



# INTENT

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**D.T.2.1.3. Integration of new indicator sets  
into online benchmarking tool**

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## Basic description of indicators and questions

Based on discussion among all involved project partners, a final multidimensional set of indicators has been defined. Questions for particular target groups were formulated in order to be included in survey and analysed using the online benchmarking tool as a part of the pilot action. Design of the survey is to be specified as a part of the particular pilot action.

The indicators are assign to particular PCCM dimensions:

- Patient Centered Culture (including Commitment to PCCC of leadership and management/Co-design of strategies and services)
- Communication, Information and Education
- Accessibility and Continuity of Care
- Shared decision making and Multidisciplinary approach
- Enhancing the Quality of Life
- Research and improving Health Technologies

The full question set is aimed to survey following target groups:

- Management (1 response per pilot site)
- Medical doctors
- Nurses
- Patients
- Expert patients

### Patient Centered Culture

| Axes Code                                     | Question   | Group          |
|---|--|----------------|
| Involvement of patients in the strategic plan |  |                |
| Axis 1_1_M                                    | Does the Board of Directors present the strategic plan (quality objectives, investments, organization of services, budgeting, ...) to the committee of volunteers? | Management     |
| Axis 1_1_P                                    | Are you informed about the strategic plan of the [name of the institute] (quality objectives, investments, organization of services, budgeting, etc.)              | Expert patient |
| Code of ethics, charter of patients' rights   |  |                |
| Axis 1_2_M                                    | In your Institute, is commitment to patient-centred care implemented in the code of ethics of staff and charter of patients' rights?                               | Management     |
| Axis 1_2_P                                    | Do you know the content of the charter of patients' rights of the [name of the Institute]?   | Expert patient |
| Axis 1_2_S                                    | Do you know the content of the code of ethics of your organisation and the charter of patients' rights?  | Doctor         |
| Axis 1_2_S                                    | Do you know the content of the code of ethics of your organisation and the charter of patients' rights?  | Nurse          |
| Volunteer associations assets                 |  |                |
| Axis 1_3_M                                    | Do you consider volunteer associations as one of your assets?  | Management     |

|            |  |                |
|------------|--|----------------|
| Axis 1_3_P | Do you plan your activities together with the Board of Directors of the [name of the institute]? | Expert patient |
| Axis 1_3_S | Do you consider volunteer associations as one of your assets?                                    | Doctor         |
| Axis 1_3_S | Do you consider volunteer associations as one of your assets?                                    | Nurse          |

#### Committee of volunteers

|            |   |            |
|------------|---|------------|
| Axis 1_4_M | Does the centre have a formal committee of volunteers*, which meets at least annually to provide inputs to hospital management? [*Group of representatives of volunteer associations and/or patients operating in your Institute] | Management |
|------------|---|------------|

#### Patient satisfaction surveys

|            |   |                |
|------------|---|----------------|
| Axis 1_5_M | Does the Board of Directors present the report on patient satisfaction to the committee of volunteers?  | Management     |
| Axis 1_5_P | Do you discuss patient satisfaction reports with the Board of Directors of the [name of the Institute]? | Expert patient |
| Axis 1_5_S | Are you informed about the results of patient satisfaction surveys and the reasons for the complaints?  | Doctor         |
| Axis 1_5_S | Are you informed about the results of patient satisfaction surveys and the reasons for the complaints?  | Nurse          |

#### Involvement of patient associations in the design of clinical pathways

|            |  |                |
|------------|--|----------------|
| Axis 1_6_M | Are patient associations involved in the design of clinical pathways?                      | Management     |
| Axis 1_6_P | Do patient associations collaborate with staff in the design process of clinical pathways? | Expert patient |

#### Volunteer associations' visibility

|            |   |            |
|------------|---|------------|
| Axis 1_7_M | Do you offer visibility to volunteer associations (e.g. website, flyers, information boards)? | Management |
| Axis 1_7_P | Are you aware of volunteer associations operating at the [name of the Institute]?             | Patient    |
| Axis 1_7_S | Do you inform patients about volunteer associations and their activities?                     | Doctor     |
| Axis 1_7_S | Do you inform patients about volunteer associations and their activities?                     | Nurse      |

## Communication, Information and Education

#### Information resources

|              |   |            |
|--------------|---|------------|
| Axis 2_1_M   | Does the Institute provide resources (written material, meetings, web, poster, ...) to patients on the following: | Management |
| Axis 2_1_M-a | cancer prevention   | Management |
| Axis 2_1_M-b | diagnostics and treatment of specific oncologic diseases  | Management |
| Axis 2_1_M-c | nutrition for cancer patients   | Management |
| Axis 2_1_M-d | social care and services  | Management |

|  |  |            |
|--|--|------------|
| Axis 2_1_M-e                             | psychological and emotional support  | Management |
| Axis 2_1_M-f                             | spiritual support  | Management |
| Axis 2_1_M-g                             | rehabilitation   | Management |
| Axis 2_1_M-h                             | sexual life during and after treatment   | Management |
| Axis 2_1_M-i                             | pain management  | Management |
| Axis 2_1_M-j                             | home care (care for the skin, wounds, stoma,...)   | Management |
| Axis 2_1_M-l                             | none of the above  | Management |
| Axis 2_1_S                               | Do you keep information for patients (written material, web, etc.) on the following on hand?                         | Doctor     |
| Axis 2_1_S                               | Do you keep information for patients (written material, web, etc.) about the following on hand?                      | Nurse      |
| Axis 2_1_S-a                             | cancer prevention  | Nurse      |
| Axis 2_1_S-b                             | diagnostics and treatment of specific oncologic diseases   | Nurse      |
| Axis 2_1_S-c                             | nutrition for cancer patients  | Nurse      |
| Axis 2_1_S-d                             | social care and services   | Nurse      |
| Axis 2_1_S-e                             | psychological and emotional support  | Nurse      |
| Axis 2_1_S-f                             | spiritual support  | Nurse      |
| Axis 2_1_S-g                             | rehabilitation   | Nurse      |
| Axis 2_1_S-h                             | sexual life during and after treatment   | Nurse      |
| Axis 2_1_S-i                             | pain management  | Nurse      |
| Axis 2_1_S-j                             | home care (care for the skin, wounds, stoma,...)   | Nurse      |
| Axis 2_1_S-l                             | none of the above  | Nurse      |
| Infrastructure for information resources |  |            |
| Axis 2_2_M                               | Does the Institute offer the following to patients:  | Management |
| Axis 2_2_M-a                             | Patient Education centre   | Management |
| Axis 2_2_M-b                             | information desk (e..g logistic, transports, directions...)  | Management |
| Axis 2_2_M-c                             | call centre  | Management |
| Axis 2_2_M-d                             | booklets and leaflets  | Management |
| Axis 2_2_M-e                             | group information sessions   | Management |
| Axis 2_2_M-f                             | web (website, mobile application, social media)  | Management |
| Axis 2_2_M-j                             | none of the above  | Management |
| Axis 2_2_P                               | At the [name of the Institute], have you been informed about the following services rendered? (check all that apply) | Patient    |

|              |   |         |
|--------------|---|---------|
| Axis 2_2_P-a | Cancer Information Service for patients (e.g. library, information desk, etc) | Patient |
| Axis 2_2_P-b | information desk (e.g logistic, transports, directions...)                    | Patient |
| Axis 2_2_P-c | call centre   | Patient |
| Axis 2_2_P-d | booklets and leaflets   | Patient |
| Axis 2_2_P-e | group information sessions  | Patient |
| Axis 2_2_P-f | web (website, mobile application, social media)                               | Patient |
| Axis 2_2_P-h | none of the above   | Patient |

#### Quality of information resources

|            |   |            |
|------------|---|------------|
| Axis 2_3_M | Does the centre have procedures to ensure that the written information given to patients and their relatives is helpful and comprehensible? | Management |
| Axis 2_3_P | At the [name of institute], did you find the printed material or website helpful and easy to understand?                                    | Patient    |

#### Involvement of caregivers

|            |   |            |
|------------|---|------------|
| Axis 2_4_M | Do patients' rights include the possibility to be with caregivers whenever patients wish (e.g. ambulatory visits, overnight stays, etc.)? | Management |
| Axis 2_4_P | At the [name of the hospital], can your caregiver be present with you (including discussion with doctors and nurses) whenever you wish?   | Patient    |
| Axis 2_4_S | Do you report caregivers' name in the patients' file?   | Doctor     |
| Axis 2_4_S | Do you report caregivers' names in the patients' files?   | Nurse      |

#### Extended visits

|            |  |            |
|------------|--|------------|
| Axis 2_5_M | Do you plan extended time slots for certain visits (e.g. first visits, discussion of the care plan, etc.)? | Management |
|------------|--|------------|

#### Communication between staff and patients

|            |  |            |
|------------|--|------------|
| Axis 2_6_M | Does the Institute organize training sessions for staff on how to improve communication with patients? | Management |
| Axis 2_6_P | Do the healthcare professionals listen to you attentively?   | Patient    |

#### Feedback from patients

|            |   |            |
|------------|---|------------|
| Axis 2_7_M | Does the Institute collect feedback on patient experience/satisfaction (e.g. by questionnaire)?   | Management |
| Axis 2_7_P | Until now, could you give feedback on your experience at the [name of the hospital] (e.g. by satisfaction questionnaire, complain box, etc.)? | Patient    |

## Accessibility and Continuity of Care

#### Accessibility of the institute

|            |  |            |
|------------|--|------------|
| Axis 3_1_M | Does the Institute have resources (e.g. phone line, website) to facilitate patient access to the Institute (e.g. public transportation, driving direction, parking)? | Management |
|------------|--|------------|

|   |  |            |
|---|--|------------|
| Axis 3_1_P  | Is it difficult to reach the [name of institute] (e.g. by public transportation, driving direction, parking)?  | Patient    |
| Axis 3_1_S  | Do you adapt the patients' care plan according to their logistic needs (e.g. work, travels, family issues, etc.)?  | Doctor     |
| Axis 3_1_S  | Do you adapt the patient care plan according to the logistic needs of patients (e.g. work, travels, family issues, etc.)?  | Nurse      |
| Navigation within the institute                                       |  |            |
| Axis 3_2_M  | Does the Institute have resources for patients (e.g. maps, signs, etc.) to easily navigate within the Institute?   | Management |
| Axis 3_2_P  | Do you find your way within the [name of institute] easily?  | Patient    |
| Waiting times for the first consultation                              |  |            |
| Axis 3_3_M  | Does the Institute have to meet time standards on waiting times for the first consultation?  | Management |
| Axis 3_3_P  | Does the staff inform you about the schedule of your care plan (e.g. time between visits, time to complete treatments, time to re-evaluate disease)?   | Patient    |
| Waiting times between the first consultation and treatment initiation |  |            |
| Axis 3_4_M  | Does the Institute have to meet time standards on waiting times between the first consultation and the start of treatment?   | Management |
| Self-management of routine home care                                  |  |            |
| Axis 3_5_M  | Do you have procedures (including informative materials) to help patients and caregivers to self-manage routine home care (e.g. urinary catheter, drainage bags/tubes, heparin self-administration)? | Management |
| Axis 3_5_S  | Do you train patients and caregivers to self-manage routine homecare (e.g. urinary catheter, drainage bags/tubes, heparin self-administration)?  | Nurse      |
| Treatment option close to patient's home                              |  |            |
| Axis 3_6_P  | Did you and your doctors discuss the possibility of receiving the same treatment in a healthcare facility closer to your home?   | Patient    |
| Axis 3_6_S  | Whenever possible, do you discuss with patients whether they would prefer to receive equivalent treatment in a healthcare facility closer to their home?   | Doctor     |
| Electronic sharing of patient's files                                 |  |            |
| Axis 3_7_M  | Within your health care system, is it possible to share or electronically transfer patient files among healthcare providers?   | Management |
| Cooperation with GPs  |  |            |
| Axis 3_8_M  | Do you have a strategy for collaboration with patients' GPs?   | Management |
| Axis 3_8_P  | Is your GP involved in the care of your disease?   | Patient    |
| Axis 3_8_S  | Do you have access to the phone number of the GP of your patients?   | Doctor     |
| Axis 3_8_S  | Do you have access to the phone number of the GP of your patients?   | Nurse      |
| Assignment of staff member to a patient                               |  |            |

|            |   |            |
|------------|---|------------|
| Axis 3_9_M | Does the Institute guarantee that each patient has one staff member that coordinates the patient's entire care plan?                                | Management |
| Axis 3_9_P | At the [name of institute] or from home, do you always contact the same person - such as a doctor or nurse - when arrangements have to be made?     | Patient    |
| Axis 3_9_S | Do you provide the name and the contact information of a staff member to each patient who is to be contacted when any arrangements need to be made? | Doctor     |
| Axis 3_9_S | Do you provide the name and the contact information of a staff member to each patient who is to be contacted when arrangements need to be made?     | Nurse      |

## Shared Decision Making and Multidisciplinary approach

### Understanding of the care plan

|            |  |            |
|------------|--|------------|
| Axis 4_1_M | Does the Institute provide patients with tools (e.g. informative material) to facilitate the understanding of their own care plan? | Management |
| Axis 4_1_P | Does the staff help you in understanding your care plan including all suitable options?  | Patient    |
| Axis 4_1_S | Do patients ask you questions about their care plan?   | Doctor     |
| Axis 4_1_S | Do patients ask you questions about their care plan?   | Nurse      |

### Feedback of patients on the involvement in the decision making of their care

|            |  |            |
|------------|--|------------|
| Axis 4_2_M | Does the Institute collect feedback from patients (e.g. using questionnaires, suggestions box) about their involvement in the decision making of their care? | Management |
| Axis 4_2_P | Does the care team consider your preferences and values when discussing your care plan?  | Patient    |
| Axis 4_2_S | Do patients tell you their preferences and values when discussing their care plan?   | Doctor     |

### MDT recommendations

|            |   |            |
|------------|---|------------|
| Axis 4_3_M | Do you receive regular (at least annually) reports on the Multi Disciplinary Team (MDT) activities? | Management |
| Axis 4_3_S | Can you consult the Multidisciplinary Team's (MDT) recommendations for your patients?               | Doctor     |
| Axis 4_3_S | Can you consult the Multidisciplinary Team's (MDT) recommendations for your patients?               | Nurse      |

### MDT for individual diagnoses

|            |  |            |
|------------|--|------------|
| Axis 4_4_M | Do you have an MDT for each tumour type according to a Standard Operating Procedure?         | Management |
| Axis 4_4_S | Have you been involved in the design process of the Standard Operating Procedure of the MDT? | Doctor     |
| Axis 4_4_S | Have you been involved in the design process of the Standard Operating Procedure of the MDT? | Nurse      |

### End-of-life care and patients' choices



|                           |   |            |
|---------------------------|---|------------|
| Axis 4_5_M                | Do you have a procedure regarding with end of life, which includes collecting and reporting patients' choices?  | Management |
| Axis 4_5_S                | Do you have access to the written statement regarding patient's choice about end-of-life?   | Doctor     |
| Axis 4_5_S                | Do you have access to the written statement regarding the patients' choice about end-of-life?   | Nurse      |
| Organization of care plan |   |            |
| Axis 4_6_M                | In clinical pathways, are roles and responsibilities clearly defined concerning diagnosis, treatment and follow-up?   | Management |
| Axis 4_6_P                | Overall, does the staff organize your care plan (e.g. visits on time, rare and timely rescheduling of visits, reduced walking from one visit to another, etc.) well at the [name of institute]? | Patient    |
| Axis 4_6_S                | Do you have access to clinical pathways that have been approved in your Institute?  | Doctor     |
| Axis 4_6_S                | Do you have access to the clinical pathways that have been approved in your Institute?  | Nurse      |

## Enhancing the Quality of Life

### Supportive services

|              |   |            |
|--------------|---|------------|
| Axis 5_1_M   | Does the Institute provide any of the following supportive services?  | Management |
| Axis 5_1_M-a | pain therapy  | Management |
| Axis 5_1_M-b | physical rehabilitation   | Management |
| Axis 5_1_M-c | nutrition support   | Management |
| Axis 5_1_M-d | psycho oncology   | Management |
| Axis 5_1_M-e | palliative care   | Management |
| Axis 5_1_M-f | speech therapy  | Management |
| Axis 5_1_M-g | stoma therapy   | Management |
| Axis 5_1_M-h | support for pressure sores  | Management |
| Axis 5_1_M-i | social support (e.g. family, work, school, ...)   | Management |
| Axis 5_1_M-j | spiritual support   | Management |
| Axis 5_1_M-l | appearance related care (e.g. plastic care, skin and nail care, cosmetics, wigs, ...)                                 | Management |
| Axis 5_1_S   | Since the first contact, do you regularly screen (on paper or electronically) patient needs for any of the following? | Doctor     |
| Axis 5_1_S   | Since the first contact, do you regularly screen (on paper or electronically) the patients' needs for the following?  | Nurse      |
| Axis 5_1_S-a | pain  | Nurse      |
| Axis 5_1_S-b | nutrition   | Nurse      |



|   |   |            |
|---|---|------------|
| Axis 5_1_S-c  | psychological distress  | Nurse      |
| Axis 5_1_S-d  | palliation  | Nurse      |
| Axis 5_1_S-e  | other (e.g. physical and speech rehab, stoma and pressure sores care, etc...)   | Nurse      |
| Axis 5_1_S-f  | appearance related concerns (e.g. surgery outcomes, skin care, hair loss, ...)  | Nurse      |
| Axis 5_1_S-g  | social problems (e.g. family, work, school, ...)  | Nurse      |
| Axis 5_1_S-h  | spiritual concerns  | Nurse      |
| Axis 5_1_S-i  | none of the above   | Nurse      |
| Quality of life and offer of supportive services          |   |            |
| Axis 5_2_M  | Do you receive, at least annually, reports on the percentage of patients screened for supportive needs (e.g. pain, palliative, psycho-oncology, etc...)?                            | Management |
| Axis 5_2_P  | At the [name of institute], does the staff pays attention to your quality of life (e.g. pain, emotions, relationships, nutrition, appearance, sexuality, spiritual concerns, etc.)? | Patient    |
| Axis 5_2_S  | When you screen patient needs, do you collect patients' perception [e.g. PROMs] about any of the following?   | Doctor     |
| Axis 5_2_S  | When you screen patient needs, do you collect patients' perception [e.g. PROMs] on the following ?  | Nurse      |
| Axis 5_2_S-a  | practical problems (work/school, housing, transportation)   | Nurse      |
| Axis 5_2_S-b  | family problems   | Nurse      |
| Axis 5_2_S-c  | emotional and psychological problems  | Nurse      |
| Axis 5_2_S-d  | spiritual/religious concerns  | Nurse      |
| Axis 5_2_S-e  | physical problems (pain, eating, appearance, sexual, nausea, ...)   | Nurse      |
| Axis 5_2_S-f  | none of the above   | Nurse      |
| Psycho-oncological support for caregivers                 |   |            |
| Axis 5_3_M  | Does your Institute provide psycho-oncological support for caregivers?  | Management |
| Axis 5_3_S  | Do you screen psychological distress in caregivers?   | Doctor     |
| Axis 5_3_S  | Do you screen psychological distress in caregivers?   | Nurse      |
| Supportive care in clinical pathways                      |   |            |
| Axis 5_4_M  | Do clinical pathways include supportive care?   | Management |
| Axis 5_4_S  | Do you have access to the recommendations of the supportive care team (e.g. pain therapist, psycho-oncology, nutrition, etc.)?  | Doctor     |
| Comfort in thee institute premises for patients and staff |   |            |
| Axis 5_5_M  | Are the spaces (e.g. Main Lobby, Clinic Entrances, Cancer Information Service, Unit-based nurses' stations) designed to have a welcoming, comforting and "healing" impression?      | Management |

|            |   |         |
|------------|---|---------|
| Axis 5_5_P | At the [name of institute] are the spaces (Main Lobby, Clinic Entrances, Cancer Information Service for patients, Unit-based nurses' stations) welcoming, comforting and "healing"? | Patient |
| Axis 5_5_S | Is your clinic designed to be comforting and functional for your work?  | Doctor  |
| Axis 5_5_S | Is your clinic designed to be comforting and functional for your work?  | Nurse   |

## Research and Improving Health Technologies

|  |   |            |
|--|---|------------|
| Awareness of patients about research in cancer care                    |   |            |
| Axis 6_1_M   | Does the Institute promote (e.g. by publicity campaign, posters, media, conferences, etc.) the importance of research in cancer care among patients and the public as well as how patients can impact on cancer research? | Management |
| Axis 6_1_P   | Are you aware that at the [name of the hospital] we are doing research to improve patient care?   | Patient    |
| Axis 6_1_S   | Do you promote improvements in cancer care to the public, including patients (e.g. during conferences, interviews, media)?  | Doctor     |
| Patient reported outcome in clinical trials                            |   |            |
| Axis 6_2_M   | Do you receive, at least annually, reports on the number of clinical trials, which use patient reported outcome (e.g. PROMs) as clinical endpoints?   | Management |
| Axis 6_2_S   | Among clinical trials running in your centre, are there any using patient reported outcomes (PROMs)?  | Doctor     |
| Research project on patient centredness                                |   |            |
| Axis 6_3_M   | Are you the PI or member of the steering committee of at least one research project dealing with patient centredness?   | Management |
| Involvement of patients in research projects and information materials |   |            |
| Axis 6_4_M   | The centre has a policy to involve patients (e.g. in focus groups, interviews, etc.) when:  | Management |
| Axis 6_4_M-a   | planning research projects  | Management |
| Axis 6_4_M-b   | phrasing the informed consent and information material of projects  | Management |
| Axis 6_4_M-c   | none of the above   | Management |
| Axis 6_4_S   | When enrolling patients in a clinical trial, do you give them written information describing the study using lay terminology?   | Doctor     |
| Patient accrual in active clinical trials                              |   |            |
| Axis 6_5_M   | Do you monitor patient accrual in active clinical trials?   | Management |
| Enrolment of patients for clinical trials                              |   |            |
| Axis 6_7_M   | Do you have tools (e.g. databases, newsletters, etc.) to offer trial enrolment to all eligible patients?  | Management |
| Axis 6_7_S   | Do you have access to rationale and eligibility criteria of all clinical trials running in your centre?   | Doctor     |

Use of modern digital technologies

|            |  |            |
|------------|--|------------|
| Axis 6_8_M | Does the centre support Mobile Medical Apps and mHealth Devices?   | Management |
| Axis 6_8_P | Can you access your medical information and/or book an appointment in the centre through a Mobile Medical Application in your phone? | Patient    |
| Axis 6_8_S | Does the centre support Mobile Medical Apps and mHealth Devices?   | Doctor     |

## Integration process

As part of the integration of a new set of indicators from the online benchmarking tool of the Intent project, it is necessary to provide a robust software base that will enable subsequent storage, validation and preparation of data for further processing by related services. The PostgreSQL database system is used to store individual indicators and other metadata, which allows us to manipulate data using SQL language and ensure data integrity by defining complex integrity constraints.

Data from a structured questionnaire are imported into our database via a standardized export file. It is then possible to transform the data into a format that is suitable for subsequent visualization on an online benchmarking tool. Visualizations are constructed using javascript libraries, which are directly designed for this purpose (d3.js, NVD3,...).