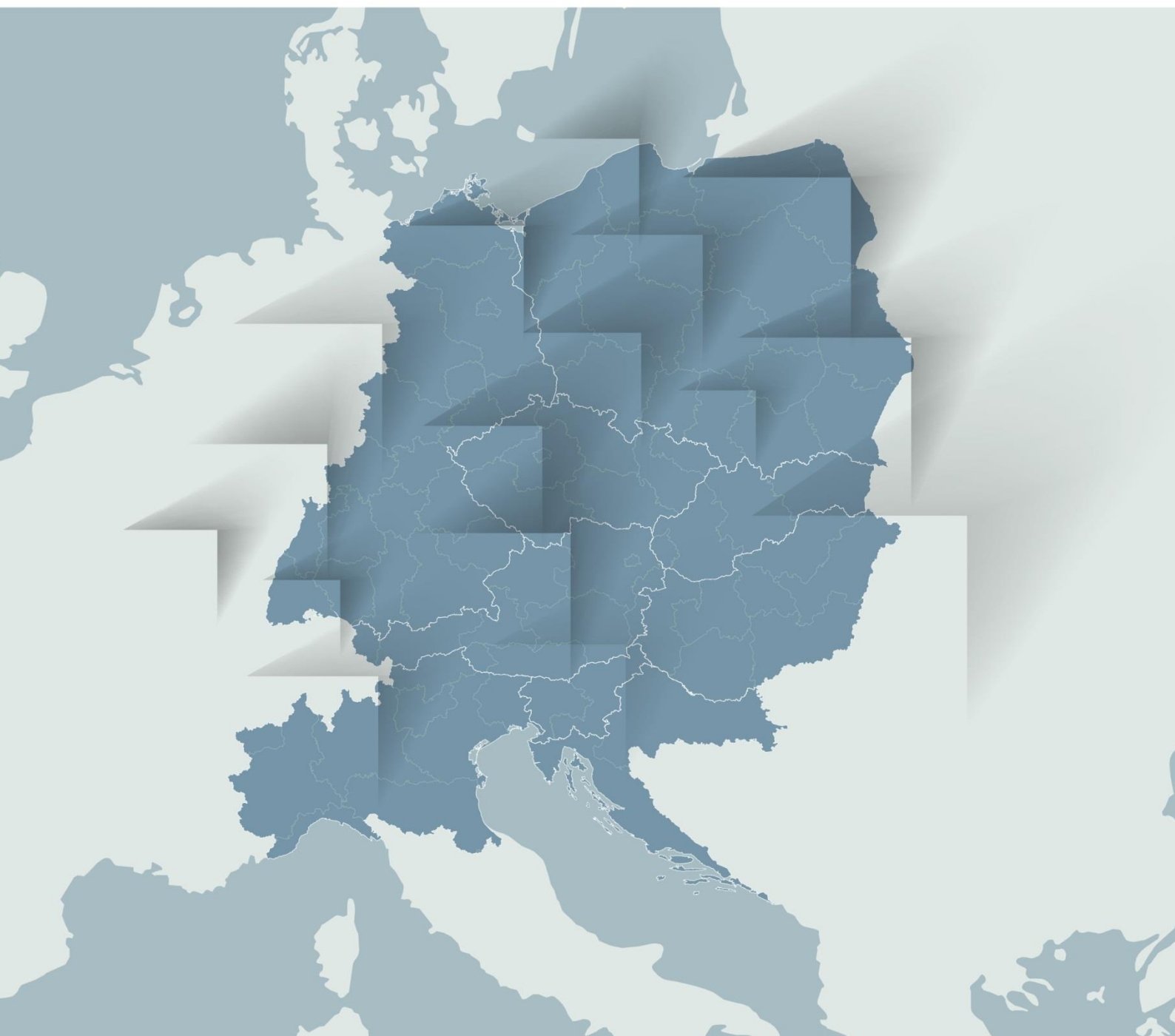




INTENT

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



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

Axis 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 the 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,...).

GROUP:

PRIORITY:
určuje pořadí

CODE:
textová reprezentace otázky, použije se jako název sloupce v exportu dat

ANNOTATION:

TITLE (en): Do patients ask you questions about their care plan?

POLOŽKY (en):

TITLE (cs): Odpovídáte pacientům na otázky týkající se jejich léčebného plánu?

POLOŽKY (cs):

TITLE (hu): A betegnek tesznek-e fel kérdéseket Önnek a kezelési tervükkel kapcsolatban?

POLOŽKY (hu):

TITLE (sl): Ali vam pacienti zastavljajo vprašanja o načrtu oskrbe, ki je predvidena zanje?

POLOŽKY (sl):

TITLE (it): I pazienti ti fanno domande sul loro piano di cura?

POLOŽKY (it):

TYPE:

AKTIVOVÁNO?: Yes No

A new dedicated backoffice module for the management of online surveys was developed, in which the following features were implemented:

- Management of users and roles
- Management of questions
- Management of translations and target groups
- Management of responses
- Management of surveys

Final surveys are accessible to target users using a frontend interface on the following level of authentication:

Managers

- One manager per hospital
- Authentication required

Hospital staff (medical doctor and nurse)

- Tens of employees
- No authentication required (but a unique URL for each respondent)

Patients and expert patients

- Hundreds of patients
- No authentication required