



State of Play WP 10: Governance of Integrated and Comprehensive Cancer Care

Ellen Griesshammer, German Cancer Society, Germany, Deputy-WP 10 Leader



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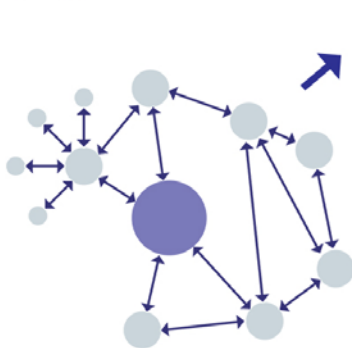
ORIGINS: FROM CANCON TO IPAAC

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How to build and operate a
Comprehensive Cancer Care Network:

A – NETWORK



B – FUNCTIONALITY



Recommendations from CanCon WP 6:

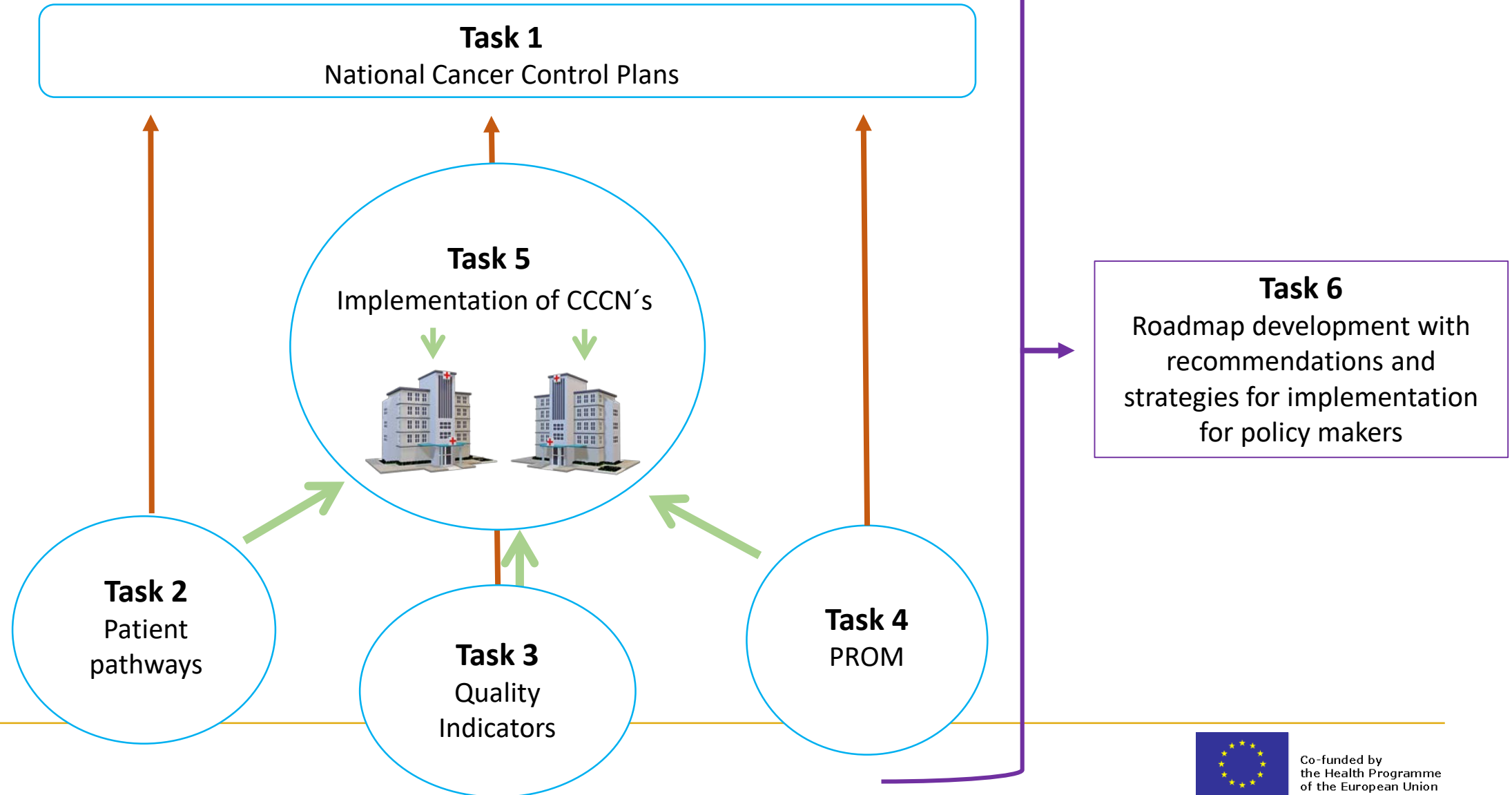
- Establishment of **tumour management groups (TMG)**
- Tumour-based **multidisciplinary and multi-professional TMG's**
- Defined **patient pathways** for the entire chain of health care must be put in place
- Definition of uniform **standard operating procedures** which comply with evidence-based guidelines
- Assessment of quality of care through **quality indicators** as well as a continuous quality improvement process

To guarantee sustainability of the CanCon JA and develop it further:

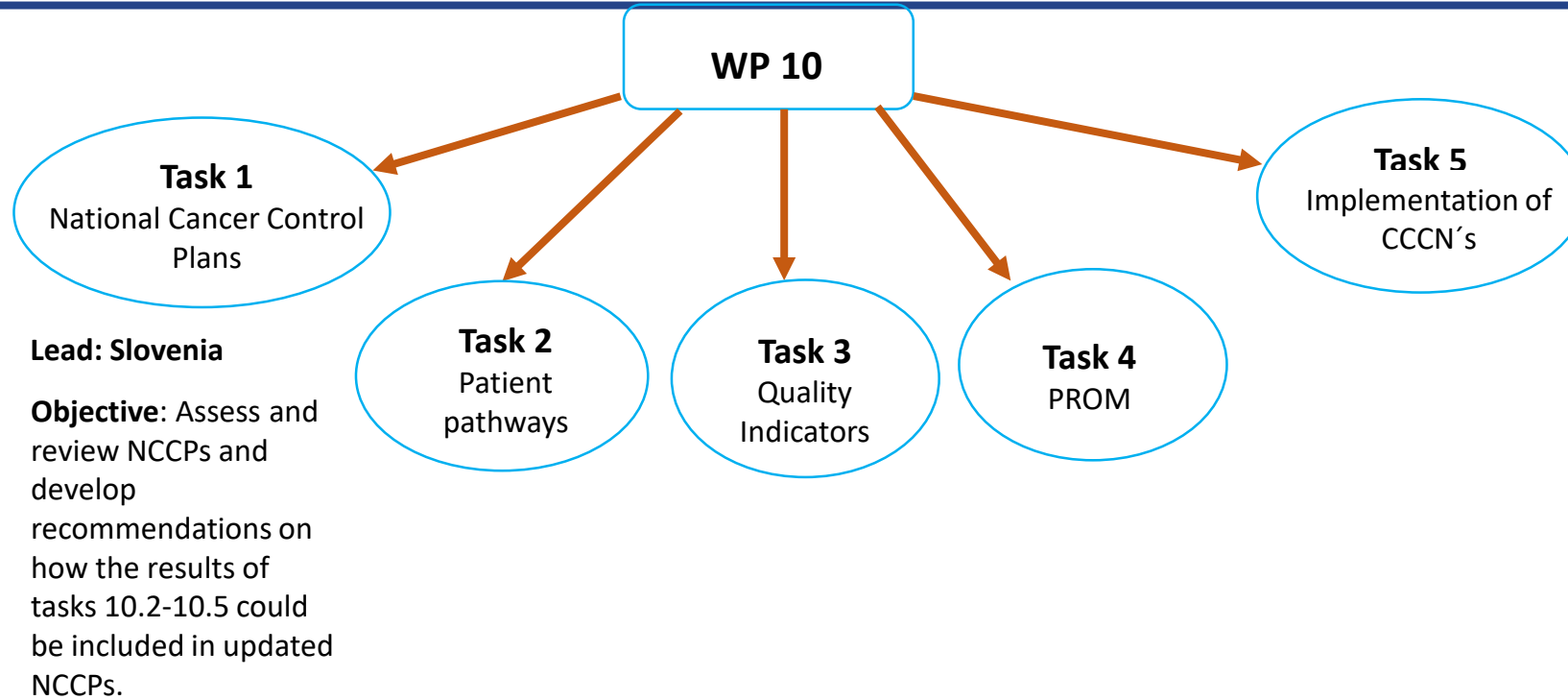
Goal of WP 10:

“...develop **practical instruments** (...) (to ensure) a standardised (...) comprehensive oncological care in all Member States that is tumour-specific and delivers (...) high-quality care to all patients. These **instruments should be used by NCCPs for the governance of oncological care**”.

WP 10: GOVERNANCE OF INTEGRATED AND COMPREHENSIVE CANCER CARE

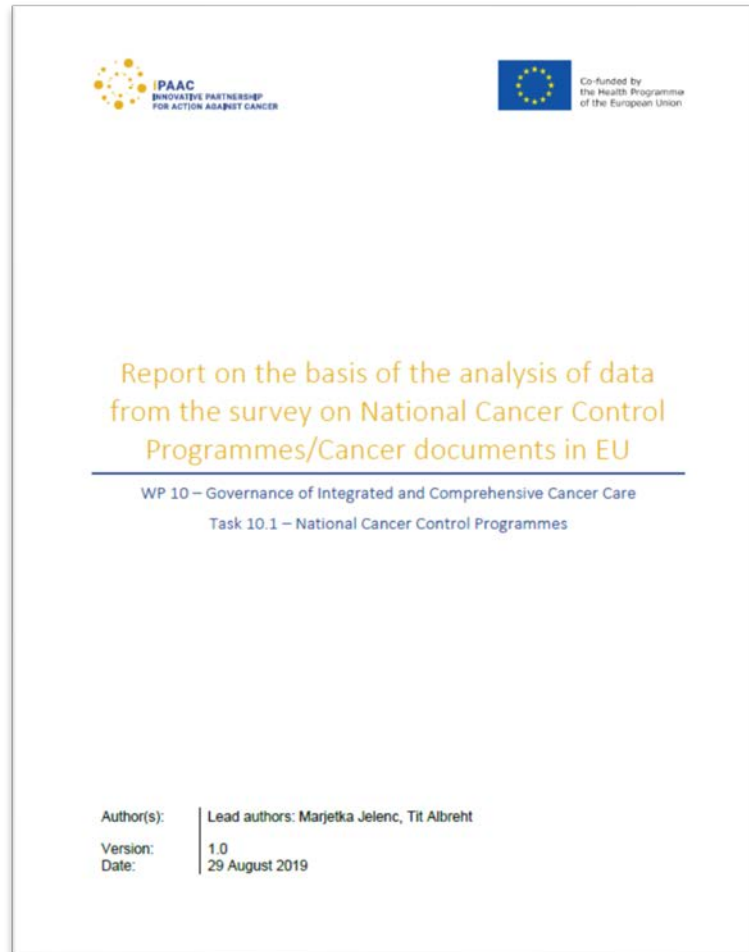


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Task 1

National Cancer Control Plans



- ⇒ MS-Survey performed in September 2018
- ⇒ Results were presented at the 2. WP 10 meeting in Rome
- ⇒ Final draft report was presented at 3. WP 10 meeting in Budapest
- ⇒ Planned: to include feedback from WP 4 CCCPIs in final report (on-going)

Task 1

National Cancer Control Plans



- ⇒ Literature review for the terminological assessment of the terms governance and stewardship in/of cancer care
- ⇒ Results were presented at 3rd WP 10 meeting in Budapest

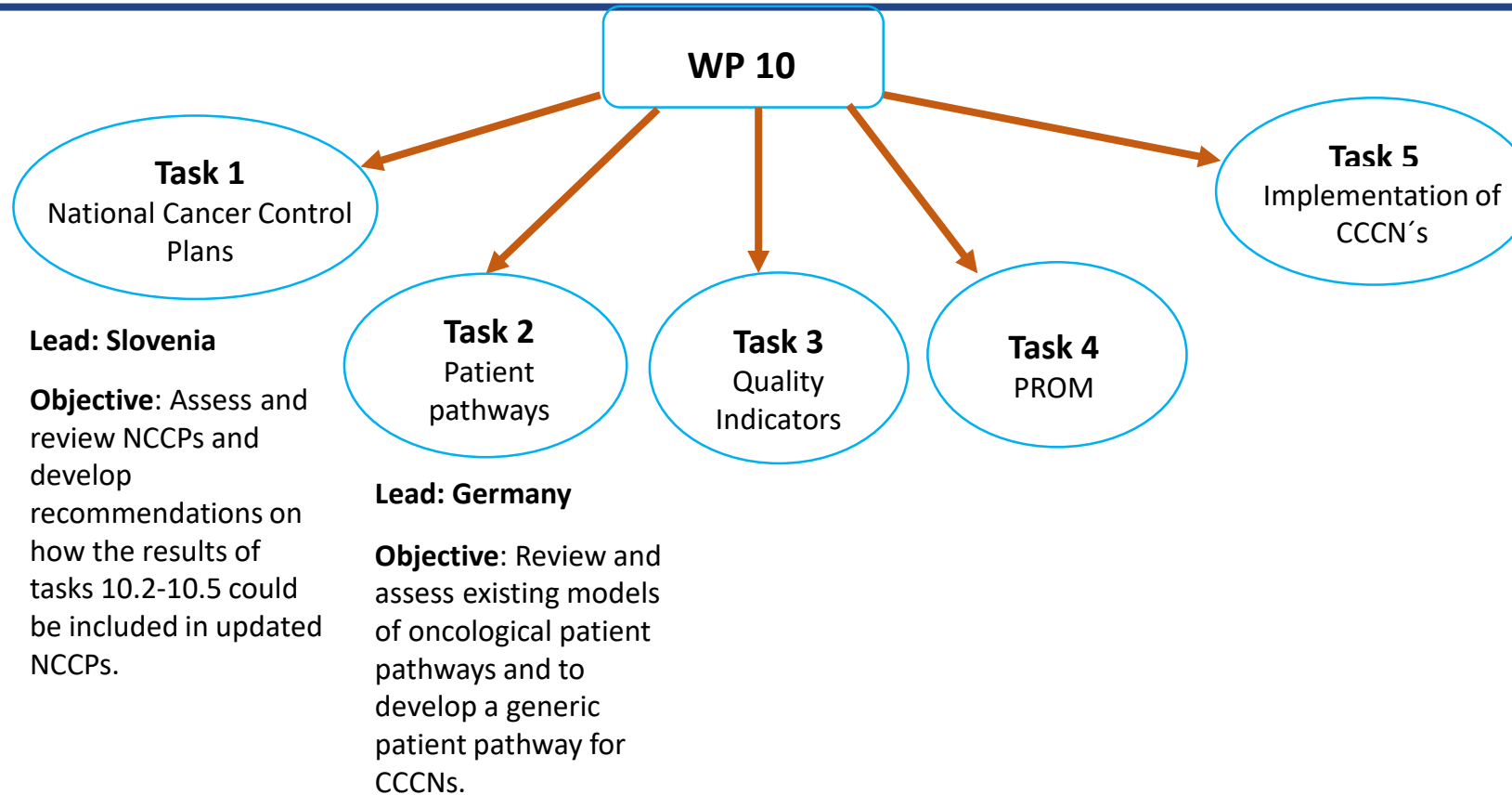
Governance in/of cancer care

„Governance in/of cancer care is a continuous process of management at macro level through which Health Care Systems can provide/assure, develop and improve quality, capacity and outcomes in cancer care.“

Stewardship in/of cancer care

„Stewardship in cancer control represents the State's highest level of responsibility in the field of cancer with the aim of reaching the national health policy objectives.“

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Task 2

Patient pathways

Patient pathway survey among iPAAC WP 10 members



Dear iPAAC WP10 member,

we invite you to participate in this patient pathway survey that aims at examining the understanding and implementation of oncological patient pathways on the network level as well as personal experiences with patient pathways among iPAAC WP10 members. The survey draws upon general characteristics of patient pathways identified in a systematic scoping review. Based on this, a patient pathway definition is proposed and shall be rated by the survey participants. So, if you are, in any way, involved with patient pathways (e.g. in research, development, management, usage, analysis of patient pathways), we invite you to participate in this survey.

Thank you in advance for participating and kind regards from Dresden,
Peggy and Hannes



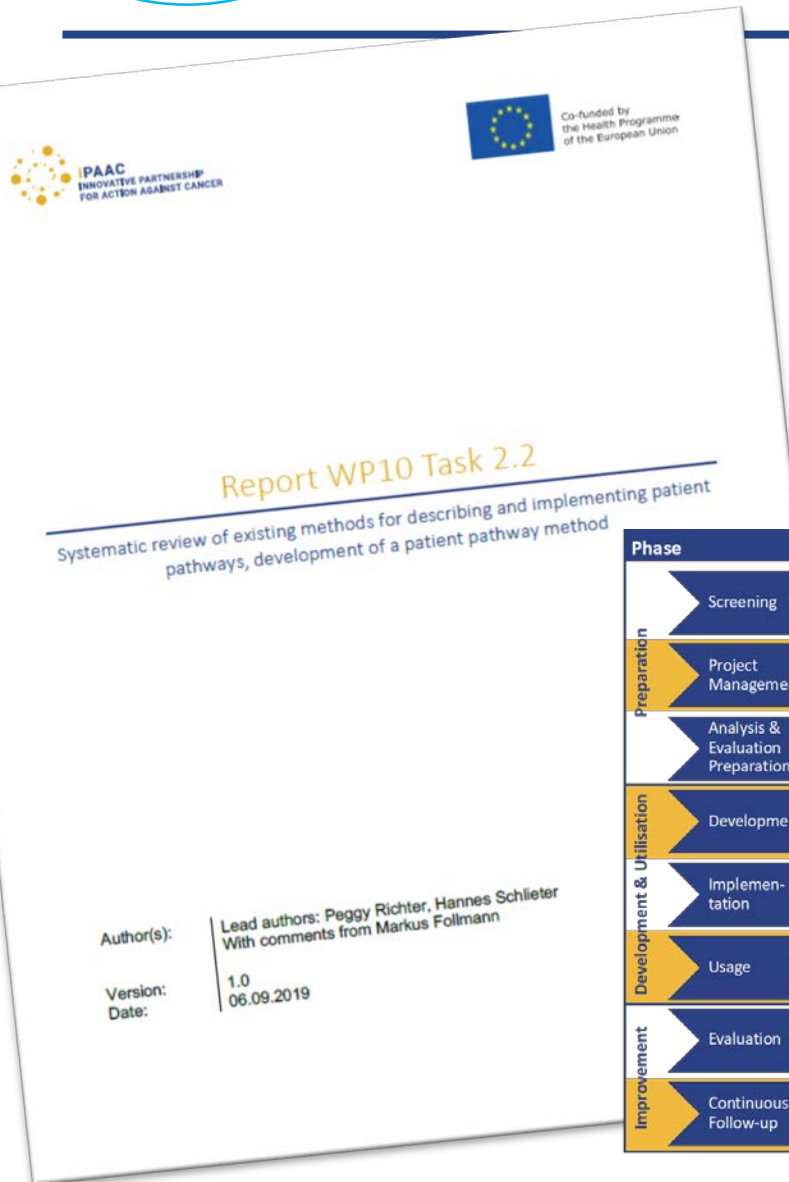
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- ⇒ Survey and Scoping Review was conducted in 2018
- ⇒ Results were presented at the 2. WP 10 meeting in Rome
- ⇒ Development of the definition of patient pathways

“A patient pathway is a 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.”

Task 2

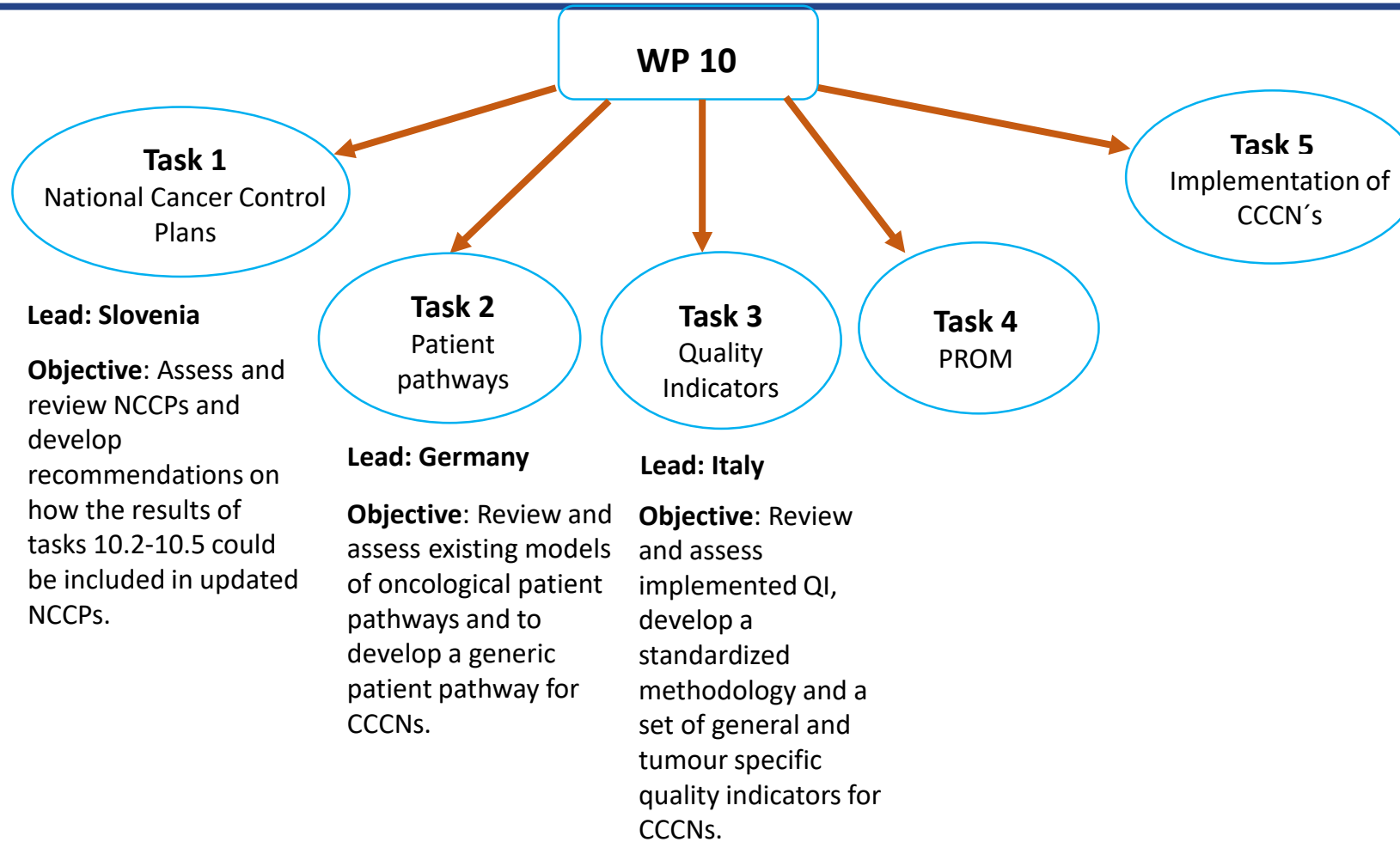
Patient pathways



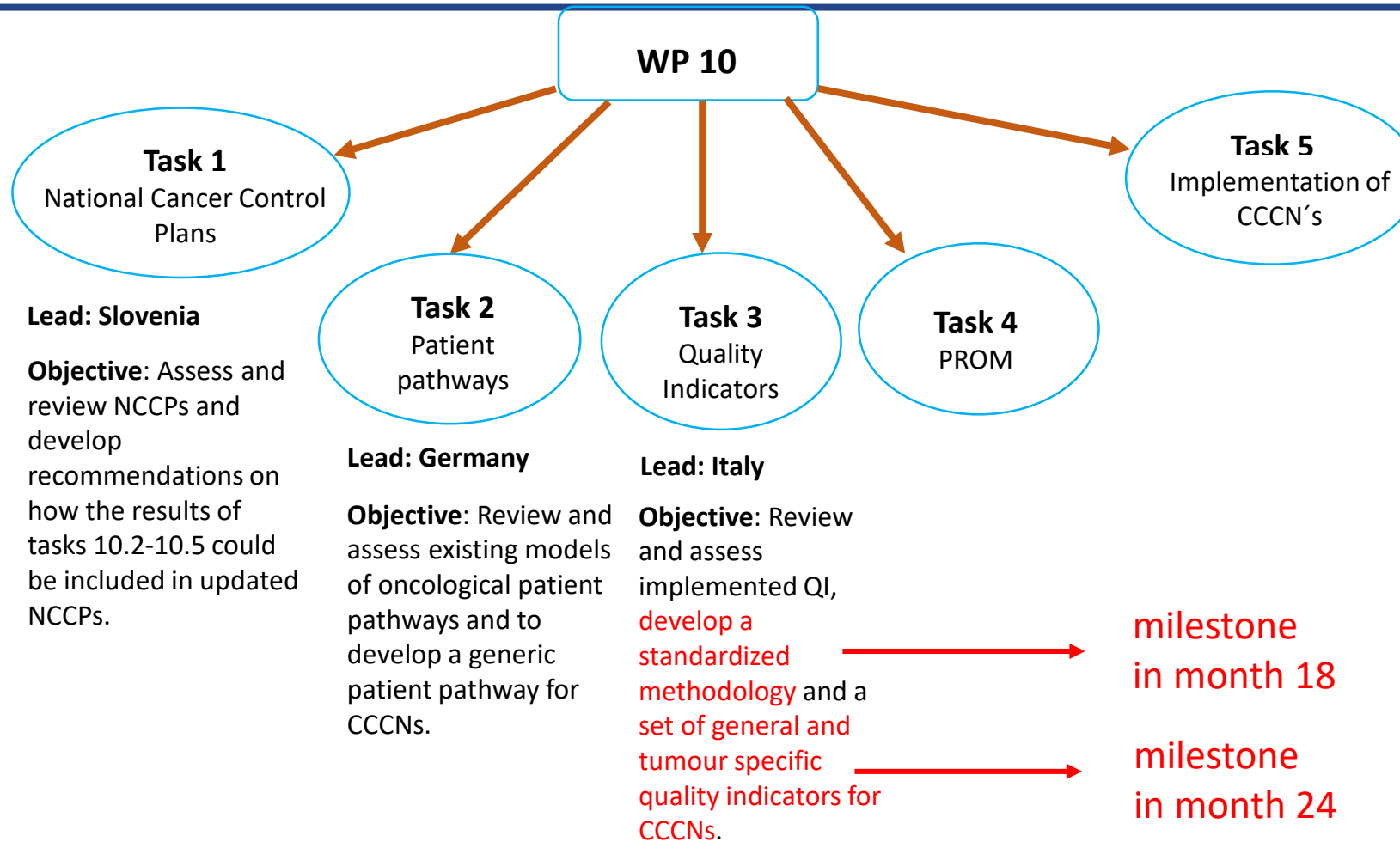
- ⇒ Literature Review of existing methods for describing and implementing patient pathways
- ⇒ Development of patient pathways method
- ⇒ Results were presented at 3rd WP 10 meeting in Budapest

Phase	Purpose	Steps
Preparation	Screening	<ul style="list-style-type: none"> To gain an overview of the current environment and evidence. Identify need for and appropriateness of PP Analyse environment (evidence, domain, setting) Check for existing PP templates and good practice examples
	Project Management	<ul style="list-style-type: none"> To define the PP project aim and to set up the project. Define clinical question using PICOT Establish multidisciplinary development team Set up project plan Train and educate team on PP initiative and project plan
	Analysis & Evaluation Preparation	<ul style="list-style-type: none"> To evaluate current evidence and care process. To prepare evaluation of PP implementation. Analyse current organisation of the care process from four perspectives: network and team, patient and family, available evidence and legislation, external partners Define process- and outcome indicators
Development & Utilisation	Development	<ul style="list-style-type: none"> To design and approve a CCCN-specific PP based on generic PP template. Select PP representation format Draft PP by adaption of PP template to CCCN-specific conditions Review PP draft, consensus finding, refinement, approval Document experience with adaption of PP template
	Implementation	<ul style="list-style-type: none"> To evaluate PP design, value and usability in pilot test. To refine and approve adapted PP for the CCCN. Set up implementation plan Inform and train pathway users Pilot and review PP in CCCN on limited group of patients Post pilot refinement of PP Approval of PP for the CCCN Develop messaging and dissemination strategy
	Usage	<ul style="list-style-type: none"> To use the PP in daily CCCN practice. Establish PP usage a common daily practice Individualise PP with regard to patient specifics (individual needs and preferences) if necessary
Improvement	Evaluation	<ul style="list-style-type: none"> To assess and communicate the improvements made by PP usage. Evaluate usability and define indicators Communicate evaluation results Adjust PP if necessary Add PP and evaluation documents to PP repository
	Continuous Follow-up	<ul style="list-style-type: none"> To monitor PP usage, deviations and recognise necessity for refinement. Define responsibilities for continuous monitoring Check applicability and relevance of PP at fixed time intervals Continuously evaluate PP Revise and update PP if necessary

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Task 3

Quality
Indicators

Systematic review of the Quality Indicators (QIs) to evaluate the CCCN approach in the management of oncologic patients

WP10 task 3

Author(s): Lead author: Giuseppe La Torre
Co-authors: Alice Mannocci, Rosario Andrea Cocchiara,
Valeria D'Egidio, Cristina Sestili, Lorenza Lia, Sara
Cianfanelli, Insa Backhaus, Barbara Dorelli, Matteo Ricciardi

Version: 3.0
Date: 12. 04. 2019

- ⇒ Systematic review of implemented QI and their respective methodology was conducted
- ⇒ Results were presented at the 3. WP 10 meeting in Budapest

Task 3 Quality Indicators

Development of a methodology for deriving generic and tumor-specific quality indicators in order to monitor and improve structures, processes and results of a CCCN with special focus on tumor-specific quality of care QIs

Authors

Markus Follmann, Henning Adam, Ellen Griesshammer, Simone Wesselmann (German Cancer Society)
Giuseppe La Torre, ?, (La Sapienza Università di Roma)

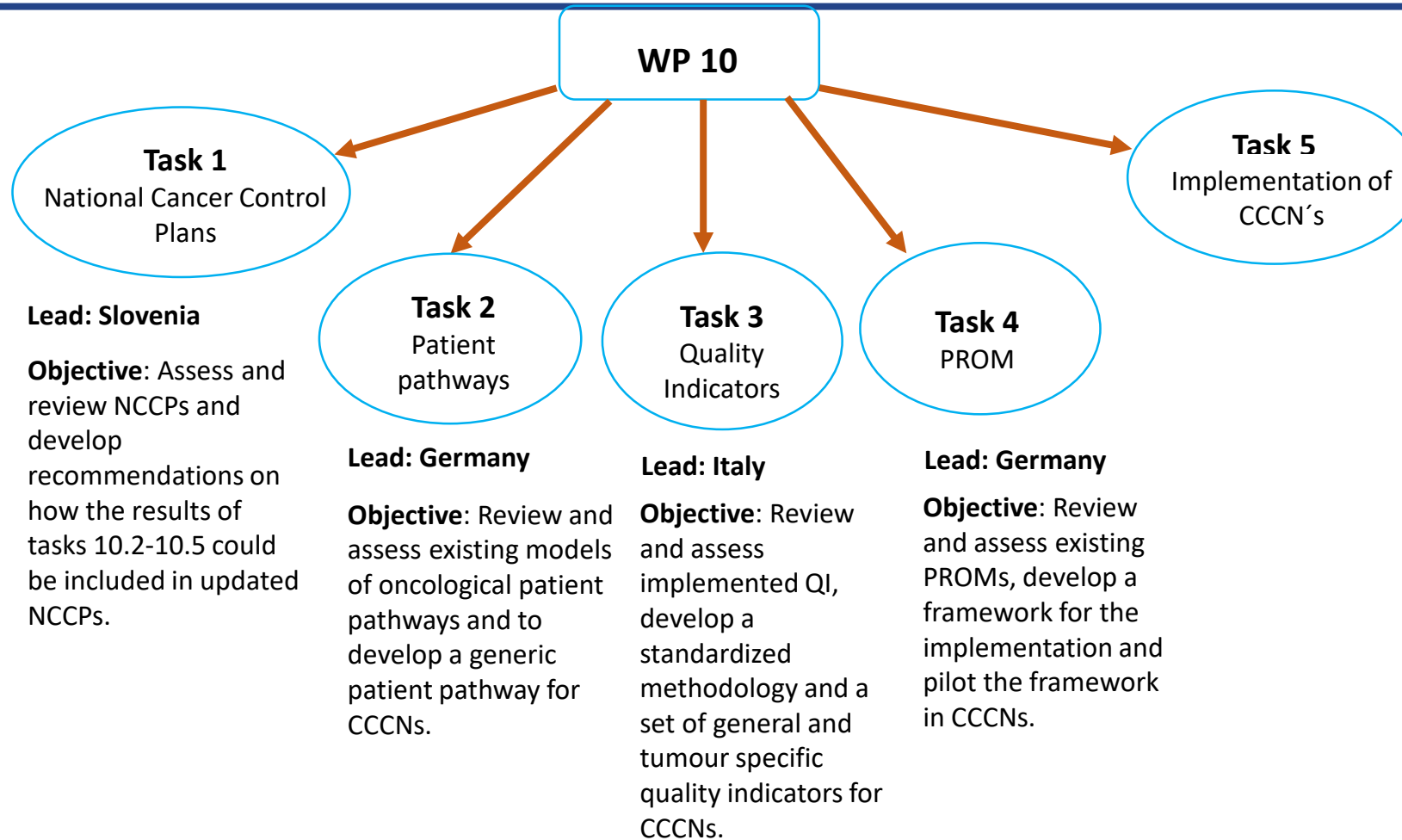
Table 1: Criteria according to defined reporting standards [1] and assessment of the proposed methodologic steps*

Criteria	Description	Comments	Vote: Y: agree / N: disagree	Vote result (%) preliminary result:
development process of performance measures	First step of selection [2]: A1) duplication A2) lack of understandability A3) not feasible for the European NCCN setting A4) defining of numerator and denominator not possible	<i>done by the steering group (members of WP10, task 3 group)</i>	Y/N	37 in favor 0 against 1 abstain

... and covered multiple tumor entities and non-entity
For the next step of task 3.3, the indicators for pancreatic cancer and colorectal cancer
represent the primary pool of indicators, as decided by the working group. An additional

- ⇒ Draft for methodology for deriving quality indicators were presented at the 3. WP 10 meeting in Budapest
- ⇒ Final method paper is planned for December 2019
- ⇒ Preparation for deriving a set of generic and tumour-specific QI have started (in cooperation with WP7 in order to identify synergies)

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Task 4 PROM

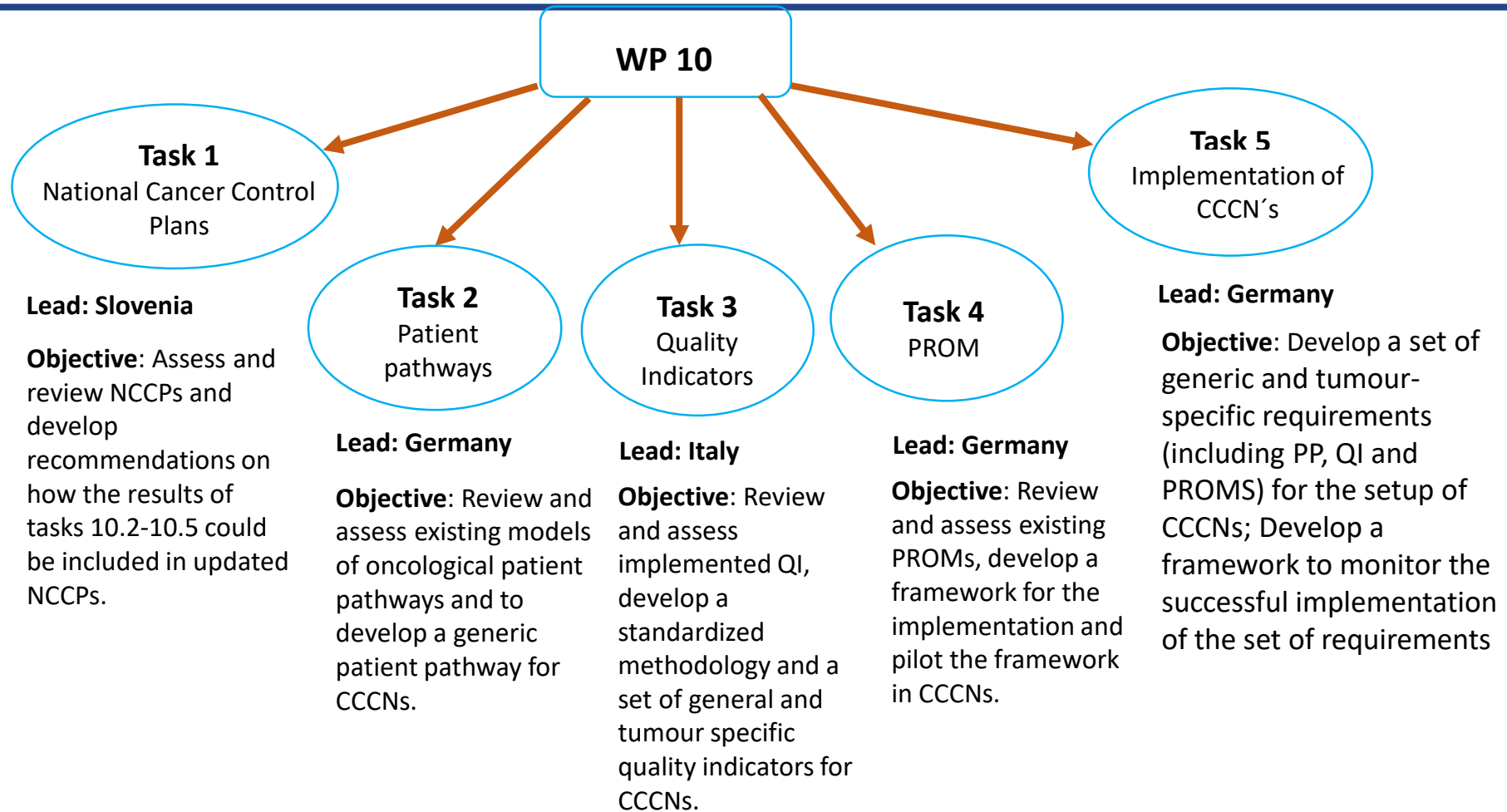
Implementation of patient-reported outcome assessment in routine cancer care – a systematic review of multicentric programs in Europe

RECOMMENDATIONS

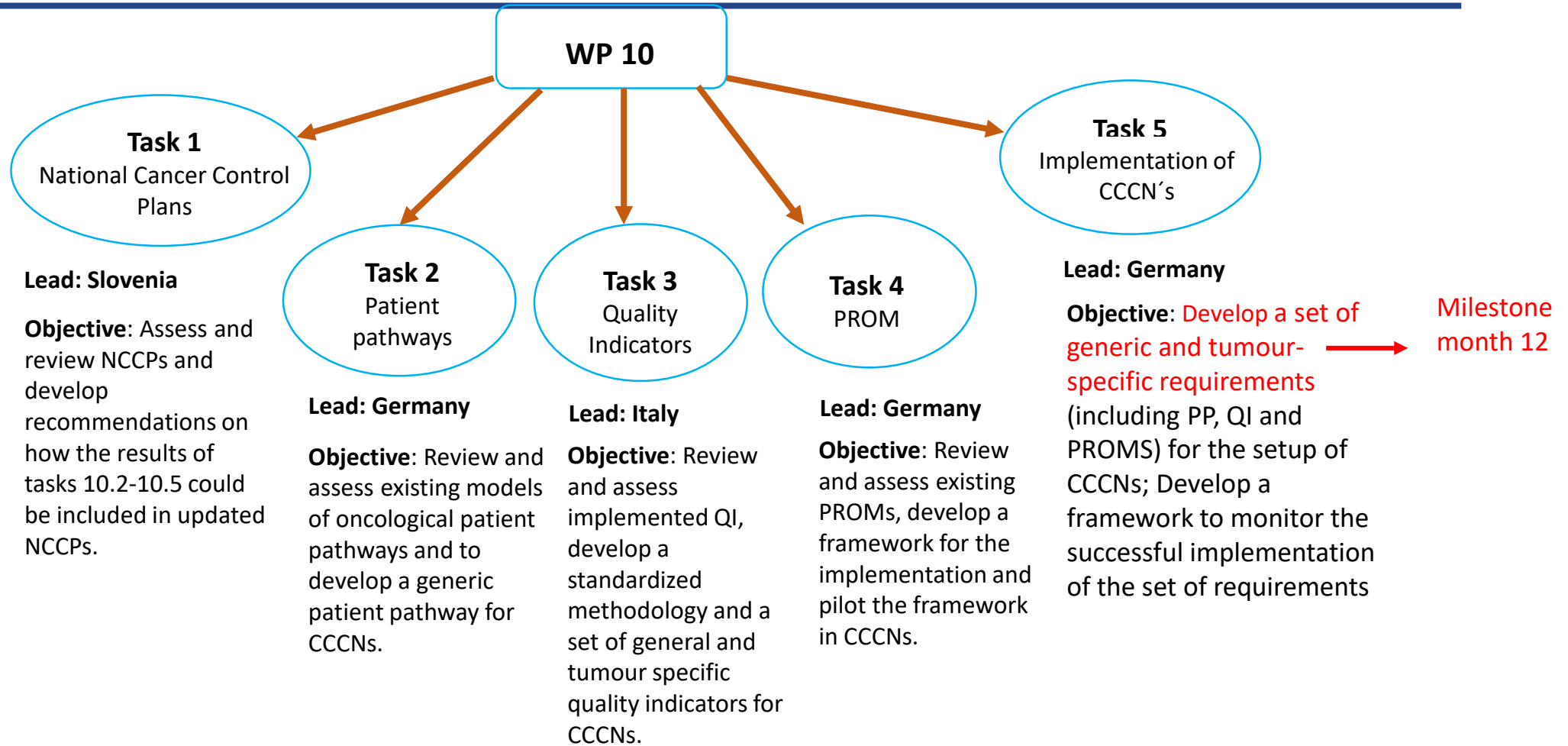
1. Plan an initial meeting to clarify the main objective of PRO assessment (screening/ monitoring vs benchmarking) as well as the exact group of cancer patients (eg kind of cancer, tumor stage and setting of care).
2. Involve at minimum one PROM coordinator per comprehensive cancer care center and preferable also an administrative support team that is eg responsible for reminding patients to complete questionnaires.
3. Organize a meeting with all relevant stakeholders to discuss which PROs are important and at what time of cancer treatment this information are needed. Taking the main objective of PRO assessment into account, all stakeholders are involved in the decision which questionnaires are used and when PROs are collected and evaluated. Carefully decide which data need to be collected to allow for case mix adjusted comparisons. Consider using an established standard data set, like those developed by ICHOM.
4. Decide how PROs can be looked up (eg paper-based or integrated in the electronic health record) and about the mode of presentation (literal, numerical or graphical).
5. Choose the mode of data collection and data capture dependent on the personnel and infrastructural resources, patient abilities and the possibility of integration in the clinical workflow. Avoid a change from a paper-based collection to an electronic presentation and vice versa as it requires additional resources. Make sure additional providers can join later in the process, i. e. once the program is established.
6. Ensure that data collection and data recording is in accordance with data security issues.
7. Allow for flexible data access in daily clinical routine and benchmarking as well as data usage for clinical trials and research purposes.
8. Decide who is responsible for which task in data collection, recording and evaluation and train all stakeholders in their specific tasks.
9. Develop strategies for responding to issues identified by the questionnaires, for example use decision tree pocket-cards.
10. Continuously monitor the implementation process, even in the maintenance phase.

- ⇒ Literature review of existing models of collecting PROMs in routine cancer care as well as in studies with a European focus
- ⇒ Results were presented at 3. WP 10 meeting in Budapest
- ⇒ The draft recommendations for the implementation of PROM in routine cancer care were presented

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Task 5 Implementation of CCCN's



Comprehensive Cancer Care Networks (CCCN's)

Standard for
Comprehensive Cancer



Comprehensive Cancer Care Net- works (CCCNs)

Standard for Colorectal and Pancreatic
Cancer Care Networks

Developed in the context of iPAAC from the working group of
Work Package 10

2 pilot centres

(Lower Silesian Oncology Centre, Wroclaw/Poland
and Charité, Berlin/Germany)

⇒ Set of Standards for CCCN and Set of
Standards for Colorectal and Pancreatic
Cancer Care was presented at the 2. WP
10 meeting in Rome

Data sheet:

ID	Definition of indicator	Indicator target	Numerator	Population (or denominator)	Unit	Target	Actual value
1	Prevalence of colorectal cancer	Prevalence of colorectal cancer	Number of patients with colorectal cancer	All patients with CRC and all patients with stage IV CRC	%	< 10%	Actual value
2	Prevalence of pancreatic cancer	Prevalence of pancreatic cancer	Number of patients with pancreatic cancer	All patients with stage IV pancreatic cancer	%	< 10%	Actual value
3	Post-operative presentation of cases	Post-operative presentation of all primary cases	All operative and endoscopic primary cases who have been presented at the post-operative conference	Operative and endoscopic primary cases	%	< 10%	Actual value
4	Psychosocial support	Appropriate use of psychosocial support	Number of patients who have been given psychosocial support (range of 0-100)	Total primary cases	%	< 10%	Actual value
5	Challenging by social services	As high a rate of patients as possible who have been challenged by the social services	Number of patients who have been challenged by the social services	Total primary cases	%	< 10%	Actual value
6	Participation in studies	Indicator of as many patients as possible in studies	All patients of the CCCN who have been included in a study or a clinical practice study	Total primary cases	%	< 10%	Actual value
7	CRC patients with a positive family history	Indicator of as many patients as possible with a positive family history	Number of primary case patients with CRC and positive family history	Total primary cases	%	< 10%	Actual value

Task 5

Implementation of CCCN's



⇒ Framework to monitor the successful implementation of the set of requirements was developed and agreed at 3. WP 10 Meeting

Table of content

1. Prologue
2. Division of authority
3. Documents needed for certification
4. Auditors
5. Audit
 - a. Audit plan
 - b. On-site audit
6. Certificate
7. Example

NEXT STEPS

4th WP 10 Meeting

14 – 15 January 2020

Monday, 14 January 2020:

Time	Topic	Documents name	Presenter
11:00	Early Lunch		
12:00 – 12:30	TOP 1 Welcome to National Institute of Oncology Welcome and updates from the IA		<i>Dr. Zoltán Takácsi-Nagy</i> Deputy Director General NIO <i>Simone Wesselmann,</i> WP 10 Leader
12:30 – 13:30	TOP 2 Task 10.2.2 »Systematic review of existing methods for describing and implementing patient pathways«, proposal of patient pathway method Presentation and agreement	10.2.2. Patient Pathway report.pdf	<i>Hannes Schlieter,</i> Task leader 2 <i>Peggy Richter</i>
13:30 - 14:30	TOP 3 Task 10.1.1 National Cancer Control Programmes and Task 10.1.3. Literature review stewardship/governance of cancer care Presentation and agreement	10.1.1 NCCCP REPORT iPAAC Final draft 29 Aug 2019e.pdf 10.1.3 NCCP Report GS Final Aug 2019e.pdf	<i>Tit Albrecht,</i> Task leader 1 <i>Marjetka Jelenc</i>
Coffee break			
15:00 – 16:00	TOP 4 Task 10.3.1 and 10.3.2 (Milestone) »Literature review of already implemented QIs and their respective methodology which was used« and »Development of a standardised methodology to derive specific, measurable, achievable and timebound QIs for the use in CCCNs« Presentation and agreement	10.3.2. QI development of a methodology.doc	<i>Giuseppe la Torre,</i> Task leader 3
16:00 – 17:00	TOP 5 Task 10.4.1 »Literature review of existing models of collecting PROM in routine cancer care« Presentation and agreement	10.4.1 PROM_Scheibe-M-2019-iPAAC-20190801.doc 10.4.1 PROM Appendix 2 Query reply Schepers.doc 10.4.1 PROM Appendix 1 Searchstring.xls	<i>Christoph Kowalski</i> Task leader 4

4. WP 10 meeting, takes place in Ljubljana, 14. - 15. January 2020

Aim:

Presentation of the (interim) results and preparation of the next steps

OVERVIEW TIMETABLE WP 10

WP Meeting 1 M1 (May 2018) Germany (Berlin) <i>Kick Off</i>	WP Meeting 2 M 10 (27.-28. February 2019) Italy (Rome) <i>confirmed</i>	WP Meeting 3 M 16 (16.-17. September 2019) Hungary? <i>confirmed</i>	WP Meeting 4 M 20 (ca. December 2019) Slovenia? <i>confirmed</i>	WP Meeting 5 M 24 (ca. April 2020) Poland? <i>tbc</i>	WP Meeting 6 M 30 (ca. September 2020) Germany (Berlin) <i>Closing</i>
Activities	Activities	Activities	Activities	Activities	Activities
Introduction Goal and aim of WP 10 Introduction task leaders and tasks Overview to do's, deadlines, deliverables Agreement on meetings, agenda etc. Decision on tumour entity Publication of task results	Presentation of: - Task 1.1. (M10) - Review NCCP (draft) - Task 1.3 (M12) - Stewardship - Task 2.1 (M12) - Literature review PP - Task 3.1 (M12) - Literature review QI - Task 5.1 (M12) - Requirements for CCCN	Presentation of: -Task 1.1 (M16) - Assessment NCCP -Task 2.2 (M18) - Review models PP -Task 3.2 (M18) - Methodology QI -Task 4.1 (M12) - Literature review PROMs -Task 5.2 (M18) - Development framework CCCN	Presentation of: -Task 2.3 (M24) - development of methodology PP -Task 3.3 (M24)- set of QI for the use in CCCN -Task 4.2 (M24) - Framework for PROMs	Presentation of: -Task 1.2 (M34) -Recommendations NCCP -Task 1.4 (M24) - survey results stewardship -Task 2.4 (M30) - Use of PP in CCCN -Task 5.3 (M34) -Implementation of CCCN -Task 6.1 (M34) - Start Road Map for WP 10	Presentation of: -Task 6.1 (M34) -Finalization Road Map for WP 10 -Task 5.3 (M34) - Peer Review CCCN Report
	<div data-bbox="377 739 453 782">EU Deliverable</div> <div data-bbox="326 782 466 882">Definition of CCCN pilot sites (M 3) - Milestone 10.1</div> <div data-bbox="364 861 504 961"></div>	<div data-bbox="766 739 843 782">EU Deliverable</div> <div data-bbox="728 782 835 1053">Generic and tumour-specific requirements for the setup of CCCN's are defined (M12) - Milestone 10.2</div> <div data-bbox="721 1053 861 1153"></div>	<div data-bbox="1161 739 1238 782">EU Deliverable</div> <div data-bbox="1123 782 1230 932">Standardised Methodology to derive QI (M18) - part 1 Milestone 10.3</div>	<div data-bbox="1556 739 1633 782">EU Deliverable</div> <div data-bbox="1503 782 1648 903">A set of Qis for the use in CCCN's is agreed (M24) - part 2 Milestone 10.3</div>	<div data-bbox="1989 739 2066 782">EU Deliverable</div> <div data-bbox="1949 782 2333 1096">Roadmap on Implementation and Sustainability of Cancer Control Actions in the field of governance of integrated and comprehensive cancer care (M34) - Deliverable 10.</div>
Preparation of: -Task 1.1. (M10) - Review NCCP (draft) -Task 1.3 (M12) - stewardship -Task 2.1 (M12) - Literature review PP -Task 3.1 (M12) - Literature review QI -Task 5.0 (M10) - Definition of pilot CCCN sites -Task 5.1 (M12) - Requirements for CCCN	Preparation of: -Task 1.1 (M16) - Assessment NCCP -Task 2.2 (M18) - Review models PP -Task 3.2 (M18) - Methodology QI -Task 4.1 (M18) - Literature review PROMs -Task 5.2 (M12) - Development framework CCCN	Preparation of: -Task 1.4 (M24) - survey results stewardship -Task 2.3 (M24) - development of methodology PP -Task 3.3 (M24)- A set of QI for the use in CCCN is derived -Task 4.2 (M24) - Framework for PROMs	Preparation of: -Task 1.2 (M34) - Recommendations NCCP -Task 2.4 (M30) - Use of PP in CCCN -Task 3.3 (M24)- A set of Qis for the use in CCCN is agreed -Task 5.3 (M34) - Implementation of CCCN -Task 6.1 (M34) - Start Road Map for WP 10	Preparation of: -Task 6.1 (M34) -Finalization Road Map for WP 10 -Task 5.3 (M34) - Peer Review CCCN & Report	



Thank you very much



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