network has social accountability [19-22]: it has to respond its social responsibility toward the citizens and the stakeholders. The objectives are: to increase trust, communicate performance, guarantee transparency. The process of "social responsibility" is growing in healthcare organizations. In particular 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. 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).

- Medical staff replies to patients' complaints within a defined timeframe.

3. Accessibility and Continuity of Care

Definition: Facilitation of timely access to healthcare tailored to the patient's needs [1]. This includes: logistics, architectural aspects, administrative services, (e.g.: The appointment-making process is easy, clinic wait times are minimized, the services is efficient [2])etc.
When treatments are not available in place, patients receive an adequate continuity of care plan. The referral to other institutes is efficient and managed with standardized procedures.

Recommendations
Network plans and shares procedures among its members.
- Network staff includes case managers, who provide a link between the patient and the hospitals.
- Network members share common clinical patient pathways.
- Network share procedures for rare tumors: rare tumor patients are referred or consulted to highly specialized centres for rare diseases.
- GPs are key player for the continuity of care both for patients that leave within the geographical premises of the network and also for patients coming from other regions.
- Patients have one physician throughout the different phases of the disease.
- Network monitor waiting times and set maximum thresholds. Procedures are in place to act when waiting times are above set thresholds.

Network infrastructures.
- An Information and Communication Technology system is in place to exchange electronically information (e.g. patients' files) among partners of the network. Patient records are kept in a electronic form.
- Multidisciplinary teams use IT tools to report their activity.
- Network provides phone lines or online tools to schedule appointments.

Network works centrally and locally.
- Network operates centrally when highly specialized training is required; however, standard operating procedures are in place in secondary care organizations, which guarantee equal quality for less specialized procedures (e.g. chemotherapy, pain therapy, palliative care) to offer services closer to patient' house.
- Treatments are harmonized with supportive care activities, which are possibly closer to patient' home.
- Fast track clinical pathways (e.g. one day surgery for breast cancer) to impact less on patient quality of life.

4. Shared decision making and Multidisciplinary approach

Definition: clinicians and patients work together to make decisions concerning treatments and care plans based on clinical evidence that balances risks and expected outcomes, based on the best-available evidences, coupled with patient preferences and values [2, 4]. Patients are actively involved in the decision making, special attention is given to patient's preferences [1]. Treatment and care plans are discussed by a multidisciplinary team (MDT), who is composed by members from many disciplines, and is supported by a wide array of technical facilities in various services, which cooperate to provide optimal treatment [5]. The physician, who presents patient case to the MDT, reports patient preferences and values, which are taken into account by the MDT. Recommendations from the MDT are discussed with the patient and plan set jointly.

Recommendations

Shared decision making:
- More and more patients are aware that they are part of the decision-making and they seek information from doctors to comprehend. Care teams foster this attitude in all patients respectfully of each patient wishes and attitude.
- Shared decision making includes objectives of the care plan to be sustainable physically and emotionally by the patient. Shared care plan can be updated according to patient wishes at every time. Care plan is accessible to each member of the care team.
- Patients should be asked whether their caregivers take part to the discussions concerning the care plan.
- Care team fosters patient empowerment: i) support patients who are willing to ask for second opinions ii) inform patients with evidence-based information, inform patient about alternative medicine usefulness and risks
- During long term follow-ups, care team discusses with patients the meaning of cure and the perception of patients regarding it (e.g. long term survivorship [23]).

Multidisciplinary is the key
- Multidisciplinary approach and clinical pathways are shared throughout the region to guarantee equal treatment quality in the region and avoid discrepancies.
- MDT composition and activity should be monitored. Nurses and supportive disciplines (e.g. rehabilitation, nutritionist, psycho-oncologist, palliative expert) are part of the MDTs.
- The network can use team building competences to foster MDTs.
- Ideally 100% of newly diagnosed patients should be discussed by a multidisciplinary team

5. Enhancing the Quality of Life

Definition: The organization has specific strategies in place to promote, enhance, and record the quality of life and wellbeing of patients, i.e. using patient reported outcome measures (PROMS) [24]. The organization should incorporate policies, protocols and processes to ensure the implementation of practices that, based on evidence, have been shown to protect the patient from preventable harm [6]
Patient support: a set of procedures that ensure physical support to patients (e.g. pain management, assistance with daily living needs) and emotional support (e.g. screening of the patient's emotional state and if needed emotional support) [1].

5. **Recommendations**
   5.1. The care team defines with each patient quality of life needs.
   5.2. Enhancing quality of life of patients in one of the primary goals of clinical patient pathways. Nutrition, rehabilitation (physical and socioeconomical), and psychological are part of the cancer care pathway.
   5.3. Network has in place screening tools to identify early signs that require intervention of supportive disciplines (e.g. distress screening, nutrition screening, etc). Taking into account that in 95% of cases caregivers are relatives, disease burden is on the family, and network provides support to families as well (please refer to deliverables D.T.1.2.1 Online Survey of stakeholder expectations).
   5.4. Also caregivers should be screened (e.g. psychological support).
   5.5. Network monitors quality of life in patients (thermometer distress, PROMS, PREMS, social distress) overtime and also after hospital discharge (e.g. through m-health solutions). Procedures are in place to respond to patient needs (e.g. contact point that activate response to patient needs).
   5.6. All rehabilitation disciplines (e.g. psycho-oncolgy, 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.
   5.7. Network supports long term survivors in collaboration with patient associations (e.g. Return to life) [23, 25].
   5.8. Patient quality of life is part of the social accountability of the Network along with overall survival, treated patients, activity, etc...

6. Research and improving Health Technologies

Definition. Research is a continuous process for improvement in all aspects of care: from basic to translational research, from testing new drug compounds to impact survival, from improving quality of life to explore new strategies to implement patient centeredness in the cancer care. Research deals also with technological improvements of cancer care (e.g. imaging instruments, robotic surgery, genomic analysis, etc…).

6. **Recommendations**
   6.1. **Patients' engagement in cancer research**
      6.1.1. Research projects include patients' needs: research planning engages community patients or caregivers, who can bring their own perspectives and understandings of community life and health issues to a project [26-28]. For instance, patient feedbacks collected through satisfaction questionnaires (axis2) or tools that monitor patient quality of life (e.g. PROMS) (axis5) provide new hypothesis to investigate, or patients can provide new outcomes that are not explored yet (e.g. definition of disease free state and impact on patient's quality of life).
      6.1.2. 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 [27, 29-31].
      6.1.3. Structured Focus groups between patients/caregivers and researchers are useful tools to facilitate communication among stakeholders.
      6.1.4. Clinical trials conducted in the network always include as objective, if pertinent, quality of life. Quality of life is collected using appropriate tools [24, 32-34].
   6.2. **Communicating the research**
      6.2.1. Research projects currently running in the network are described in lay terminology to patients/caregivers/visitors in public spaces using posters or on the web/social media [35-37]. Contact info and leaflets are provided as well.
      6.2.2. Network researchers inform patients/caregivers using lay terminology about the results and the opportunities they have by participating in clinical trials.
      6.2.3. Network researchers inform patients about clinical trials currently enrolling in the cancer centre/network, about risks and benefits and contact info [38, 39].
      6.2.4. Communication and patient accrual is harmonized throughout the network: all health care providers are recruiting patients for clinical trials run throughout the network.
   6.3. **Research strategy/approach**
      6.3.1. **Topics**: The network includes: Clinical Trials to test most updated drugs/treatments, phase I clinical trials, Cancer genome programs, molecular board, translational research programs (bridge from the research to the clinic). Cancer network conducts research on the organization of services and PCCC to foster improvement and new tools. Research on supportive and palliative care is a strategic asset of the network equally to research on new anti-cancer therapies [40, 41].

6.3.2. **Governance**: Organizational tools are in place to guarantee that care and research are bound together: a strategy is in place to timely transfer results of research to the clinic and vice versa. This includes multidisciplinary approach in the patient care with formalized meetings between researchers and clinicians. MDs have allocated time to attend translational labs and to visit patients. There is in place a procedure to implement in the practice novel diagnostic tools. Shared equipment platforms are accessible to every researcher. Dedicated budget is allocated for internal research seed projects. The network regularly evaluates internally research performance and takes advantage of an external reviewer board to periodically gather feedbacks on the strategy and planning and adjust accordingly.

Implementation guidelines

The implementation guidelines herein described are meant to be a tool for INTENT partners and other cancer centres to facilitate implementation of the PCCC model in their own existing cancer care models. Health care organizations (e.g. cancer care centres or cancer care networks) are complex management structures, in which improvement projects are daunting tasks. For this reason, by applying the SWOT (i.e. Strengths, Weaknesses, Opportunities and Threats) analysis to the former PCCC model, herein we suggest potential Strengths (within the organization) and Opportunities (outside the organization), which can be leveraged to overcome Weaknesses (within the organization) and Threats (outside the organization). At the same time, cancer care centres or cancer care networks rely on political decisions (e.g. budget constraints, IT infrastructures, health care organization), which the management of the organization cannot control but only use. For this reason, some of the results of the SWOT analysis will provide suggestions to the policy recommendations developed in the last part of WP1 and delivered by D.T1.3.2.

In the first part of the implementation guidelines, for each axis, we listed the Strengths, Weaknesses, Opportunities and Threats each numbered progressively from axis 1 to 6 and proceeded by a letter (i.e. S, W, O, or T). Order does not relate to importance. In the second part of the implementation guidelines, we listed all Weaknesses and Threats in a table format and when available we suggest strategies to overcome each one of them by using specific Strengths and Opportunities belonging to all axes. Cancer centres/networks can combine these implementation guidelines with the results of the benchmarking tool (developed in WP2 of INTENT) and by identifying axes that need improvement, Weaknesses and Threats responsible of, they can set an improvement plan by leveraging on their Strengths and Opportunities.

1. SWOT_Patient Centered Culture (including Commitment to PCCC of leadership and management/Co-design of strategies and services).

- **Strengths:**
1. Rationalization, increased efficiency, cost reduction (opportunity to invest the surplus), improved quality of service. Improved company climate. Reduced physician seclusion.
2. Harmonization across the region/equity.
3. Patient associations are actively involved.
4. Network implementation can create new job positions/competences in different partners hosted in the network.
5. Social entrepreneurship (e.g. participation of patient associations in cancer care) is a growing phenomenon despite not fully developed yet.

- **Weaknesses:**

W.1   Network is a complex organization to manage/control/monitor

W.2   Professionals do not like to loose activities/Organization are seeking to keep their own budget.

W.3   Regional networks are not completely autonomous: some changes require discussions at national level.

W.4   Asymmetric information among different stakeholders: some patient associations do not carry a formal preparation on health management topics; some health professionals are still lagging behind on soft skill preparation.

W.5   Operating by activity volumes within the network requires reshuffling of activities (either professionals or patients have to move to deliver or receive care).

- **Opportunities:**

O.1 Project Management expertise [42, 43]

O.2 ICT/eHealth tools (e.g. PROMs, Internet of Things).

O.3 Reimbursement of activities linked to volume activities (services are reimbursed only if certain volumes are reached).

- **Threats:**

T.1.   Rationalisation and increased efficiency are expected to reduce cost; consequent budget surplus may be moved from cancer care to other sectors with a net decrease of investments, which are mandatory for some changes (e.g. further implementation of case managing and supportive disciplines).

T.2.   Different stakeholders may have competing interests

2. SWOT_Communication, Information and Education

- **Strengths:**
6. Effective communication to patients and caregivers make them active actors in the process, decreases legal disputes and complains [44-46].
7. Effective communication reduces unnecessary medical interventions/visits, workload of the care team, and positively impact on the outcomes (survival and quality of life) [44-46].
8. Complains or satisfaction questionnaires provide valuable indicators to plan care team training on soft skills including communication training containing specific question concerning the communication.

- **Weaknesses:**

W.6   Communication training requires financial and time resources.

W.7   Typically, patients envision them selves as passive providers of feedbacks in an anonymous ways. This makes difficult to involve them in the communication concerning topics not related to their own disease.

- **Opportunities:**

O.4 New communication tools (e.g. social, M-health, website tools) offer easy access to content in real-time.

- **Threats:**

T.3.   Website and social tools are not verified sources of information.

T.4.   National legislations can differ and may not rule that patient defines who is his/her own caregiver.

3. SWOT_Accessibility and Continuity of Care

- **Strengths:**
9. Care teams are usually very well trained.
10. Networks already cooperate with patient associations to implement services to help patients.
11. Patient associations are highly motivated to collaborate with the network to realize new services.
12. The public, patients and caregivers are eager to have a better care service.
13. A structured network outside the cancer care centres already exists.

- **Weaknesses:**

W.8   It is a daunting task to create procedures between hubs (e.g. cancer centres) and spokes (e.g. general districts or hospitals) to respond patients' needs (e.g. pain therapy in response to pain alert, psycho-oncology intervention in case of distress).

W.9   Patients prefer to interact directly (i.e. by person) with the care team of the cancer centre.

W.10   Patients and staff are not keen to shift activities locally (i.e. spokes).

- **Opportunities:**

O.5 Other regions already implemented part of this model and they can provide valuable hints (e.g. Oncological Regional Network of Veneto or Slovenia in the newest multiannual plan)

O.6 ICT tools or Internet of Things are ideal opportunities to collaborate with research centres (e.g. universities), data science departments, computational centres, or private enterprises.

- **Threats:**

T.5.   In order to work centrally and locally, good public infrastructures (roads, railroads, public transportations, ICT systems) must be in place.

4. SWOT_Shared decision making and Multidisciplinary approach

- **Strengths:**

14. Strong bond between the care team and the patient-caregiver.
15. Strong motivation of patients to take part of the decision-making process.
16. Reduced legal disputes.
17. Increased patient compliance with care plans.
18. Create care pathways for different phases of intervention.
19. Holistic approach to patient care.

- **Weaknesses:**

W.11   Informing patients/caregivers and discussing together takes time, which in some cases in not sustainable due to time or workload constrains.

W.12   Formalized multidisciplinary teams are still recent and not fully functional.

W.13   Staff members have not a formal training on soft skills.

W.14   Existing asymmetric information exists between patients and physicians.

-

- **Opportunities:**

O.7 Prevalence of multi-professional teams in other organisations (e.g. private enterprises), diffusion of cooperative learning and soft skill training.

- **Threats:**

T.6.   Budget cuts in the health system, which impact the number of care team members, timeslots and workload.

5. SWOT_Enhancing the Quality of Life

- **Strengths:**

20. Supportive disciplines (e.g. nutrition, psychological, rehabilitation) are key aspects for patients.
21. Monitoring quality of life of patients and responding to patient needs impacts disease outcomes [33].
22. Care teams and patient associations are becoming more and more aware about the role of supporting disciplines
23. Cancer-specific specializations are present in the supportive disciplines.

- **Weaknesses:**

W.15   Due to financial and human resources reduction, supportive disciplines are under staffed both centrally (e.g. cancer centres) and locally (e.g. local districts and general hospitals), generating difficulties to respond to patient needs.

W.16   In order to monitor quality of life of patients, there is no consensus on the tools to be used (e.g. PROMs) (ref)

W.17   Digital divide: elderly people might experience difficulties to use online tools (e.g. ePROMs).

- **Opportunities:**

O.8 Create new tools to collect patient needs and support them (e.g. IT).

O.9 The impact of supportive disciplines on cancer patient outcomes is an expanding field with more and more good practices.

- **Threats:**

6. SWOT_Research and improving Health Technologies

- **Strengths:**

24. Patients recognize the importance of cancer research and they are willing to participate in clinical trials.

25. Research is the most shared goal among the interviewed managers of cancer centres.

26. Social entrepreneurs (e.g. patient associations) support research both financially (e.g. fund raising) and socially (e.g. public events to raise awareness).

27. Research projects are currently dealing with patient centeredness.

- **Weaknesses:**

W.18   There is insufficient public financial investment in research.

W.19   Lack of a strategic plan in the medium and long run.

W.20   Researchers are typically oriented to work by themselves (i.e. lonely thinkers), which typically implies difficulties to team up.

- **Opportunities:**

O.10   Technological innovations can fuel cancer and patient centeredness research (e.g. big data, IT tools)

O.11   Research is a shared value with other stakeholders (the public and private sector). Stakeholders are well aware that research is strategic to improve cancer patient outcome.

O.12   Ethical committees safeguard patients' rights and scientific approach.

- **Threats:**

T.7.   Too intense publicity of research results could provide false hopes in patients/general population.

T.8.   Commercial clinical trials are prioritized above academic clinical trials or trials dealing with supportive and palliative care.

T.9.   Research is time and resource consuming: it requires invest today to deliver in the future.

1. Implementation_Patient Centered Culture (including Commitment to PCCC of leadership and management/Co-design of strategies and services).

Weaknesses:	Strengths and Opportunities to leverage on
W.1 Network is a complex organization to manage/control/monitor	O.1[1]; O.6
W.2 Professionals do not like to loose activities/Organization are seeking to keep their own budget.	S.1(2); S.4(3)
W.3 Regional networks are not completely autonomous: some changes require discussions at national level.	S.11
W.4 Asymmetric information among different stakeholders: some patient associations do not carry a formal preparation on health management topics; some health professionals are still lagging behind on soft skill preparation.	S.11, S.4 (4), S.5(4), S.26(5)
W.5 Operating by activity volumes within the network requires reshuffling of activities (either professionals or patients have to move to deliver or receive care).	S.2(6), S.12(7)

Notes:
(1) Project management helps to plan and monitor these processes.
(2) These are strengths that may counterbalance W.2.
(3) Reshuffling of activities may determine that healthcare professionals move within the network and therefore being exposed to different work environment and potentially exchange good practices.
(4) Health care professionals can acquire new competences and collaborate with patient associations to organize meetings, seminars to share knowledge, experiences.
(5) Patient associations can financially support educational events in collaboration with the public sector.
(6) The harmonization of cancer care treatment across the region outweigh discomfort of the reshuffling.
(7) This is a driver to overcome W.5.

Threats:	Strengths and Opportunities to leverage on
T.1. Rationalisation and increased efficiency are expected to reduce cost; consequent budget surplus may be moved from cancer care to other sectors with a net decrease of investments, which are mandatory for some changes (e.g. further implementation of case managing and supportive disciplines).	S.5[1]
T.2. Different stakeholders may have competing interests	S.25[2], S.26[2], O.11[2], S.15, S.11, S.12, O.1

Notes:
(1) Patient associations can help to leverage on the policy makers.
(2) Implementation of cancer care network can offer new opportunities for research projects; research is a shared value among different stakeholders.

2. Implementation_Communication, Information and Education

Weaknesses:	Strengths and Opportunities to leverage on
W.6 Communication training requires financial and time resources.	S.1[1], S.27[2], S.26[2], S.16[3], S.7[3]
W.7 Typically, patients envision them selves as passive providers of feedbacks in an anonymous ways. This makes difficult to involve them in the communication concerning topics not related to their own disease.	S.5[4]

Notes:
(1) Budget surplus that may derive from S.1 can be reinvested in communication training.
(2) Communication training and impact of communication on cancer patient outcomes can be subject of research projects, which can also provide some initial budget to support training.
(3) Improved patient-doctor communication may reduce costs by reducing workload, unnecessary interventions, and reduce legal disputes. Cost reduction may be reinvested in communication training.
(4) Patient associations can help cancer care networks to involve more patients in an active communication (e.g. creation of patient boards or events targeting patients).

Threats:	Strengths and Opportunities to leverage on
T.3. Website and social tools are not verified sources of information.	O.2[1], S.25[1], S.26[1]
T.4. National legislations can differ and may not rule that patient defines who is his/her own caregiver.	

Notes:
(1) The same new tools can be implemented by the cancer care network, which may become provider of verified information. Research projects can financially support, at least initially, this improvement projects.

3. Implementation_Accessibility and Continuity of Care

Weaknesses:	Strengths and Opportunities to leverage on
W.8 It is a daunting task to create procedures between hubs (e.g. cancer centres) and spokes (e.g. general districts or hospitals) to respond patients' needs (e.g. pain therapy in response to pain alert, psycho-oncology intervention in case of distress).	O.1, O.2, S.1[1]
W.9 Patients prefer to interact directly (i.e. by person) with the care team of the cancer centre.	S.6[2], S.7[2], S.8[2], O.2[3]
W.10 Patients and staff are not keen to shift activities locally (i.e. spokes).	Refer to W.2

Notes:
(1) Financial surplus generated by S.1 may be re-invested to financially support W.8.
(2) Effective communication between patients and the care team is an essential asset to encourage patients to be treated and visited locally (i.e. spokes of the cancer care network).
(3) Alternative tools may be used in order to avoid patients visiting the cancer center.

Threats:	Strengths and Opportunities to leverage on
T.5. In order to work centrally and locally, good public infrastructures (roads, railroads, public transportations, ICT systems) must be in place.	

Notes:

4. Implementation_Shared decision making and Multidisciplinary approach

Weaknesses:	Strengths and Opportunities to leverage on
W.11 Informing patients/caregivers and discussing together takes time, which in some cases in not sustainable due to time or workload constrains.	S.1[1], S.7[2]
W.12 Formalized multidisciplinary teams are still recent and not fully functional.	S.2, S.4
W.13 Staff members have not a formal training on soft skills.	Refer to W.6
W.14 Existing asymmetric information exists between patients and physicians.	S.6[3], S.7[3], S.8[3]

Notes:
(1) Reshuffling activities across the entire network may redistribute workload and create the opportunity to extend visit time.
(2) Improving communication may reduce workload overtime and offer the opportunity to extend time visit.
(3) Effective communication between patients and the care team is an essential asset to counterbalance existing asymmetric information.

Threats:	Strengths and Opportunities to leverage on
T.6. Budget cuts in the health system, which impact the number of care team members, timeslots and workload.	S.1[1]

Notes:
(1) This is an opportunity to reinvest financial surplus, which may derive from network creation.

5. Implementation_Enhancing the Quality of Life

Weaknesses:	Strengths and Opportunities to leverage on
W.15 Due to financial and human resources reduction, supportive disciplines are under staffed both centrally (e.g. cancer centres) and locally (e.g. local districts and general hospitals), generating difficulties to respond to patient needs.	S.1[1]
W.16 In order to monitor quality of life of patients, there is no consensus on the tools to be used (e.g. PROMs) (ref)	S.27[2]
W.17 Digital divide: elderly people might experience difficulties to use online tools (e.g. ePROMs).	S.25[3], S.26[3], O.11[3]

Notes:
(1) This is an opportunity to reinvest financial surplus, which may derive from network creation.
(2) This may represent an opportunity for new research projects comparing different available tools.
(3) Tailoring IT tools to elderly can certainly be matter of new research projects and of private and public investment.

Threats:	Strengths and Opportunities to leverage on
none	

Notes:

6. Implementation_Research and improving Health Technologies

Weaknesses:	Strengths and Opportunities to leverage on
W.18 There is insufficient public financial investment in research.	S.26[1], O.11[1]
W.19 Lack of a strategic plan in the medium and long run.	O.1[2]
W.20 Researchers are typically oriented to work by themselves (i.e. lonely thinkers), which typically implies difficulties to team up.	O.1[3]

Notes:
(1) S.26 and O.11 may represent alternative financial resources.
(2) Planning is among project management activities, improving project management culture may overtime counterbalance the current lack of strategic vision.
(3) Team work is among the skills of the project managing.

Threats:	Strengths and Opportunities to leverage on
T.7. Too intense publicity of research results could provide false hopes in patients/general population.	
T.8. Commercial clinical trials are prioritized above academic clinical trials or trials dealing with supportive and palliative care.	S.26[1], S.1[1]
T.9. Research is time and resource consuming: it requires invest today to deliver in the future.	O.1[2]

Notes:
(1) S.26 and S.1 represent alternative financial sources for investigator driven clinical trials together with public grants. Cancer care networks should monitor the percentage of spontaneous and private driven clinical trials and clearly state policy dealing with this matter.
(2) Project management can help to plan and monitor the process; nevertheless, research still remains a daunting process (time and resource wise) and this should be clearly communicated to the public.

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