Task 4.2 Development and Agreement of Lung Cancer Patient Pathway Template

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Project Information

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Abbreviations and Acronyms

CCC	Comprehensive Cancer Centre
CCCN	Comprehensive Cancer Care Network
EC	European Commission
EU	European Union
IPAAC	Innovative Partnership for Action Against Cancer
MTB	Molecular Tumorboard
TB	Tumorboard
WP	Work Package

Executive Summary

This Deliverable D6.4 presents a comprehensive lung cancer patient pathway template designed for application within Comprehensive Cancer Care Networks (CCCNs). The template was developed using and enhancing the pathway development method established in the previous Joint Action iPAAC, with a focus on increasing patient-centredness.

The development process relied on current evidence for lung cancer and included numerous workshops and feedback loops with lung cancer care specialists. To ensure high-quality outcomes and incorporate the patient perspective, patient representatives and their associations were actively involved throughout the process.

The lung cancer patient pathway template encompasses the following phases: CCCN entry, staging diagnostics, treatment planning, treatment, follow-up/end-of-life care, and the conclusion of CCCN care. Major activities such as "patient consultation," "staging diagnostics," "standard tumour board (TB) meeting," "molecular tumour board (MTB) meeting," and "treatment" are elaborated in separate sub-pathway models. Additionally, quality indicators (refer to D6.3 Set of Standards for Lung Cancer Care and Set of Quality Indicators for Lung Cancer) are integrated along the pathway.

To further enhance patient-centeredness within CCCNs using the lung cancer patient pathway template, we have provided a comprehensive toolbox of patient-centered practices for each phase of the pathway. These practices are specifically designed to ensure that the patient pathway is genuinely focused on the patient's needs, thereby supporting CCCNs in delivering truly patient-centered care effectively.

Although developed for the context of CCCNs, the pathway's generic nature makes it equally applicable in Comprehensive Cancer Centres (CCCs).

1 Background and Preliminary Activities

A patient pathway is defined as "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" (Richter, Hickmann, & Schlieter, 2021).

To create a patient-centred pathway for lung cancer patients, it was essential to first explore the concept of patient-centredness within a Comprehensive Cancer Care Network (CCCN). This process began with preliminary activities aimed at establishing a consensus among Work Package (WP) participants on the definition and dimensions of patient-centredness in CCCNs. A systematic meta-review and a WP survey were conducted, leading to a unified definition and model for patient-centeredness within CCCNs.

Consensus with WP6 members could be achieved for the following definition of patient-centredness in a CCCN: *"Patient-centredness in a Comprehensive Cancer Care Network (CCCN) is a philosophy of care prioritising cancer patients' physical, emotional, and social needs, as well as personal values on every step of the patient pathway. In patient-centred CCCNs, patients are empowered and engaged to become active partners in healthcare in relation to their individual preferences and capabilities with the goal of providing personalised, high-quality, holistic care with the best possible outcomes."*

The agreed-upon model of patient-centeredness in CCCNs (Figure 1) comprises eight main dimensions, each encompassing two to four subdimensions. Each dimension and subdimension has been clearly defined, and an extensive list of patient-centred activities has been developed to facilitate the practical implementation of the model across all dimensions. The arrangement of boxes in the model is not indicative of any specific hierarchy or order. Digital health, performance monitoring, and the patient pathway have been identified as overarching themes that permeate all dimensions.
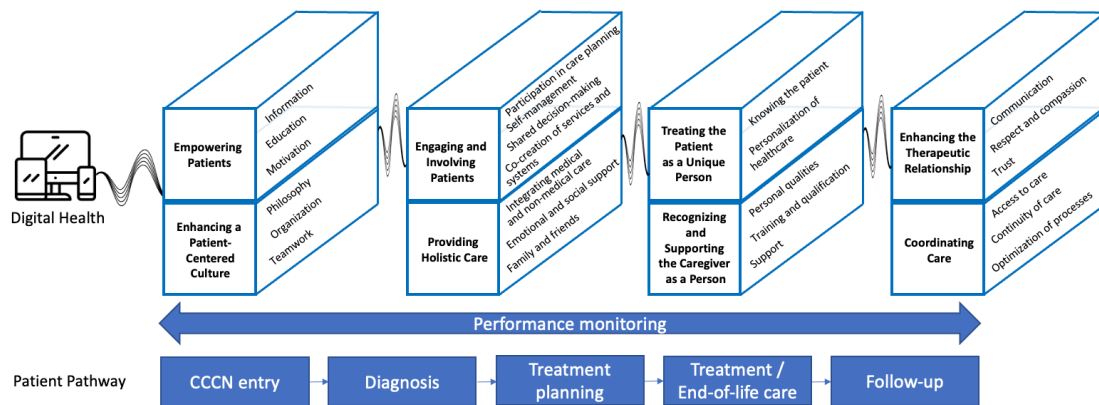
Figure 1. Model of Patient-Centredness in Comprehensive Cancer Care Networks

Subsequently, the established definition and model of patient-centredness were utilised to refine the iPAAC methodology for developing and implementing patient pathways (Richter & Schlieter, 2023), with a focus on patient-centred practices.

The patient-centeredness definition and model in CCCNs were then employed to develop a set of design principles for patient-centred pathways, following the guidelines proposed by Möller, Guggenberger, & Otto (2020). This effort yielded 16 design principles categorised into five meta-requirements, which provided a systematic framework for incorporating concrete patient-centred practices into the iPAAC method. Patient-centred practices aim to create pathways that meet the needs and objectives of patients. These practices are formulated for each phase of the pathway lifecycle:

- Preparation and Analysis (Table 1),
- Development and Implementation (
- Table 2) and
- Continuous Improvement (Table 3).

An evaluation and revision of the patient-centred practices were conducted with a focus group of five experts from European Cancer Care Organisations, each with substantial experience in designing and implementing patient pathways. This focus group was held online in June 2023. Parallel to the focus group, each participant completed a survey, in which Likert scales were utilised to receive a concrete assessment the relevance and feasibility of the individual patient-centred practices. While relevance was defined as the appropriateness and significance of the practices to enhance patient-centred care in the pathway development and implementation method, feasibility was referred to as the practicality or possibility of implementing the patient-centred practices in "real life". The average ratings on relevance and feasibility,

as provided by the participants of the focus group, are detailed in the last column of the respective Table 1,

Table 2, and Table 3.

Table 1. Patient-centred practices to enhance the patient pathway lifecycle phase "Preparation and Analysis" (R = Relevance, F = Feasibility, both rated from 1 = Poor, 2 = Fair, 3 = Good, 4 = Very Good, 5 = Excellent)

Phase	Patient-Centred Practices	Evaluation
Screening	Utilise the pathway to optimise and redesign processes, focusing on patient-centred aspects, such as continuity of care, communication, or transparency.	R = 4,6 F = 4,0
Screening	Collect feedback from patients, their families and/ or patient representatives to gain insights into the environmental context, the necessity for a pathway, and specific problem areas the pathway should address.	R = 4,0 F = 2,6
Project Management	Specify the patient group in terms of their general willingness and capability to be engaged in care.	R = 3,4 F = 2,0
Project Management	Ensure that patient(s) (representatives) are part of the pathway development team and that they can substantively engage in every development stage.	R = 4,0 F = 2,8
Project Management	Explore opportunities to collaborate with the local community connected to the specific condition.	R = 4,2 F = 2,8
Project Management	When training the development team on the pathway development process, place the patient in the centre of attention, e.g., address the need for: - incorporating methods and tools that can enhance patient engagement and empowerment, - seeking opportunities to inform and educate patients about their condition, - designing flexible pathways that accommodate individual preferences and needs.	R = 4,6 F = 3,6
Analysis/ Evaluation Preparation	Clarify and evaluate the current care process from the perspective of patients and involving patients.	R = 4,4 F = 3,0
Analysis/ Evaluation Preparation	Prepare for pathway evaluation by defining measures that capture the patient's perspective of outcomes and experiences.	R = 4,8 F = 3,2
Analysis/ Evaluation Preparation	Use the information obtained through the patient-focused measures to support understanding of patient's goals, values, and preferences, individualise care and optimise processes.	R = 4,8 F = 3,4

Table 2. Patient-centered practices to enhance the patient pathway lifecycle phase "Development and Implementation" (R = Relevance, F = Feasibility, both rated from 1 = Poor, 2 = Fair, 3 = Good, 4 = Very Good, 5 = Excellent)

Phase	Patient-Centered Practices	Evaluation
Development	Maximise possibilities along the pathway for patient information and education, e.g., by: - detailing when and by whom patients are informed, - providing tailored information and health education programs, - providing access to consultation summaries.	R = 4,4 F = 3,6

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	Integrate a shared decision-making (SDM) module and consequently accommodate for different pathway variations.	R = 4,8 F = 3,4
	Provide (digital) SDM tools to caregivers and patients.	R = 4,4 F = 3,6
	Explore further possibilities for pathway steps in which patient feedback can help determine pathway variations or tasks.	R = 4,6 F = 3,4
	Maximise possibilities along the pathway to enhance patients' self-management, e.g., by: - offering access to self-management tools, - collaboratively developing a self-management plan, - offering specific self-management trainings.	R = 4,8 F = 3,8
	Continuously offer emotional and social support along the pathway, e.g.,: - providing information on self-help programs, spiritual care, or peer groups, - assessing and being responsive to the extent to which patients want family and/ or friends involved in their care.	R = 4,8 F = 3,2
	Facilitate access to carers, ancillary disciplines, and non-medical care provision.	R = 4,2 F = 2,6
	Develop a patient version of the pathway and give patients access.	R = 4,6 F = 3,8
Implementation and Usage	Educate pathway users on patient-centred topics, e.g, about: - patient empowerment and engagement, - SDM, - newly introduced self-management or information tools, and - communication.	R = 4,6 F = 3,6
	Control, monitor and document unpredictable and unexpected deviations from the pathway.	R = 4,4 F = 2,8

Table 3. Patient-centred practices to enhance the patient pathway lifecycle phase "Continuous Improvement" (R = Relevance, F = Feasibility, both rated from 1 = Poor, 2 = Fair, 3 = Good, 4 = Very Good, 5 = Excellent)

Phase	Patient-Centered Practices	Evaluation
Evaluation	Assess patient-reported measures (PROMs) defined in phase one and, if necessary, improve accordingly.	R = 4,0 F = 3,6
	If not introduced already, include specific patient empowerment, patient engagement, and SDM measures to the evaluation process, such as: - the "Patient Activation Measure" - the "Patient Empowerment Scale" - the "Patient Preferences for Participation" - "CollaboRATE", "SDM-Q-DOC", "OPTION"	R = 4,4 F = 3,0
Follow-Up	Engage with patients and their families to ensure their perspectives and experiences of the pathway are continuously incorporated.	R = 4,8 F = 3,2
	Continuously search for and update the pathway regarding new evidence on patient-centeredness.	R = 4,6 F = 3,2

In addition to the results obtained through the systematic literature review and WP survey, the current state-of-the-art on patient-centeredness in existing patient

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pathway development and implementation methods was also utilised to guide the formulation of the practices detailed in Table 1, Table 2, and Table 3.

2 Methods: Creation of the Lung Cancer Patient Pathway Template and Review of Patient-Centred Practices

2.1 Pathway Development

For the development of the lung cancer patient pathway template, the methodology provided with the iPAAC patient pathway guide (iPA^2-Guide) was applied (Richter & Schlieter, 2023). Several workshops and feedback loops were conducted. A hybrid hands-on patient pathway workshop in Luxembourg at the INC in conjunction with the WP6 meeting (27th Nov 2023) was performed. Several video conferences with members of the patient pathway working group were held to discuss revisions.

In addition to the results from the workshops and revision loops with the experts of the WP10 patient pathway working group, the following documents were used to develop the CRC patient pathway template to be used in CCCNs:

- Recommendations from the WP6 Standard for Lung Cancer Care Networks
- Recommendations from clinical practice guidelines
- Existing pathways and guidelines from the WP6 patient pathway working group partners
- Existing pathways from cancer organisations (online available)

To describe the relevant information for each phase in the patient pathway template, the following characteristics were used and described. This information was used to develop the patient pathway template model.

- **Phase name**
- **Patient inclusion criteria**: which patient population is addressed?
- **Responsible/involved CCCN unit(s)**: who is/should be involved?
- **Necessary resources (what?)**: e.g. medical technology, infrastructure
- **Phase inputs**: e.g. information, lab results
- **Process**: interventions, decisions, consultations, tasks related to medical, nursing, supportive care (physical, psychological, social, information, spiritual domains), administrative
- **Timeframes**: information about time criticalities, time recommendations, iterations
- **Phase outputs**: what are outputs of the process?
- **Measures/evaluation criteria**: e.g. quality indicators to be assessed during the phase
- **References**: what literature/evidence is the process description based on?
- **Patient-centred practices**
- **Adaptation notes**: required, optional steps; national, regional, local conditions to be considered for the development of a CCCN-specific patient pathway based on the template

2.2 Modelling of the lung cancer patient pathway template

The pathway templated was created utilising a BPMN.io based modelling environment deployed for CraNE project purposes by the Research Group Digital Health of the TUD Dresden Technical University (see Figure 2). It provides a template gallery and features to create pathway models, including quality indicators (see Figure 3).
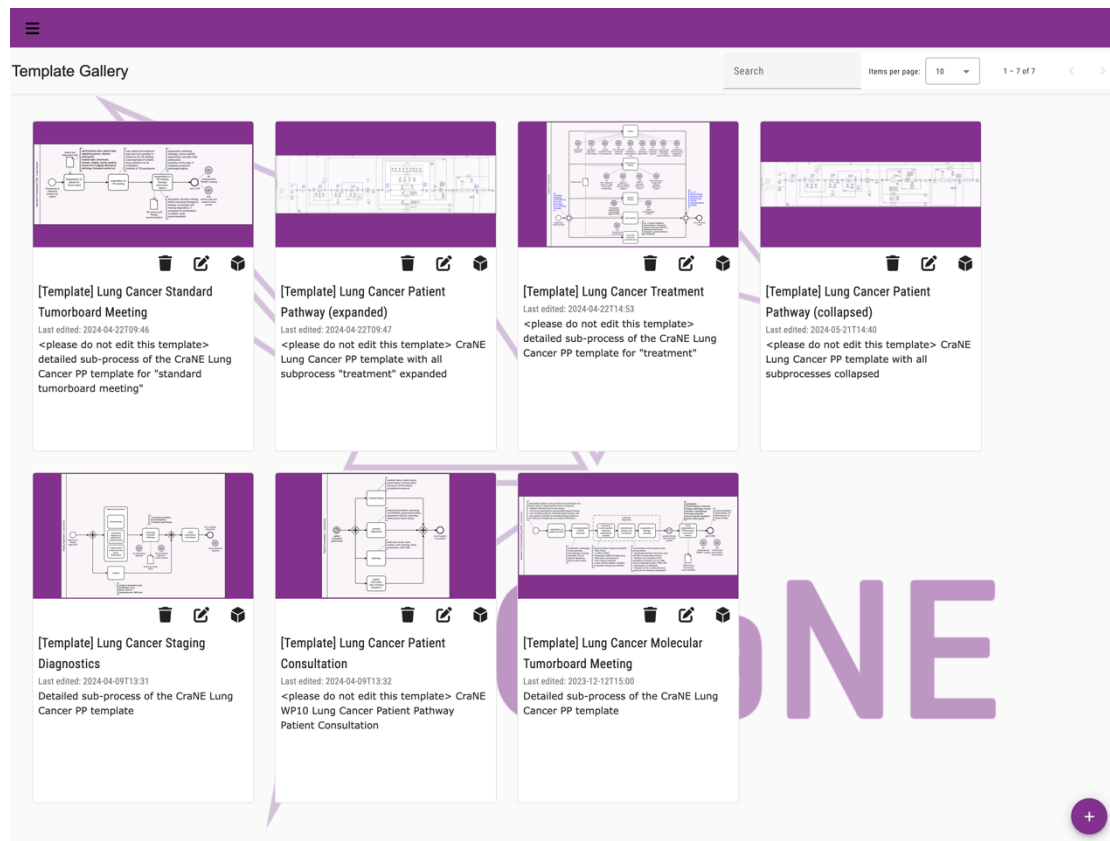

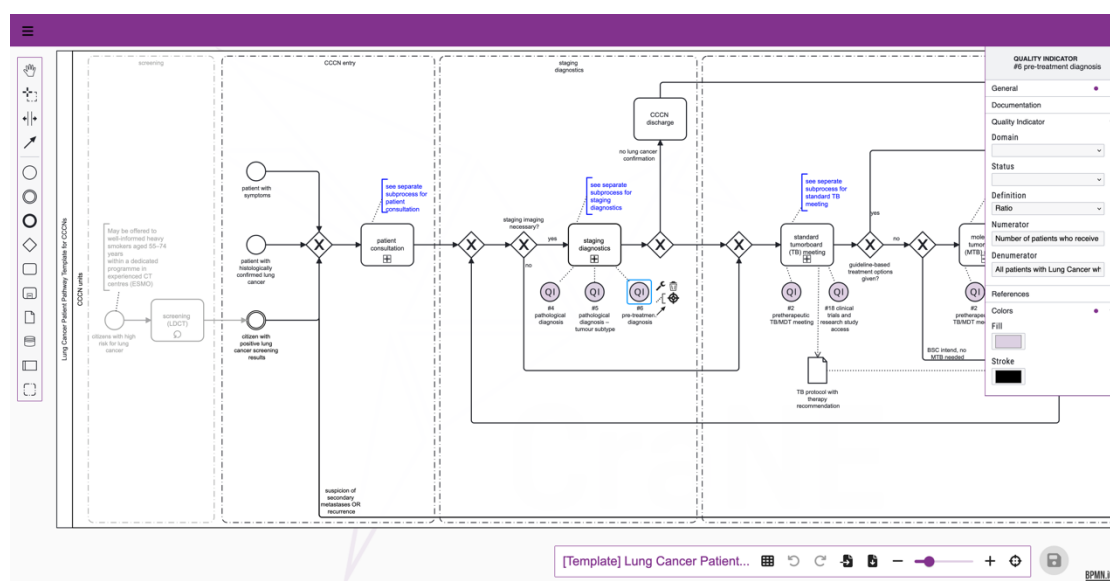Figure 2. Screenshot of the modelling tool used (template gallery)

Figure 3. Screenshot of the modelling tool used (pathway view)

The lung cancer patient pathway template is displayed using an extended Business Process Model and Notation (BPMN). For a description of the symbols used, we refer to the BPMN notation poster to be found under: http://www.bpmb.de/images/BPMN2_0_Poster_EN.pdf

2.3 Systematic literature review on patient-centred practices for lung cancer patients

Given the complex nature of lung cancer, it is essential to recognise that patients have unique needs that must be identified to help Comprehensive Cancer Care Networks (CCCNs) offer more patient-centred care (Giuliani et al., 2016). To address this, a systematic literature review was conducted, specifically examining patient-centered practices in lung cancer care. In January 2024, the following search string was utilised in a PubMed query:

(Patient*) AND (Engag* OR Empower*) OR (Patient Centered* OR Patient Centred* OR shared decision making OR patient participation OR patient involvement) AND (cancer OR oncology OR tumour OR tumor) AND (lung* OR pulmon*)

A total of 116 publications were retrieved and screened by two independent researchers. Articles that explored patient-centered practices, such as shared decision-making or reporting of screening results, for lung cancer patients were included. Ultimately, 87 articles met the inclusion criteria and were categorised according to the respective phase of the patient pathway in which the described practice would be utilised (Table 4). Of these 87 articles, 64 focused solely on shared decision-making for lung cancer screening.

Table 4. Number of included records for each patient pathway phase

Patient Pathway Phases	Number of records
Screening	64
CCCN Entry	4
Staging and Diagnostics	0
Treatment Planning	14
Treatment	0
End-of-life Care	2
Follow-up	3
End of CCCN Care	0

The described patient-centered practices were systematically extracted from the articles and are described in chapter 3 Results: Lung Cancer Patient Pathway Template for each phase.

2.4 Workshops with patient representatives

To gain further insights into how the lung cancer patient pathway can support a patient-centered approach in Comprehensive Cancer Care Networks (CCCNs), two workshops with patient representatives were conducted by the "Institut National du Cancer (INC)" in Luxembourg in April 2024. The first workshop included six patient representatives, and the second workshop included four. Due to the difficulty of finding patient representatives specifically for lung cancer, representatives who had personally experienced any type of cancer, were included.

During the workshops, the session commenced with an introductory segment offering an overview of the patient pathway. Delving deeper, the participants embarked on the creative task of storyboarding, unravelling the intricate steps of their individual journeys and reflecting on their unique experiences. Following this, a series of specific questions were posed to elicit detailed responses from each participant. Flexibility was encouraged to ensure comprehensive insights. The workshops further facilitated group discussions, allowing participants to exchange perspectives, share insights, and identify common themes or concerns. Finally, the sessions concluded with a wrap-up segment, summarising key takeaways and outcomes gleaned from the discussions.

The outcomes of these dynamic workshops have been integrated into patient-centered practices along the phases of the lung cancer patient pathway, as elaborated in 3 Results: Lung Cancer Patient Pathway Template.

3 Results: Lung Cancer Patient Pathway Template Accompanied with Patient-Centred Practices

3.2.1 Overview

The lung cancer patient pathway template is outlined and detailed below, encompassing the following major phases: CCCN entry, staging diagnostics, treatment planning, treatment, follow-up/end-of-life care, and the conclusion of CCCN care (see Figure 4). Screening is integrated as a key interface, marking one of the starting points of the lung cancer patient pathway care in CCCNs. In addition to the figures in this deliverable report, the lung cancer patient pathway models are also provided in a separate PDF file.
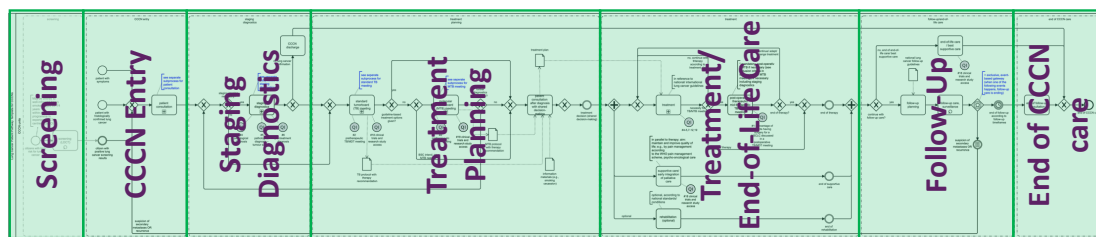

Figure 4. Overview of the Lung Cancer Patient Pathway and its phases (screening as interface)

For each phase, patient-centred practices derived from systematic literature reviews and workshops with patient representatives are described. These practices ensure the pathway is genuinely patient-centred, supporting CCCNs in delivering effective patient-centred care. They will be provided to CCCNs as a working document and toolbox for each pathway phase.

In the workshops, some patient-centred practices were elicited from the patient representatives, which are valid for every phase of the patient pathway. These practices are described in the following:

- Administrative support was identified as essential, covering tasks such as booking appointments, arranging examinations and treatments, managing social security formalities, handling billing, and assisting with the patient's return to work and normal life.
- Supportive care and holistic well-being were also highlighted, with patients pointing to the benefits of services like sophrology, onco-aesthetics, acupuncture, physiotherapy, reflexology, massage therapy, proactive psychological counselling for patients and their families, nutritional advice, neurological care, patient groups, spiritual support, and volunteering opportunities.
- After diagnosis, patients stressed the necessity of providing a comprehensive treatment notebook or folder. This should encompass their care pathway, examination and treatment schedules, useful information, support resources, medical appointments, and details about supportive care options. This aligns

with findings in the literature, such as a study by Tsianakas et al. (2012), which demonstrated an increased need for more information among lung cancer patients post-surgery. Instead of a folder or notebook, patients could be provided with digital summaries and navigation support through a patient portal or an app (Kneuertz et al., 2020).

- Patients also highlighted the need empathetic and increased communication from healthcare professionals, as well as active listening.
- Furthermore, following European and international guidelines and recognising the importance of the case manager were deemed crucial.

3.2.2 Screening

The patient pathway working group agreed to include screening not as a phase of the patient pathway itself but as an interface starting point. This decision was made because screening addresses not only lung cancer patients but also a broader population. Consequently, screening is depicted in light grey in the patient pathway, accompanied by additional information and references (see Figure 5).
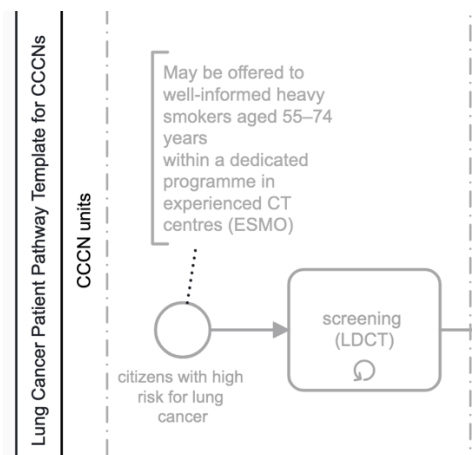

Figure 5. "Screening" excerpt from the Lung Cancer Patient Pathway Template

The following patient-centred practices can be used to accompany the screening phase.

Patient-Centred Practice: Shared Decision-Making Aids for Lung Cancer Screening
A) **Dimension(s) and subdimension(s) in model:** Engaging and Involving Patients; Shared decision-making
B) **Patient-centeredness aim:** Patient information and engagement
C) **Description:** Shared decision making (SDM) is a collaborative process between healthcare providers and patients, wherein both parties share information, discuss treatment options, and make healthcare decisions together based on the patient's preferences, values, and clinical evidence. In SDM, patients are actively involved in understanding their health condition, considering available treatment options, and choosing the course of action that aligns best with their goals and preferences ('NHS England » Shared Decision-Making', n.d.).

SDM empowers patients to participate in the decision-making process regarding whether or not to undergo screening by weighing the potential benefits and risks based on their individual circumstances (Slatore, Sullivan, Pappas, & Humphrey, 2014; Tanner & Silvestri, 2019; G. X. Wang et al., 2019).

D) **Links to existing materials:**
- https://effectivehealthcare.ahrq.gov/sites/default/files/wysiwyg/lung-cancer-screening-decision-aid.pdf
- https://effectivehealthcare.ahrq.gov/sites/default/files/wysiwyg/lung-cancer-screening-patient-encounter.pdf
- https://www.thoracic.org/patients/patient-resources/resources/decision-guide-lcs.pdf
- https://shouldiscreen.com/English/home
- https://www.confluencehealth.org/documents/content/Lung-Cancer-Screening-Option-Grid.pdf
- https://www.acr.org/Clinical-Resources/Lung-Cancer-Screening-Resources

E) **Rule(s) of application:** Offer to individuals who are indecisive about performing a lung cancer screening, use SDM aid to inform and engage the general public about lung cancer screening.

F) **Further reading(s)/ Source(s):**
- Tanner NT, Silvestri GA (2019). "Shared Decision-making and Lung Cancer Screening: Let's Get the Conversation Started". *Chest.* 155(1): 21-24. https://pubmed.ncbi.nlm.nih.gov/30359617/
- Wang GX, Baggett TP, Pandharipande PV, Park ER, Percac-Lima S, Shepard JO, Fintelmann FJ, Flores EJ (2019). "Barriers to Lung Cancer Screening Engagement from the Patient and Provider Perspective". *Radiology* 290(2): 278-287. https://pubmed.ncbi.nlm.nih.gov/30620258/
- Slatore CG, Sullivan DR, Pappas M, Humphrey LL. (2014). "Patient-centered outcomes among lung cancer screening recipients with computed tomography: a systematic review." *J Thorac Oncol.* 9(7): 927-934. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9208726/

Patient-Centered Practice: Smoking Cessation Interventions

A) **Dimension and subdimension in model:** Empowering patients; Information, Education & Engaging and Involving Patients; Self-Management

B) **Patient-centeredness aim:** Patient information and engagement

C) **Description:** Smoking cessation interventions involve a variety of strategies and treatments aimed at helping individuals quit smoking. These interventions can range from counselling and behavioural therapies to pharmacological treatments such as nicotine replacement therapy (NRT) or prescription medications like varenicline or bupropion. The goal of smoking cessation interventions is to support individuals in breaking the habit of smoking and achieving long-term abstinence from tobacco use. In the context of lung cancer

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prevention, smoking cessation interventions play a crucial role in reducing the risk of developing lung cancer. By quitting smoking, individuals can significantly lower their risk of developing lung cancer and other smoking-related health conditions (Lowenstein et al., 2022; Shen et al., 2021).

D) **Links to existing materials:**
   - Refer to local addiction counselling offers
   - Brief intervention for consultation: https://www.physio-pedia.com/Smoking_Cessation_and_Brief_Intervention

E) **Rule(s) of application:** Offer to smokers in the context of the lung cancer screening.

F) **Further reading(s)/ Source(s):**
   - Lowenstein LM, Nishi SPE, Lopez-Olivo MA, Crocker LC, Choi N, Kim B, Shih YT, Volk RJ (2022). "Smoking cessation services and shared decision-making practices among lung cancer screening facilities: A cross-sectional study". *Cancer* 15; 128(10): 1967-1975. https://pubmed.ncbi.nlm.nih.gov/35157302/
   - Shen J, Crothers K, Kross EK, Petersen K, Melzer AC, Triplette M (2021). "Provision of Smoking Cessation Resources in the Context of In-Person Shared Decision-Making for Lung Cancer Screening". *Chest*. 160(2): 765-775. https://pubmed.ncbi.nlm.nih.gov/33745990/
   - Whealan J, Webster M, Li T, Luta G, Taylor KL (2022). „On Behalf Of The Lung Screening Tobacco Health Trial. Engaging Patients in Smoking Cessation Treatment within the Lung Cancer Screening Setting: Lessons Learned from an NCI SCALE Trial". *Curr Oncol.* 23; 29(4): 2211-2224. https://pubmed.ncbi.nlm.nih.gov/35448154/

Patient-Centred Practices Elicited from Workshops with Patient Representatives

Regarding the screening phase of the patient pathway, the main outcomes summarised from the patient representative workshops are:

- Enhanced recognition of symptoms and better communication of information by the patient
- Systematic execution of additional examinations upon the patient's request

3.2.3 CCCN Entry

The lung cancer patient pathway has four entry points. These are, as represented in Figure 6,

- patients with symptoms,
- patients with histologically confirmed lung cancer,
- citizens with positive lung cancer screening results, and
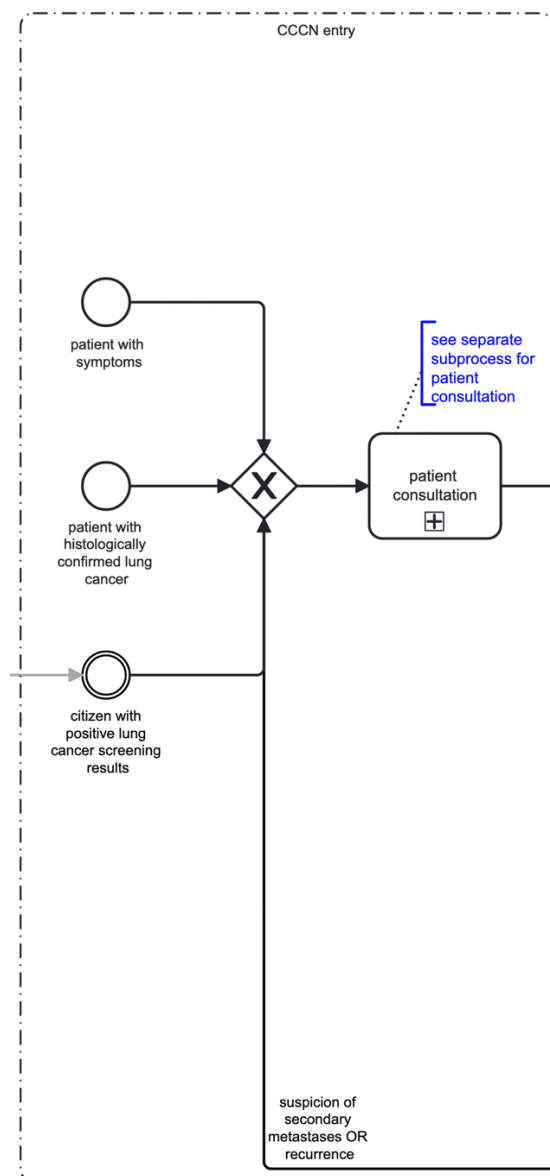- patients with suspicion of secondary metastases or recurrence.

Figure 6. "CCCN Entry" excerpt from the Lung Cancer Patient Pathway Template

The first step in the patient pathway is a patient consultation. This activity is detailed in a separate sub-pathway model (see Figure 7). It includes a medical history, general diagnostics, preparations for the laboratory, and patient information.
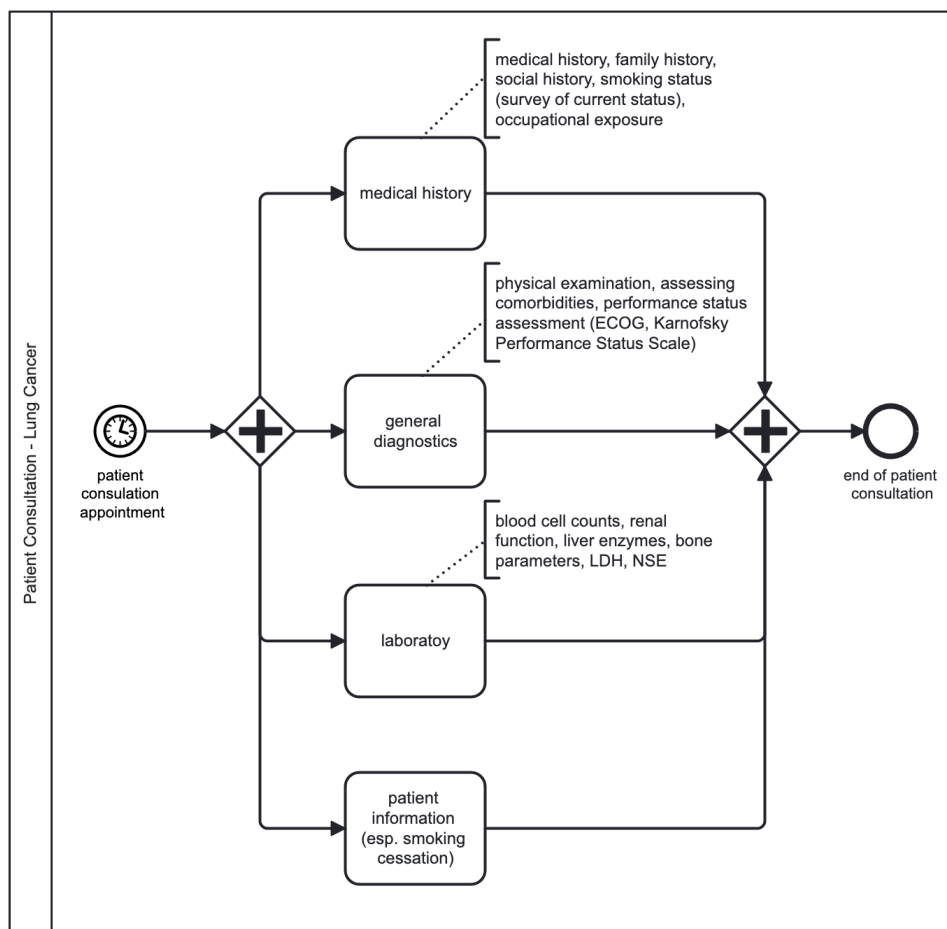
Figure 7. "Patient Consultation" details (expanded sub-process)

The following patient-centred practices can be used to accompany patient consultations.

Patient-Centred Practice: Introducing yourself, the team, and the facilities

A) **Category:** Empowering patients; Information, Education
B) **Patient-centeredness aim:** Patient information and self-management
C) **Description:** Introducing the medical team and facilities to patients is essential for building trust, supporting self-management, and ensuring patient-centered care. By familiarising patients with the professionals involved in their care, they feel more comfortable and confident in expressing concerns and participating in treatment decisions. Similarly, explaining the layout and resources of the facility helps alleviate anxiety and empowers patients to navigate their surroundings effectively. Overall, these introductions contribute to a positive patient experience, promoting trustful relationships and enabling patients to take an active role in managing their health (Arora & Press, 2014; 'Why Introductions Are Important to Patients', n.d.).
D) **Links to existing materials:**
   - Possibly navigation/ introduction brochures
   - Possibly access to a patient portal

- Template, Introducing your Care Team:
  https://aims.uw.edu/resource/introducing-your-care-team/
E) **Rule(s) of application:** For all lung cancer patients accessing the CCCN.
F) **Activity in patient pathway:** Patient consultation
G) **Further reading(s)/ Source(s):**
  - Arora VM, Press VG (2014). "Let's "face" it: time to introduce yourself to patients". *J Hosp Med.* 9(3): 199-200.
    https://pubmed.ncbi.nlm.nih.gov/24311468/
  - Hunsaker E, Young K, Ransco M. (2023). "Why Introductions are Important to Patients". *UHealth*, University of Utah.
    https://accelerate.uofuhealth.utah.edu/improvement/why-introductions-are-important-to-patients

Patient-Centred Practice: Patient-centred reporting of lung cancer screening results

A) **Category:** Empowering patients; Information & Enhancing the Therapeutic Relationship; Communication, Respect and Compassion
B) **Patient-centeredness aim:** Patient information
C) **Description:** Patient-centered reporting following lung cancer screening is critical. It lays the foundation for effective communication and support throughout the disease's course, potentially impacting patients' lives significantly. Clear, empathetic reporting of screening results alleviates anxiety, empowers informed decision-making, and fosters trust between patients and healthcare providers. Studies suggest that reports designed with an infographic format, combining simple pictures and standardised text, may be an ideal format that radiologists can pursue to provide patient-centered care (Vitzthum von Eckstaedt, Kitts, Swanson, Hanley, & Krishnaraj, 2020). A model report structure, positively received by patients, comprises a) an explanation of low-dose computed tomography, b) personalised patient outcomes, c) interpretation of the findings, and d) a roadmap for the subsequent steps in their care (Alarifi, Patrick, Jabour, Wu, & Luo, 2021). A redesign and patient-centered evaluation of radiology reports may be advisable.
D) **Rule(s) of application:** Offer to every individual who has undergone lung cancer screening.
E) **Activity in patient pathway:** Patient consultation
F) **Further reading(s)/ Source(s):**
  - Barrett SK, Patrie J, Kitts AB, Hanley M, Swanson CM, Vitzthum von Eckstaedt H, Krishnaraj A (2021). "Patient-centered Reporting in Radiology: A Single-site Survey Study of Lung Cancer Screening Results". *J Thorac Imaging* 1; 36(6): 367-372.
    https://pubmed.ncbi.nlm.nih.gov/34029279/
  - Vitzthum von Eckstaedt H 5th, Kitts AB, Swanson C, Hanley M, Krishnaraj A (2020). "Patient-centered Radiology Reporting for Lung Cancer Screening". *J Thorac Imaging* 35(2): 85-90.
    https://pubmed.ncbi.nlm.nih.gov/31913258/

- Alarifi M, Patrick T, Jabour A, Wu M, Luo J (2020). "Designing a Consumer-Friendly Radiology Report using a Patient-Centered Approach". *J Digit Imaging* 34(3): 705-716. https://pubmed.ncbi.nlm.nih.gov/33903982/

Patient-Centred Practice: Question Prompt Sheets

A) **Category:** Empowering Patients; Information & Engaging and Involving Patients; Self-Management; Participation in Care Planning

B) **Patient-centeredness aim:** Patient information and engagement

C) **Description:** Question Prompt Sheets (QPS) provide patients with an overview of questions, which have been asked frequently by other patients with the same condition. This allows patients to select which questions they would like to ask and typically provides space for them to add their own inquiries. Taking the QPS into the consultation with the physician empowers patients to obtain more information, address all their concerns, and feel more self-assured when asking these questions. It is also reported that employing the QPS facilitates the generation of new questions without prolonging the consultation visit (Arthur et al., 2017, 2016).

D) **Links to existing materials:**
   - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4982953/
   - https://www.sciencedirect.com/science/article/pii/S0738399121006625
   - https://journals.sagepub.com/doi/10.1177/0269216313483659

E) **Rule(s) of application:** Ensure that all lung cancer patients receive the information sheet before their consultation. This can be done either at the patient registration area before the consultation, allowing patients time to review the sheet in the waiting room, or it can be sent to them digitally in advance, giving them ample time to carefully read and make any personal notes in the comfort of their own home.

F) **Activity in patient pathway:** Patient consultation

G) **Further reading(s)/ Source(s):**
   - Arthur J, Pawate V, Lu Z, et al (2023). "Helpfulness of Question Prompt Sheet for Patient-Physician Communication Among Patients With Advanced Cancer: A Randomized Clinical Trial". *JAMA Netw Open* 6(5): e2311189. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2804389
   - Thomas H T (2023). "Question Prompt Lists Improve Patient Communication Without Causing Patient or System Concerns" Cancer Nursing Today. https://cancernursingtoday.com/post/question-prompt-lists-improve-patient-communication-without-causing-patient-or-system-concerns
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and cross-cultural evaluation". *Palliative Medicine* 27(8): 779-788.
https://journals.sagepub.com/doi/10.1177/0269216313483659

Patient-Centred Practices Elicited from Workshops with Patient Representatives

Regarding the CCCN entry phase of the patient pathway, the main outcome summarised from the patient representative workshops is:

- Rapid referral to a specialised healthcare professional and/or an oncologist
- Enhanced recognition of symptoms and better communication of information by the patient
- Systematic execution of additional examinations upon the patient's request

3.2.4 Staging Diagnostics

After patient consultation, the phase of "staging diagnostics" is entered. An overview of this phase is given in Figure 8. If no lung cancer was confirmed, the patient will be discharged from CCCN care. Otherwise, the pathway continues with treatment planning.
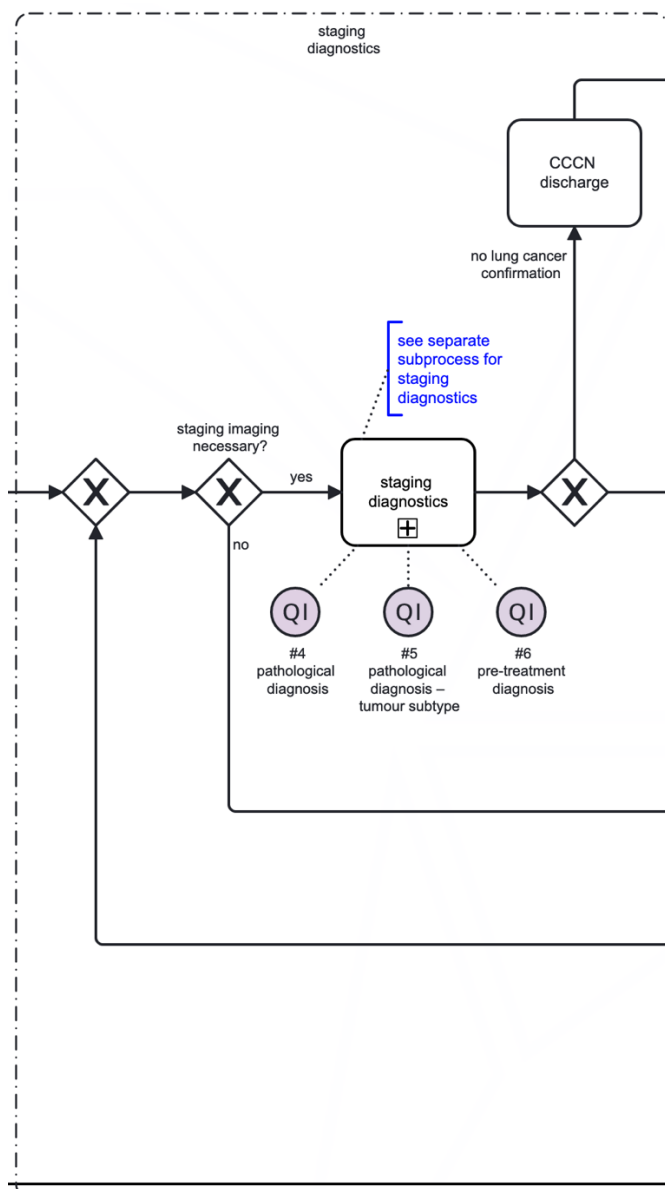
Figure 8. "Staging Diagnostics" excerpt from the Lung Cancer Patient Pathway Template

The process of staging diagnostics is detailed in a separate sub-pathway model (see Figure 9). It includes three quality indicators.
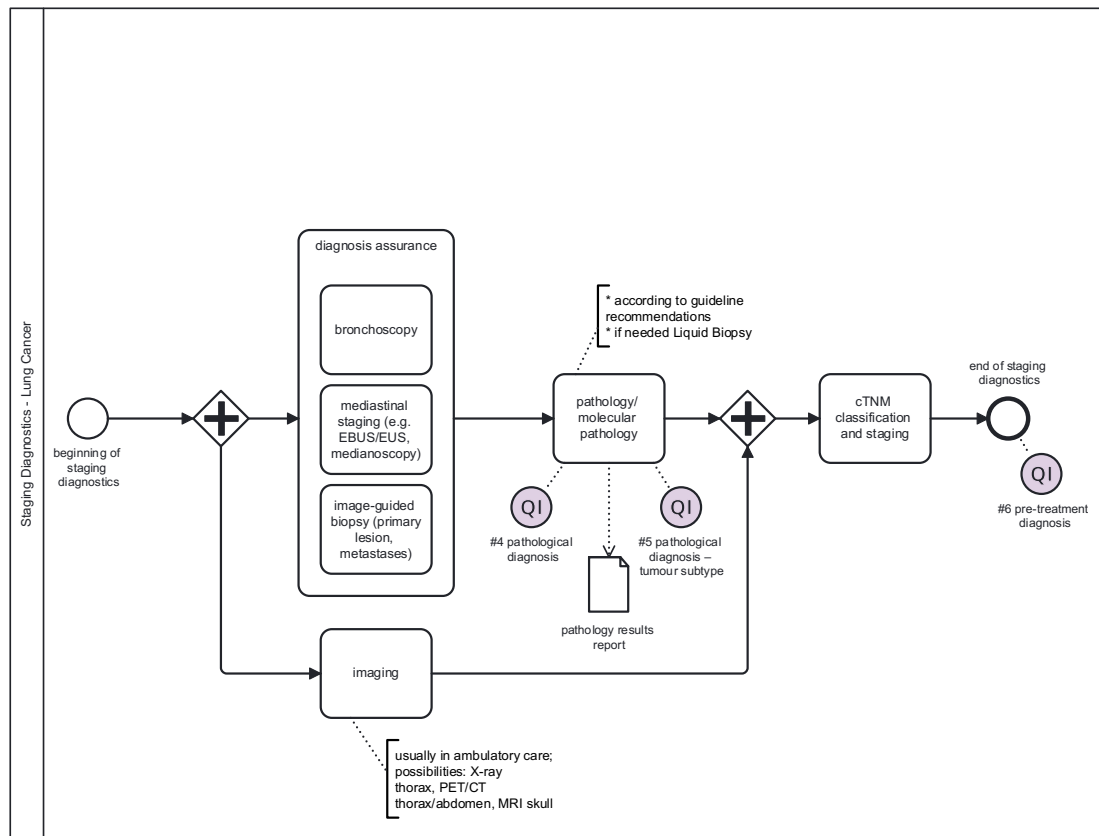
Figure 9. „Staging Diagnostics" details (expanded sub-process)

The following patient-centred practices can be used to accompany the phase of staging diagnostics.

Patient-Centred Practices from Workshops with Patient Representatives

Regarding the staging diagnostics phase of the patient pathway, the main outcomes summarised from the patient representative workshops are:

- Examination and diagnosis within a reasonable delay
- Improved access to and information on second opinion

3.2.5 Treatment Planning

After staging diagnostics, the phase of "treatment planning" is entered (see Figure 10). This phase includes two sub-pathways – for the "standard tumorboard (TB) meeting" (see Figure 11) and for the "molecular tumorboard (MTB) meeting" (Figure 12). There is a patient consultation after the diagnosis which should include shared decision-making. Overall, four quality indicators are allocated to the steps of this pathway phase.
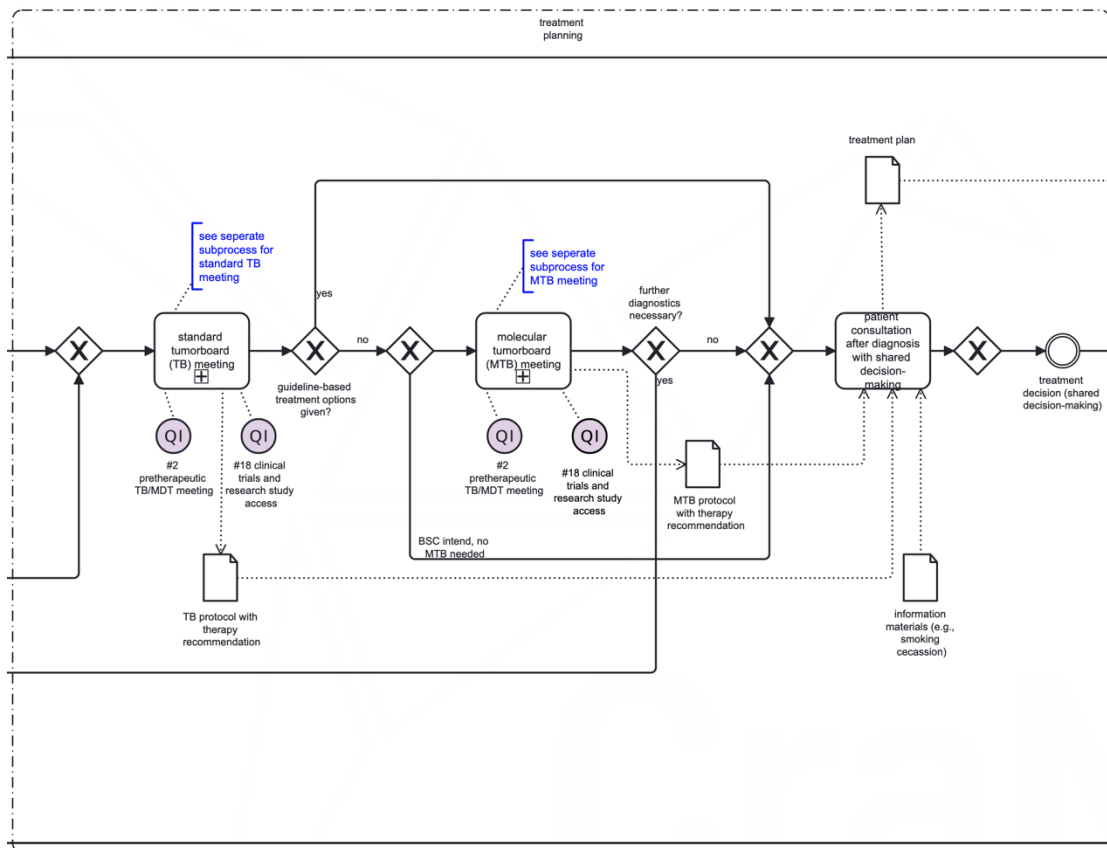
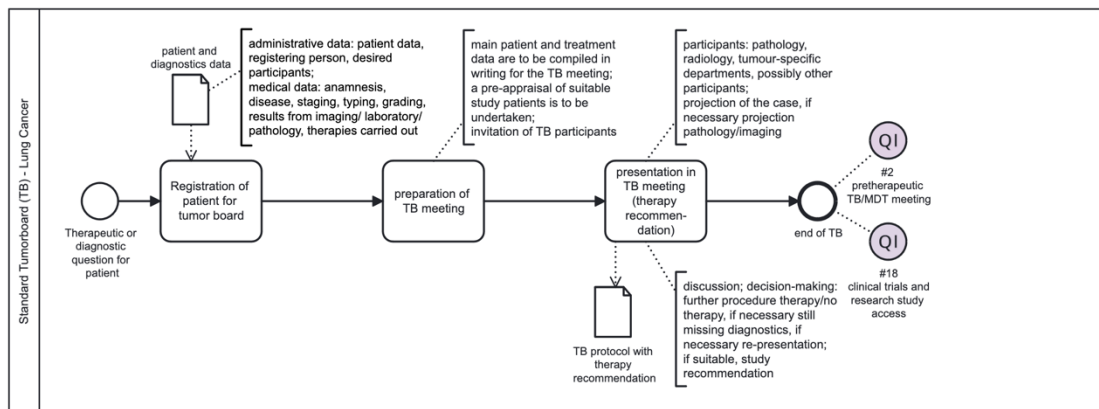Figure 10. "Treatment Planning" Excerpt from the Lung Cancer Patient Pathway Template

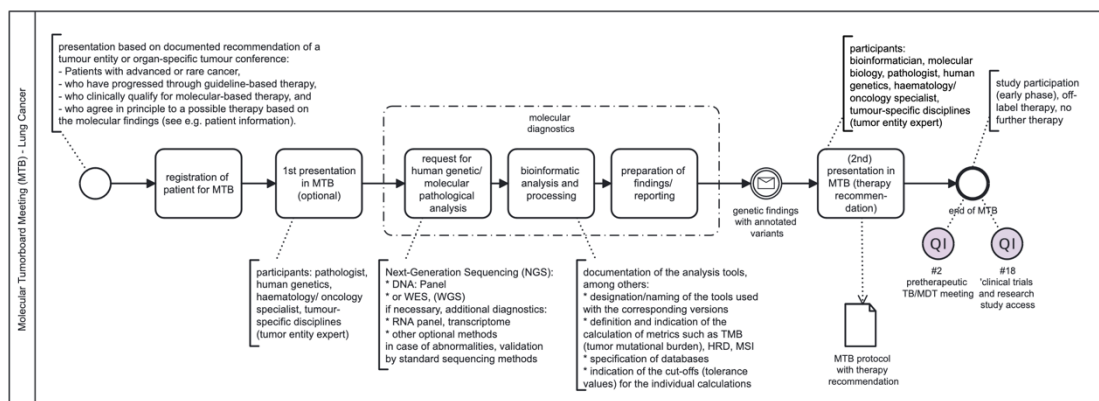Figure 11. „Standard Tumorboard (TB) Meeting" details (expanded sub-process)

Figure 12. „Molecular Tumorboard (MTB) Meeting" details (expanded sub-process)

The following patient-centred practices can be used to accompany the phase of treatment planning, with a highlight on shared decision-making.

Patient-Centred Practice: Patient Preferences for Participation

A) **Category:** Treating the Patient as a Unique Person; Knowing the Patient

B) **Patient-centeredness aim:** Individualisation of healthcare

C) **Description:** Patient participation is deemed a core value in healthcare, promoting quality and safety. Also in lung cancer, studies suggest, that physicians should check participation preferences of their patients (Pardon et al., 2009). Therefore, understanding and measuring patient participation in healthcare quality is crucial but challenging. While aspects like access and services are relatively straightforward to evaluate, patient participation is more complex and can vary greatly depending on individual preferences and circumstances. For instance, what constitutes "good" participation for one patient may not be the same for another, or even for the same person in different situations. To address this complexity, the 4Ps tool (Patient Preferences for Patient Participation) was developed. This tool considers both patient preferences and experiences to comprehensively measure healthcare quality in terms of patient participation. It draws on a combination of qualitative and quantitative studies and applies 12 attributes to capture the various facets of patient participation. Previous validation studies have demonstrated that the 4Ps tool is easy to comprehend and holds promise for effectively evaluating patient participation in both clinical practice and research. By considering both patient preferences and experiences, the 4Ps tool provides a more nuanced and comprehensive understanding of patient participation in healthcare quality (Eldh, Holmefur, Luhr, & Wenemark, 2020). The following "early" predictors of participation in shared decision-making for lung cancer patients could be found in literature:

- Predicators for higher preference to participate in shared decision-making (SDM) may include higher literacy and income, in contrast patient with stage III TNM and disease course of 3-6 months had a lower perceived importance of SDM (Y. Wang et al., 2022)

- Patients with extensive-stage small cell lung cancer prefer to be involved in SDM for prophylactic cranial irradiation (Ankolekar et al., 2021)
- Most patients with early stage non-small cell lung cancer preferred a collaborative role in SDM (Dalmia et al., 2022)

D) **Links to existing materials:** If interested, please contact Prof. Ann Catherine Eldh (https://liu.se/en/employee/annel80) for full access to the 4Ps tool.

E) **Rule(s) of application:** Patients completes the preferences section at the onset of healthcare interactions and the experiences section at a later, agreed point. This allows for the healthcare professional(s) and patient to jointly assess the individual's preferences and experiences, respectively, and most importantly, the match (or mismatch) between the patient's experiences in relation to their preferences.

F) **Further reading(s)/ Source(s):**
- Eldh, A.C., Holmefur, M., Luhr, K. *et al (2020).* "Assessing and reporting patient participation by means of patient preferences and experiences". *BMC Health Serv Res* 20, 702. https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-020-05574-y#citeas
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Patient-Centred Practice: Shared decision-making for treatment planning:

A) **Category:** Engaging and Involving Patients; Shared decision-making

B) **Patient-centeredness aim:** Patient information and engagement

G) **Description:** Shared decision making (SDM) is a collaborative process between healthcare providers and patients, wherein both parties share information, discuss treatment options, and make healthcare decisions together based on the patient's preferences, values, and clinical evidence. In SDM, patients are actively involved in understanding their health condition, considering available treatment options, and choosing the course of action that aligns best with their goals and preferences ('NHS England » Shared Decision-Making', n.d.).

In the context of lung cancer, Pardon et al. (2009) concluded, that facilitating SDM in the context of lung cancer may lead to improved emotional outcomes and less aggressive therapies.

C) **Links to existing materials:**
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8539978/, Supplementary materials: Care Plan Cards (Q &A) and Preference Reporting Form
- https://www.sciencedirect.com/science/article/pii/S000349751600271X?via%3Dihub, Shared decision-making steps and links to SDM tools for patients with operably stage I non-small cell lung cancer
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9286651/, List of PDAs and available evidence for each
- Further possible SDM tools include decision boxes, option grids, or the Teach Back Method

D) **Rule(s) of application:** Offer to individuals who are willing to participate in shared decision-making.

E) **Activity in patient pathway:** Patient consultation after diagnosis with shared decision-making

F) **Further reading(s)/ Source(s):**
- Pardon K, Deschepper R, Stichele RV, Bernheim J, Mortier F, Deliens L; EOLIC-consortium (2009). "Preferences of advanced lung cancer patients for patient-centred information and decision-making: a prospective multicentre study in 13 hospitals in Belgium". *Patient Educ Couns.* 77(3): 421-9. https://pubmed.ncbi.nlm.nih.gov/19828279/
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- Spronk I, Meijers MC, Heins MJ, Francke AL, Elwyn G, van Lindert A, van Dulmen S, van Vliet LM (2019). "Availability and effectiveness of decision aids for supporting shared decision making in patients with advanced colorectal and lung cancer: Results from a systematic review". *Eur J Cancer Care (Engl).* 28(3): e13079. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9286651/

Patient-Centred Practices Elicited from Workshops with Patient Representatives

Regarding the treatment planning phase of the patient pathway, the main outcomes summarised from the patient representative workshops are:

- No start of treatment in the case of an erroneous, poorly performed, unconfirmed or incomplete diagnostic procedure, etc.
- Improved access to and information on second opinion
- Involve the patient in treatment options, particularly before and after the tumour board
- Inform patients about their options, and for each option, provide information on side effects, statistics, etc.
- Offer access to a prehabilitation centre/ program

3.2.6 Treatment

After treatment planning, the patient pathway for lung cancer patients continues with the phase of "treatment" (see Figure 13). It includes the actual treatment together with supportive care activities and an early integration of palliative care (if needed), as well as rehabilitation activities. Altogether, there are 18 quality indicators allocated to the steps of the treatment phase.
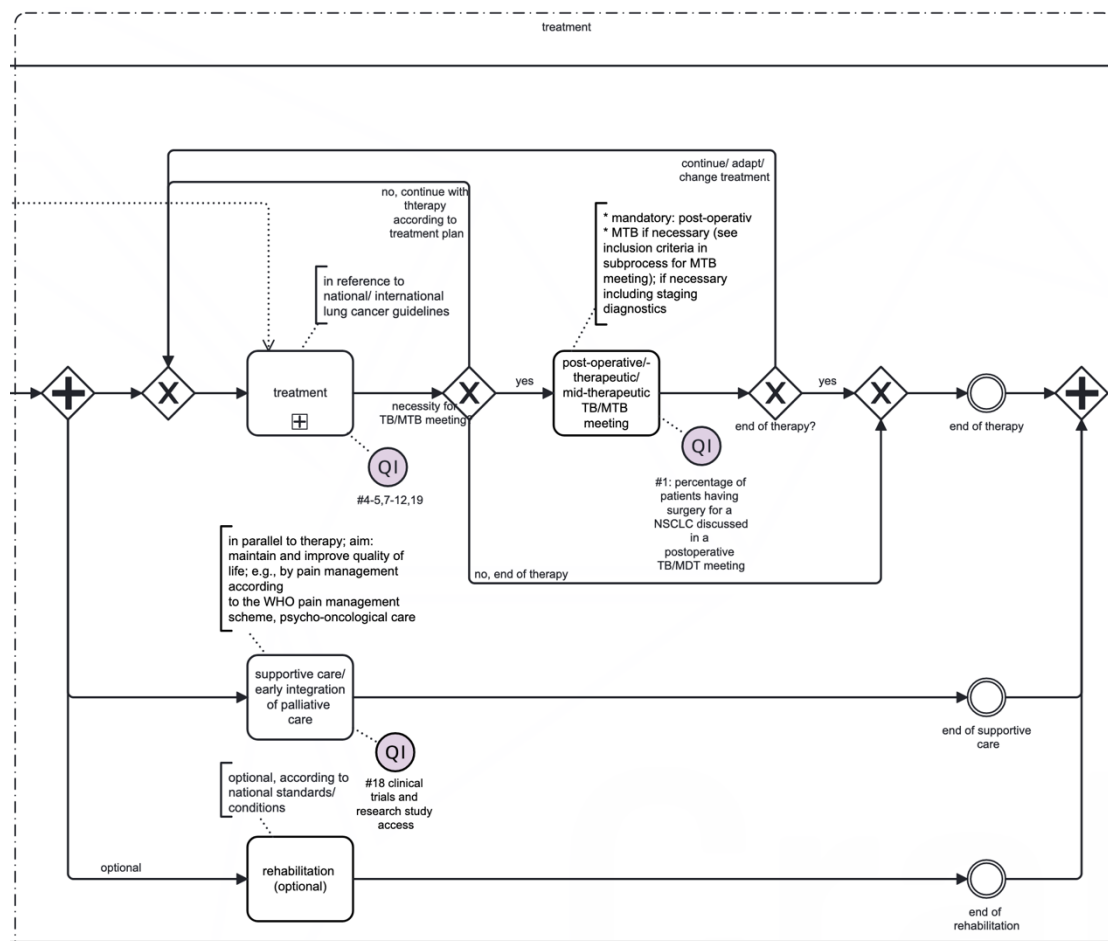

Figure 13. „Treatment" excerpt from the Lung Cancer Patient Pathway Template

The "treatment" activity is detailed in a separate sub-pathway model (see Figure 14). To ensure practicality and manageability, it was decided in the working group to maintain a high level of detail for therapy options due to their dynamic and frequently updating nature in lung cancer. Instead of providing exhaustive details within the pathway, it is more efficient to reference existing guidelines. This approach reduces the maintenance burden to reflect changes in the patient pathway.
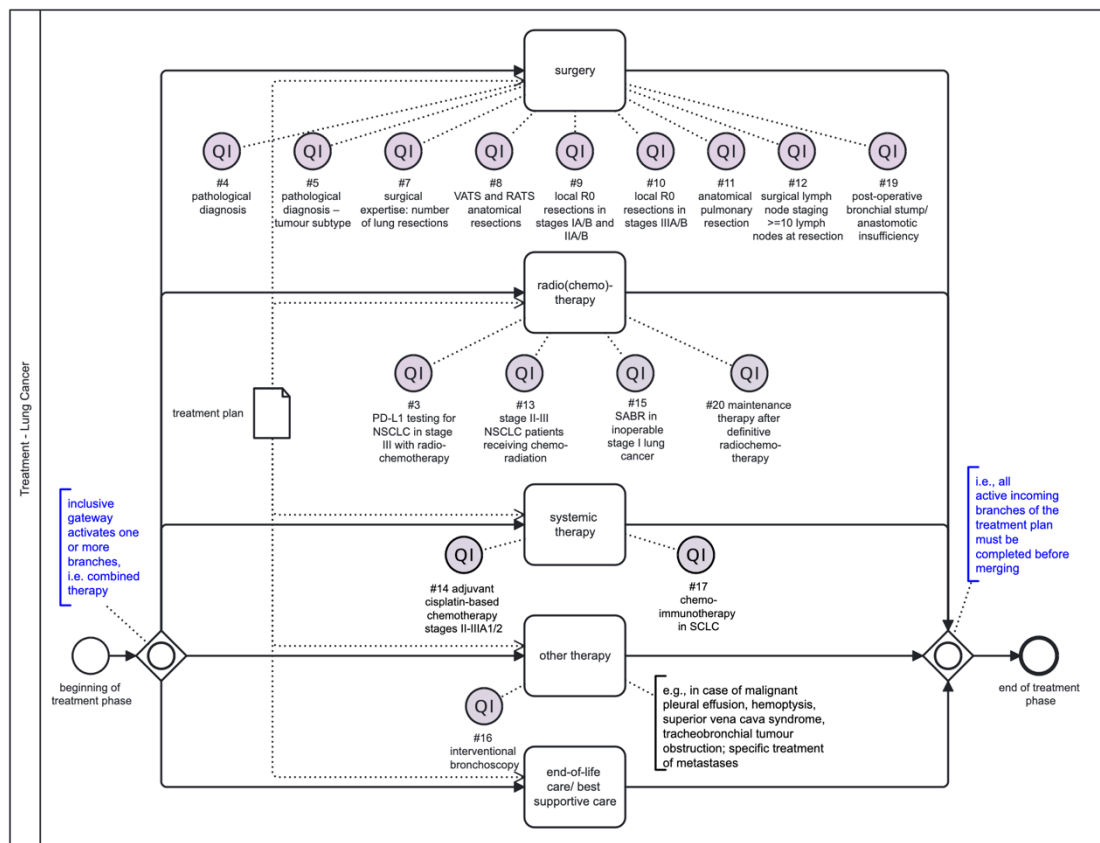
Figure 14. "Treatment" details (expanded sub-process)

The following patient-centred practices can be used to accompany the treatment phase.

Patient-Centered Practices from Workshops with Patient Representatives

Regarding the treatment phase of the patient pathway, the main outcomes summarised from the patient representative workshops are:

- Examination between treatment stages to decide whether the current procedure is still relevant
- Inform the patient about the pre- and post-treatment stages
- Medical files shared between countries, or at least possible access to the medical files between professionals

3.2.7 Follow-Up, End-of-Life Care, and End of CCCN Care

After treatment, the patient pathway for lung cancer patients continues with the phase of follow-up or end-of-life care (see Figure 15). Follow-up care should be performed

according to national or European cancer follow-up guidelines/ recommendations. This phase includes one quality indicator.
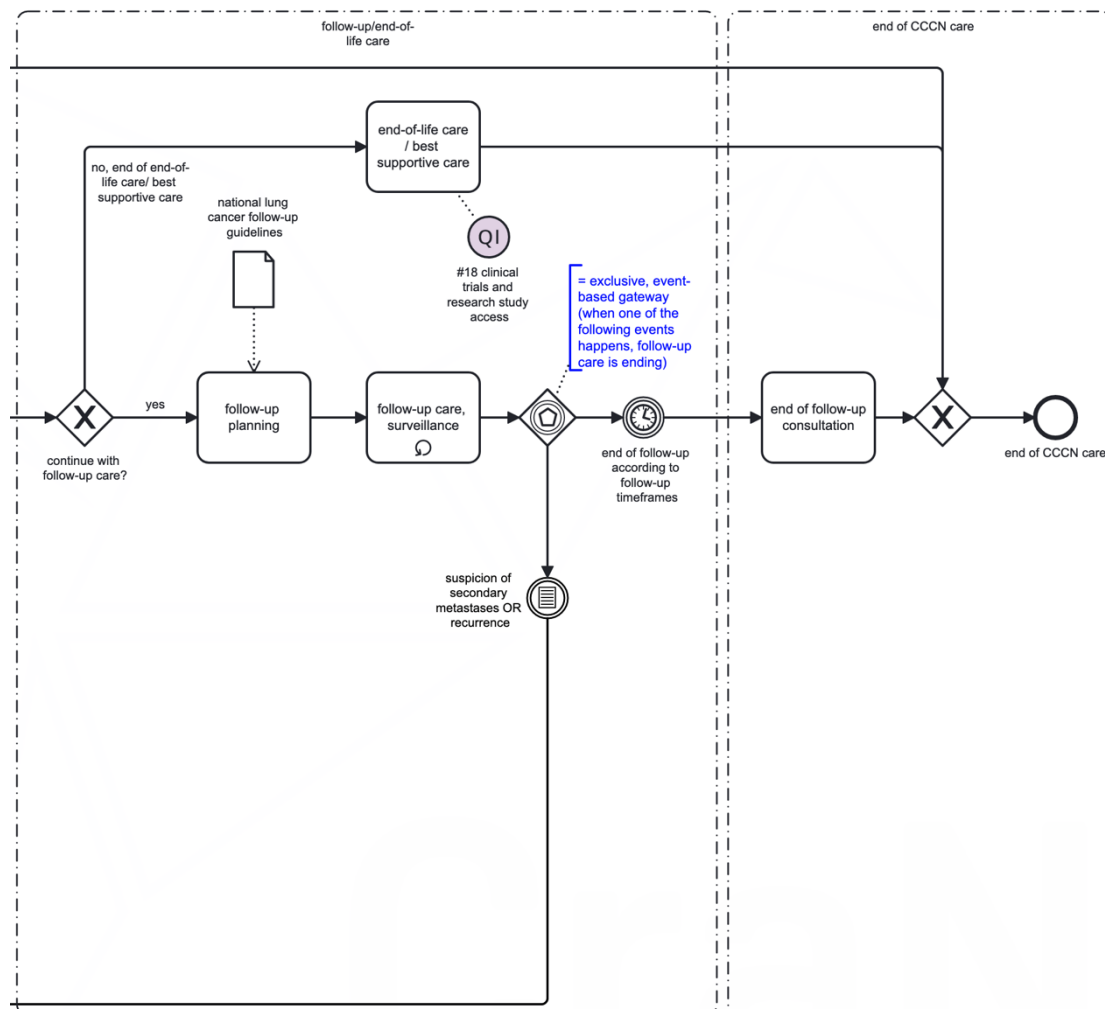

Figure 15. „Follow-up/end-of-life care" and "end of CCCN care" excerpt from the Lung Cancer Patient Pathway Template

The following patient-centred practices can be used to accompany the follow-up and end-of-life care phase.

Patient-Centered Practice: Patient advocacy

A) **Category:** Engaging and Involving Patients; Co-Creation of Services and Systems

B) **Patient-centeredness aim:** Patient engagement

C) **Description:** Winning patient advocates during the follow-up phase of lung cancer is crucial for providing essential support to individuals navigating the diagnosis. These advocates play a pivotal role in offering firsthand experience, empathy, and guidance to those currently facing the challenges of lung cancer. Moreover, their involvement in the co-creation of materials and improvement of processes ensures that the needs and perspectives of patients are accurately

represented and addressed. By collaborating with patient advocates, healthcare professionals can develop more tailored and effective resources, support systems, and treatment approaches, ultimately enhancing the overall quality of care and support for individuals affected by lung cancer (Dy, Janssen, Ferris, & Bridges, 2017).

D) **Further reading(s)/ Source(s):**

- Dy SM, Janssen EM, Ferris A, Bridges JF (2017). "Live, Learn, Pass It on: A Patient Advocacy Engagement Project on the Lived Experience of Lung Cancer Survivors". *J Patient Exp.* 4(4): 162-168.
https://pubmed.ncbi.nlm.nih.gov/29276762/

Patient-Centered Practices from Workshops with Patient Representatives

Regarding the follow-up, end-of-care and end of CCCN care phases of the patient pathway, the main outcomes summarised from the patient representative workshops are:

- Continue regular follow-up by the oncologist and/or a specialised healthcare professional, with complete check-ups
- Offer access to a rehabilitation centre/ program

4 Dissemination Activities

The results presented in Deliverable 6.4 were currently disseminated as shown in Table 5. Further dissemination activities are planned.

Table 5. Dissemination activities

Publication	Description
Hickmann, E., Richter, P., Schlieter, H., Cemazar, M., Dudek-Godeau, D., Grapentin, N., Griesshammer, E., Jelenc, M., Liutkauskienė, S., Ravaud, A., Troussard, X., Wesselmann, S. (2024): "Operationalizing Patient-Centered Care: A Conceptual Framework for Comprehensive Cancer Care Networks.", in: JMIR Cancer. (Manuscript submitted, preprint available via https://preprints.jmir.org/preprint/59683)	The manuscript includes the definition and framework of patient-centeredness within Comprehensive Cancer Care Networks (CCCNs). It elucidates each subdimension within the framework and includes an appendix listing all patient-centred activities comprehensively.
Richter, P. (2024): "Navigating Patient-Centered Care: A Conceptual Framework for Comprehensive Cancer Care Networks.", presented as a poster presentation, 36th German Cancer Congress.	The presentation introduces the definition and framework of patient-centeredness within Comprehensive Cancer Care Networks (CCCNs). Additionally, it showcases exemplary dimensions within the framework along with corresponding patient-centred activities.

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Dy, S. M., Janssen, E. M., Ferris, A., & Bridges, J. F. (2017). Live, Learn, Pass It on: A Patient Advocacy Engagement Project on the Lived Experience of Lung Cancer Survivors. *Journal of Patient Experience*, *4*, 162–168.

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