



What Quality Cancer Care and Research means for Patients



Report on the INTENT project from Central and Eastern Europe on patient-centred care

Péter Nagy, National Institute of Oncology

06.14.2023

OECI Oncology Days, Paris





Authors



INTENT

Edit Marosi¹, Riccardo Spizzo², István Kenessey¹, András Wéber¹, Olga Sapožnikov³, Ondřej Májek⁴, Martin Komenda⁴, Piero Selle⁵, Tanja Marinko⁶, Laura del Campo⁷, Marek Svoboda³, József Lövey¹, Csaba Polgár¹, Péter Nagy¹

¹National Institute of Oncology, Budapest, Hungary ²National Cancer Institute IRCSS CRO AVIANO, Aviano, Italy, ³Masaryk Memorial Cancer Institute, MMCI Brno, Czech Republic, ⁴Institute of Health Information and Statistics of the Czech Republic, Prague, Czech Republic, ⁵Veneto Institute of Oncology IRCCS IOV, Padova, Italy, ⁶Institute of Oncology, Ljubljana Ol LJ, Slovenia, ⁷Italian Association of Cancer Patients, Relatives and Friends, AIMAC, Rome, Italy



Research background



- The growing incidence of cancer is placing an increasing burden on health care systems.
- Increasing patient/clinician ratio, less time for each patient.
- The INTENT project aimed to develop a **Patient Centered Cancer Care Model (PCCCM)** as a potential solution for the Central and Eastern European region.

Website: <https://programme2014-20.interreg-central.eu/Content.Node/INTENT.html>



Definition of PCCCM in the INTENT project



- **1) Improving patients' active role in care and research**
- Key words: Active involvement, health literacy, decision making, education and empowerment, patient safety

- **2) Improving health gain, including quality of life**
- Key words: MDTs, quality of life, continuity of care, measurements, public disclosure of results, patient oriented research

- **3) Actively contributing to organizational learning and continuous improvement in this field** PCC in our project finally aims to modify current practices by defining an innovative and shared model of care



Methodology



A two-phase survey carried out in the framework of the pilot project:

- (1) questionnaire for stakeholders, i.e. patients and caregivers, about the expectations of PCCCM and based on the results
- (2) a benchmarking questionnaire on patient-centred cancer care.

Pilot sites



Pilot cancer centres of the INTENT project

- Veneto Institute of Oncology IRCCS IOV, Padova, Italy
- National Cancer Institute IRCSS CRO AVIANO, Aviano, Italy
- Institute of Oncology, Ljubljana OI LJ, Slovenia
- Masaryk Memorial Cancer Institute, MMCI Brno, Czech Republic
- National Institute of Oncology, OOI Budapest, Hungary - leader of the pilot exercise



Methodology:

Building consensus on the development of the PCCCM dimensions based on the Delphi Method



- Evaluation of 26 dimensions of PCCC based on literature search
 - 13 dimensions from the perspective of **patient**
 - 13 dimensions from the perspective of **healthcare institution**
- 19 experts (Awareness, Agreement, Choice)

Zill JM, Scholl I, Härter M, Dirmaier J. Which dimensions of patient-centeredness matter? - Results of a web-based expert Delphi survey. PLoS One 2015;10. <https://doi.org/10.1371/journal.pone.0141978>.

Dalkey N, Helmer O (1963). "An Experimental Application of the Delphi Method to the use of experts". *Management Science*. 9 (3): 458–467. [doi:10.1287/mnsc.9.3.458](https://doi.org/10.1287/mnsc.9.3.458)



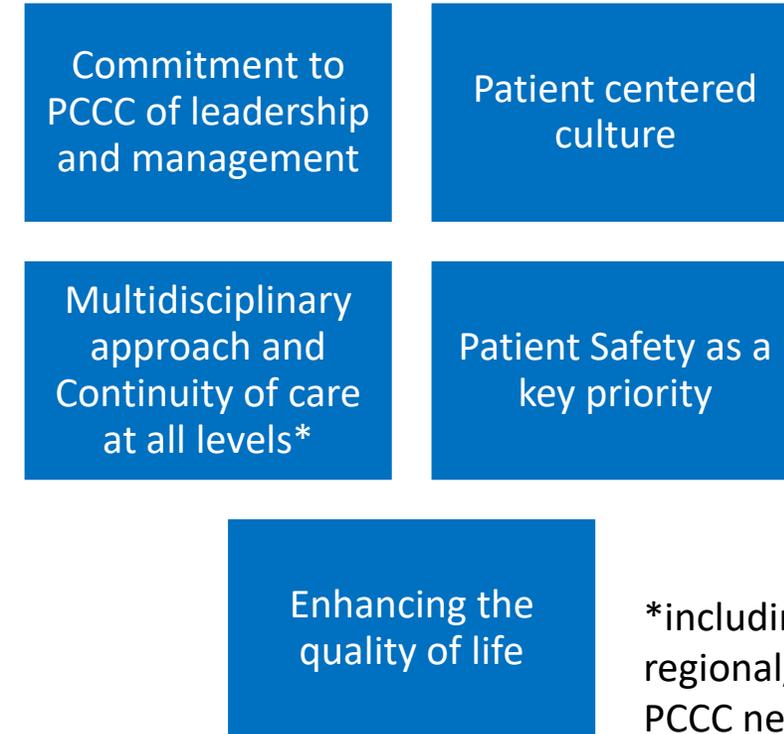
11 dimensions were selected (10 +1)

INTENT

FOCUS: PATIENT



FOCUS: ORGANIZATION



*including regional/national/international PCCC networks





Methods: 6 dimensions of PCCCM



INTENT

1. Patient Centered Culture

Including Commitment of leadership, Co-design of strategies and services and Patient Safety

2. Information Communication Education

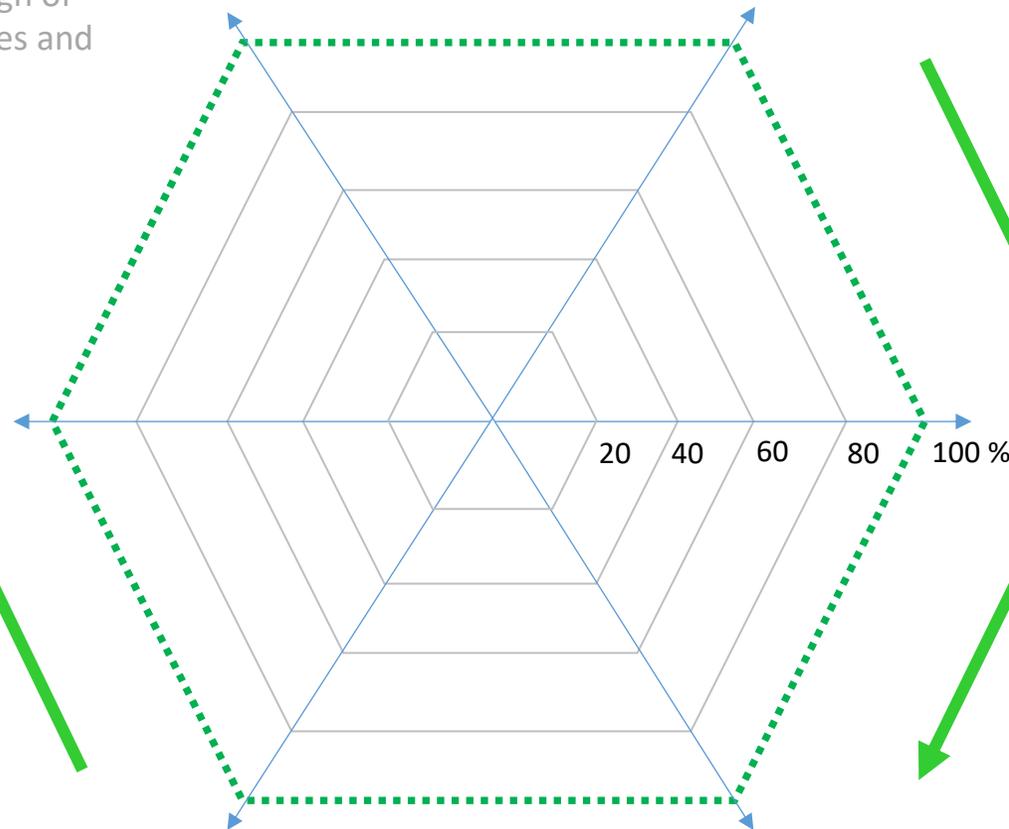
3. Accessibility & Continuity of Care

6. Research

5. Enhancing the quality of life

Including Physical and emotional support and PROMs

4. Shared Decision Making & Multidisciplinary approach





Results: Questionnaire on stakeholder expectations of PCCCM



INTENT

- 1148 patients and 914 caregivers interviewed
- Generally, characteristics of patients and caregivers differ in the 5 regions:
 - Sex: females are slightly prevalent (66%-56%).
 - Age: 50 - 64 years (40%).
 - About 50% of patients are under curative treatment, 25% either in metastatic stage or follow-up.
 - 94% of caregivers are relatives of the patients.

Results: Questionnaire on stakeholder expectations of Sample (Patients)



Patients	Czech Republic	Slovenia	Hungary	Italy	P (Chi-square)
Total	395 (100%)	150 (100%)	280 (100%)	323 (100%)	323 (100%)
Primary cancer site					
 Breast	105 (26.6%)	48 (32.0%)	84 (30.0%)	118 (36.5%)	8.9x10 ⁻¹⁴
Lung	20 (5.1%)	34 (22.7%)	23 (8.2%)	20 (6.2%)	
Colorectal	58 (14.7%)	18 (12.0%)	45 (16.1%)	37 (11.5%)	
Prostate	36 (9.1%)	7 (4.7%)	22 (7.9%)	20 (6.2%)	
Skin (non-melanoma)	13 (3.3%)	6 (4.0%)	14 (5.0%)	22 (6.8%)	
Melanoma	2 (0.5%)	2 (1.3%)	4 (1.4%)	2 (0.6%)	
Kidney	13 (3.3%)	4 (2.7%)	16 (5.7%)	9 (2.8%)	
Stomach	14 (3.5%)	4 (2.7%)	11 (3.9%)	3 (0.9%)	
Esophageal	4 (1.0%)	1 (0.7%)	1 (0.4%)	3 (0.9%)	
Uterine	25 (6.3%)	2 (1.3%)	8 (2.9%)	5 (1.6%)	
Ovarian	28 (7.1%)	0 (0.0%)	4 (1.4%)	16 (5.0%)	
Oral cavity and laryngeal	16 (4.1%)	3 (2.0%)	10 (3.6%)	9 (2.8%)	
Bladder	10 (2.5%)	3 (2.0%)	2 (0.7%)	4 (1.2%)	
Pancreatic	9 (2.3%)	3 (2.0%)	6 (2.1%)	9 (2.8%)	
Thyroid	0 (0.0%)	2 (1.3%)	4 (1.4%)	14 (4.2%)	
Lymphoma	7 (1.8%)	8 (5.3%)	19 (6.8%)	13 (4.0%)	
Other	35 (8.9%)	5 (3.3%)	7 (2.5%)	19 (5.9%)	



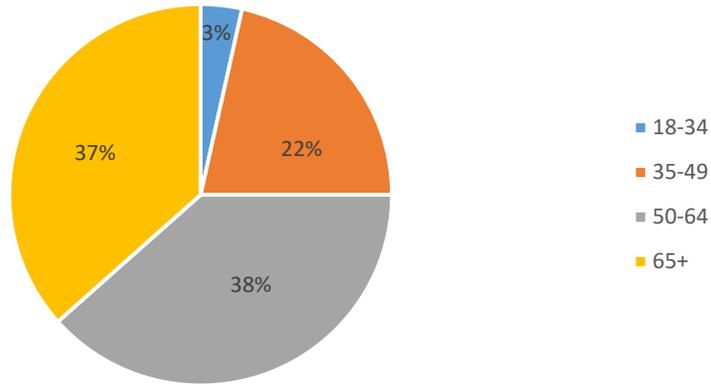
Demographic Data



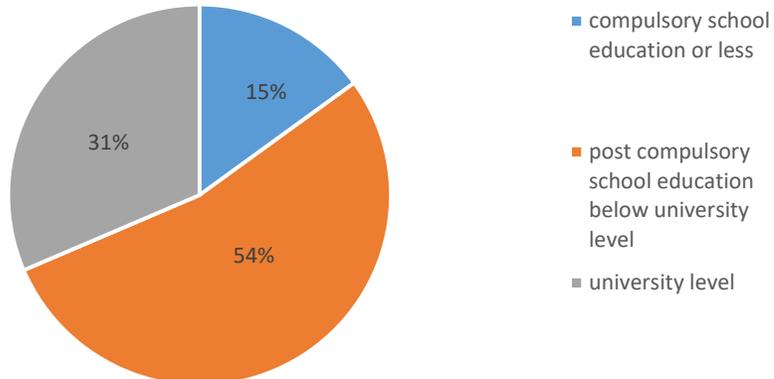
INTENT

PATIENT

Age distribution (%)

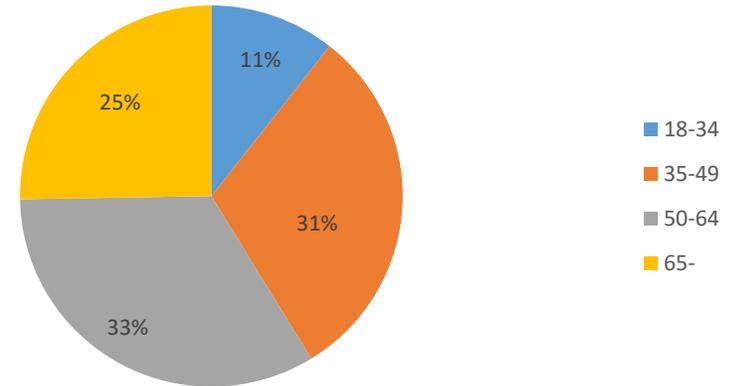


Education level (%)

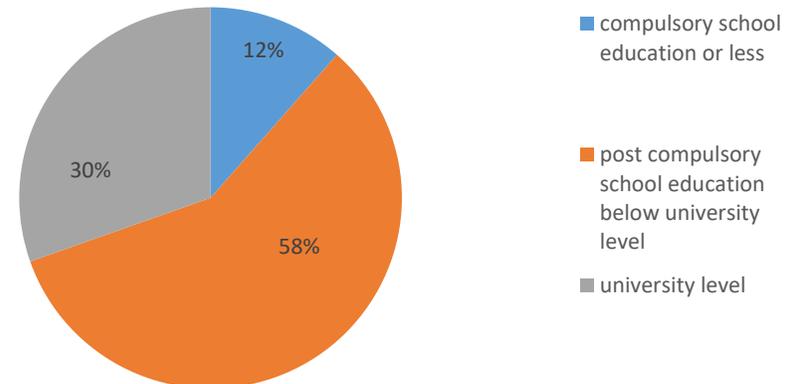


CAREGIVER

Age distribution (%)



Education level (%)





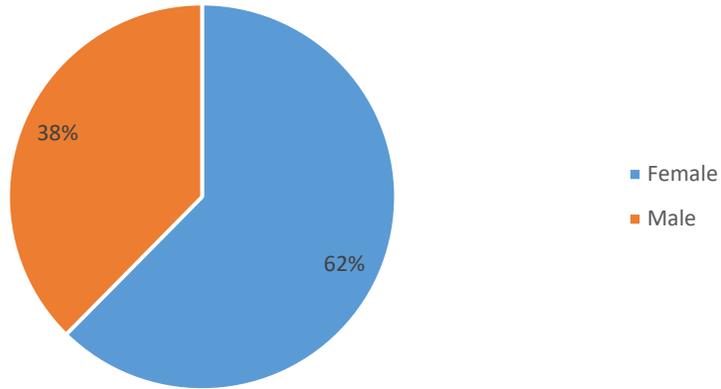
Demographic Data



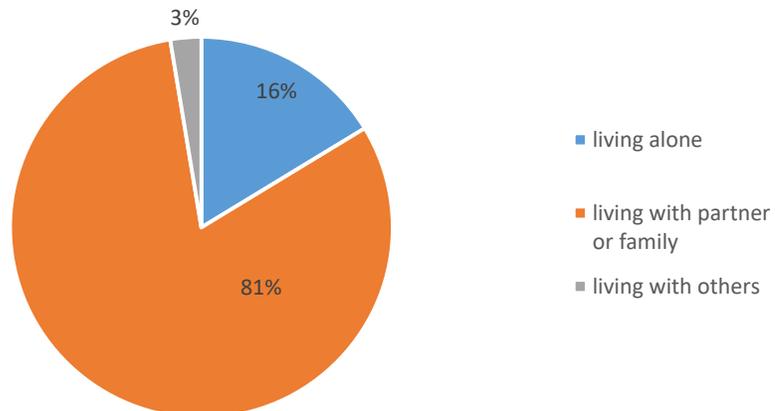
INTENT

PATIENT

Sex of patient respondents (%)

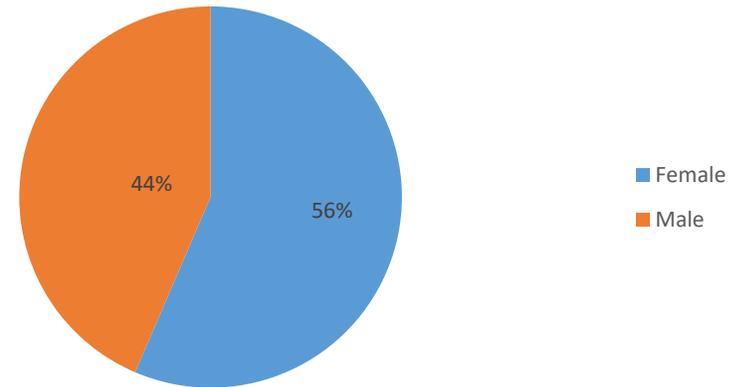


Living situation (%)

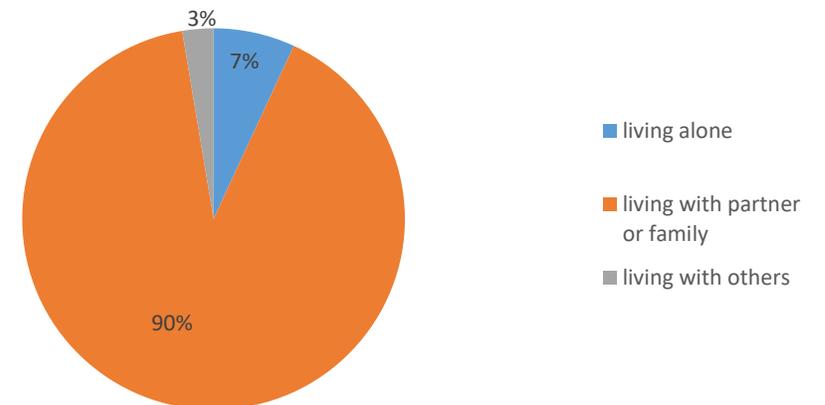


CAREGIVER

Sex (%)



Living situation (%)





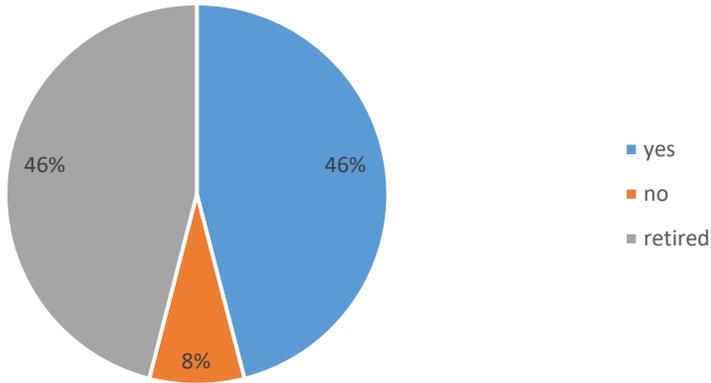
Demographic Data



INTENT

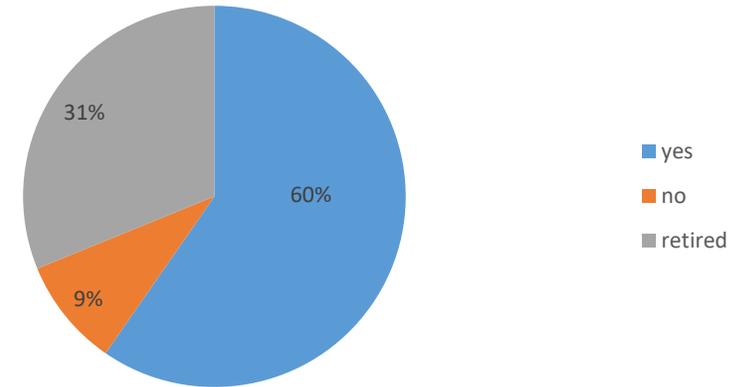
PATIENT

Employment (%)

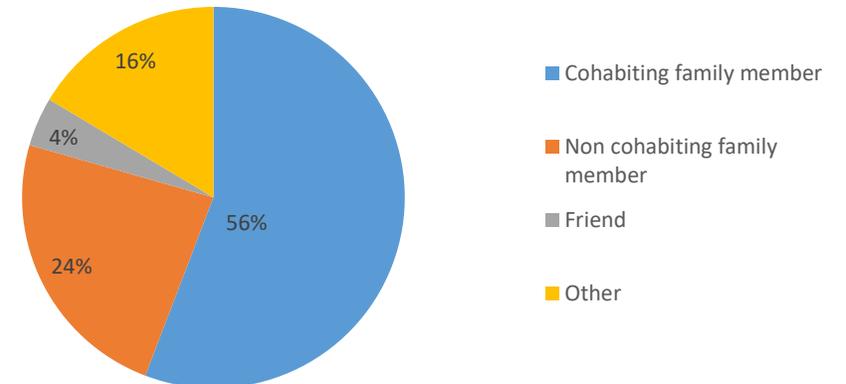


CAREGIVER

Employment (%)



Relation (%)



Results: Questionnaire on stakeholder expectations of PCCCM



1. Information, Communication, Education

1. Could you point out at least three channels to **receive information on disease, care pathways and treatment options**, beginning from the most important?

	Caregivers					Patients				
	NIO	MMCI	CRO	IOV	OI-Lj	NIO	MMCI	CRO	IOV	OI-Lj
In person meeting with healthcare professional	90	95	97	98	96	93	99	96	93	97
Website/forum different by the healthcare provider website	58	63	18	17	42	48	64	9	18	54
A cancer information desk in the hospital	49	39	51	72	75	38	40	51	56	54
A dedicated helpline	31	13	29	62	30	24	12	32	44	23
Group information sessions organized by the healthcare provider	18	4	35	25	16	25	3	34	27	20
Booklet and leaflets	35	42	15	16	38	48	45	20	18	46

2. Could you point out at least three channels to receive information on **social and economic aspects, insurance, and social security**, beginning from the most important?

	Caregivers					Patients				
	NIO	MMCI	CRO	IOV	OI-Lj	NIO	MMCI	CRO	IOV	OI-Lj
In person meeting with healthcare professional	70	87	73	76	87	77	86	77	75	87
Website/forum different by the healthcare provider website	68	63	24	26	44	54	62	18	18	55
A cancer information desk in the hospital	57	49	65	76	77	41	43	62	69	57
A dedicated helpline	33	12	34	66	31	32	15	44	54	33
Group information sessions organized by the healthcare provider	13	3	29	24	15	20	5	23	24	20
Booklet and leaflets	46	37	23	25	44	48	38	23	24	47

Results: Questionnaire on stakeholder expectations of PCCCM



1. Information, Communication, Education

3. Could you point out at least three channels to receive information on **quality of life (nutrition, fitness, beauty, sexuality, rehabilitation etc.)** beginning from the most important?

	Caregivers					Patients				
	NIO	MMCI	CRO	IOV	OI-Lj	NIO	MMCI	CRO	IOV	OI-Lj
In person meeting with healthcare professional	75	89	87	88	84	84	90	83	84	87
Website/forum different by the healthcare provider website	67	65	19	29	52	50	65	19	24	60
A cancer information desk in the hospital	40	36	47	72	66	34	37	52	58	48
A dedicated helpline	29	11	27	46	26	23	11	31	37	22
Group information sessions organized by the healthcare provider	25	5	41	37	19	31	6	34	33	26
Booklet and leaflets	49	50	29	21	48	59	53	26	26	54

4. Could you point out at least three services that **volunteer associations should offer you within the cancer center,** beginning from the most important?

	Caregivers					Patients				
	NIO	MMCI	CRO	IOV	OI-Lj	NIO	MMCI	CRO	IOV	OI-Lj
Front desk	51	33	19	37	23	51	29	27	31	27
Recreational services	7	12	10	13	17	13	22	9	6	21
Psychological support	61	34	60	61	72	55	40	50	53	69
Transportation to/from the hospital	41	45	42	40	42	31	43	37	41	43
Logistic support	44	52	29	31	33	30	43	28	28	25
Information on non-health related services	27	37	44	54	57	35	37	47	45	50
Quality of life services	32	33	37	38	43	48	33	42	43	49
Contact point	22	29	18	20	9	23	30	13	19	15

Results: Questionnaire on stakeholder expectations of PCCCM



2. Continuity of care and shared decision making

5. (Caregiver) After hospital discharge of the patient that you care for, if needed, how do you prefer to interact with the healthcare team?

8. (Patient) After hospital discharge, how do you prefer to interact with the healthcare professionals in the cancer center (except for the emergency situation)?

	Caregivers					Patients				
	NIO	MMCI	CRO	IOV	OI-Lj	NIO	MMCI	CRO	IOV	OI-Lj
Direct contact in person at the hospital	93	91	93	93	91	88	92	90	89	89
E-mail	71	64	62	88	76	64	64	53	63	83
By internet	33	24	19	19	48	31	19	14	11	51
By phone	86	75	69	93	81	84	76	69	76	74

Results: Questionnaire on stakeholder expectations of PCCCM

3. Accessibility (Easy access to care and services)

10. (Caregiver) When you attend doctor visits or treatment sessions at the cancer center, what would make things easier for you? Please choose 3 alternatives, beginning from the most important? (being 1 the first choice, and 3 the third)

6. (Patient) When accompanying your loved one to doctor visits or treatment sessions at the cancer center, what would make things easier for you? Please choose 3 alternatives, beginning from the most important. (being 1 the first choice and 3 the third choice)

	Caregivers					Patients				
	NIO	MMCI	CRO	IOV	OI-Lj	NIO	MMCI	CRO	IOV	OI-Lj
Simplified administrative procedures	46	24	34	38	50	47	23	36	24	54
Waiting time to access the diagnostic tests	18	25	13	5	35	15	27	5	6	33
Waiting time between diagnosis and treatment	31	31	48	36	34	38	27	47	48	51
Short operating hours for diagnostic tests and visits	37	28	44	28	32	35	34	37	34	33
Logistics problems resolution	51	39	49	49	4	59	50	51	51	37
I am already satisfied	47	28	39	51	39	36	36	41	44	46

Results: Questionnaire on stakeholder expectations of PCCCM

3. Accessibility (Easy access to care and services)

8. (Caregiver) After hospital discharge of the patient that you care for, from what services would the patient and you benefit the most at home instead of at the hospital? Please choose 3 alternatives, beginning from the most important. (being 1 the first choice, and 3 the third choice)

11. (Patient) After hospital discharge, from what services would you benefit the most at your home instead of at the hospital? Please choose 3 alternatives, beginning from the most important. (being 1 the first choice, and 3 the third choice)

	Caregivers					Patients				
	NIO	MMCI	CRO	IOV	OI-Lj	NIO	MMCI	CRO	IOV	OI-Lj
Nursing support	56	53	62	78	61	46	48	60	68	61
Physical therapy	20	44	33	38	49	26	43	31	48	55
Smart-phone application	58	43	35	44	49	56	48	48	40	51
Pain control care	46	50	51	43	59	36	46	39	42	44
Occupational therapy	24	21	23	26	32	35	23	29	21	28
Social counseling	14	15	7	12	13	11	18	9	13	21
Psychological support	53	39	47	50	36	40	38	26	34	38



Results:



INTENT

Results of the benchmarking questionnaire

- 100 patients (50 male, 50 female)
 - Preferably inpatients or outpatients who already have a diagnosis and have started their treatment plan.
- 5 expert patients
 - Any expert patients from patient associations, who are also familiar with the operation of the pilot site.
- 10 doctors
 - Both junior or senior physicians who have been at the pilot site for at least 2 years.
 - Following departments could be covered: surgery, medical oncology, radiotherapy, etc.
- 10 nurses
 - Both junior or senior nurses who have been at the pilot site for at least 2 years.
 - Following departments could be covered: surgery, medical oncology, radiotherapy etc.
- 1 manager (official statement of institute)

Benchmarking questionnaire (Patient – sample)

- PATIENT -

PATIENT-CENTRED CANCER CARE AND HEALTH INNOVATION INDICATOR SETS

WP2 (D.T2.1.1-2) Version 1 - 01 2020

Dear Madam or Sir,

[Name of the institute] is part of the INTENT project. The INTENT project aims to increase the participation of patients and include patients' voices in the organization of the [Name of the hospital]. For these reasons, it would be very helpful if you could dedicate about 20 minutes to fill out this anonymous questionnaire about your experience at the *[Name of the institute]*.

Participating in this anonymous survey is voluntary, if you do not want to participate, feel free to reject this request. Your decision will have no effect on the care that is given to you at this center.

This questionnaire is currently being distributed to hundreds of patients at participating cancer centers in the Czech Republic, Hungary, Italy and Slovenia. The INTENT project is funded by the European Commission in the framework of the INTERREG Central Europe Program.

Thank you for your time

The INTENT Project Partners

More information is available at the INTENT project website (<https://www.interreg-central.eu/Content.Node/INTENT.html>)

1. Is it difficult to reach the *[name of institute]* (e.g. by public transportation, driving direction, parking)?
 - No
 - Partially
 - Yes

2. 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"?
 - No
 - Partially
 - Yes

3. Do you find your way within the *[name of institute]* easily?
 - No
 - Partially
 - Yes

4. 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]*?
 - No
 - Partially
 - Yes



Benchmarking questionnaire (Nurses – sample)

- Nurses -

PATIENT-CENTRED CANCER CARE AND HEALTH INNOVATION INDICATOR SETS

WP2 (D.T2.1.1-2) Version 1 - 01 2020

Your Organisation is part of the INTENT project, which is funded by the European Commission in the framework of the INTERREG Central Europe Program.

The overall aim of the INTENT project is to develop and pilot an innovative model of cancer care to improve patient centeredness. In this context, we have developed a set of qualitative indicators to monitor and benchmark the patient centered care in four countries (the Czech Republic, Hungary, Italy and Slovenia) across Central Europe. For these reasons, we are asking you to fill the following anonymous questionnaire on the situational analysis of your center concerning six main axes:

- Shared decision making and Multidisciplinary approach
- Accessibility and continuity of care
- Enhancing quality of life
- Information, communication, education
- Patient centered culture

Filling the questionnaire takes approximately 15 minutes.

Thank you for your collaboration.

The INTENT Project Partners

More information is available at the INTENT project website (<https://www.interreg-central.eu/Content.Node/INTENT.html>)



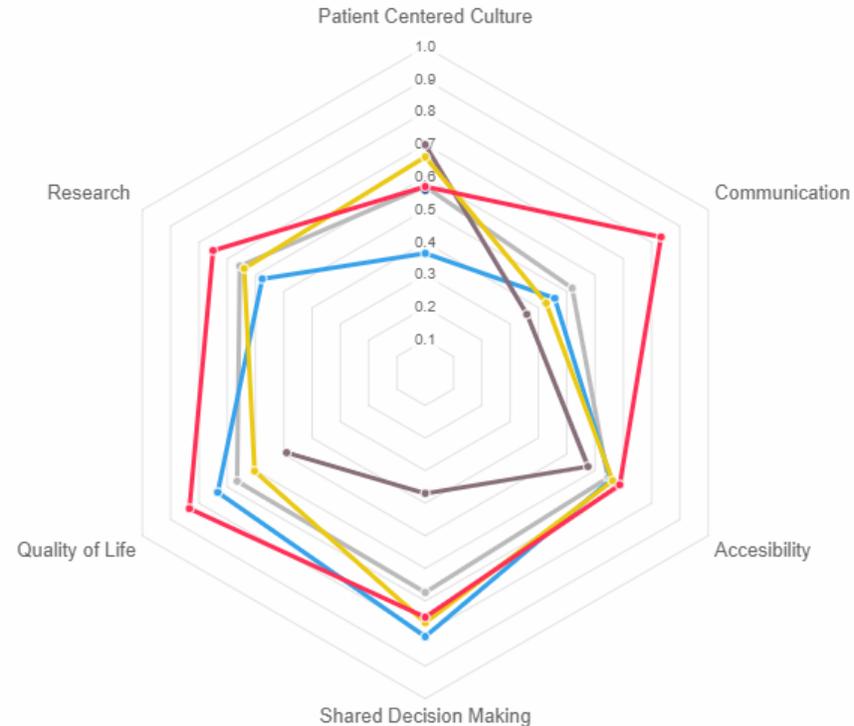
1. Do patients ask you questions about their care plan?
 - No
 - Partially
 - Yes
2. Do you adapt the patient care plan according to the logistic needs of patients (e.g. work, travels, family issues, etc.)?
 - No
 - Partially
 - Yes
3. Do you provide the name and the contact information of a staff member to each patient who is to be contacted when arrangements need to be made?
 - No
 - Partially
 - Yes
4. Do you have access to the phone number of the GP of your patients?
 - No
 - Partially
 - Yes



Results: Results of the benchmarking questionnaire



Management Medical Doctors Nurses Patients Expert Patients Total score



Sustainable outcome

Integration of indicators on patient centeredness into the OECl Accreditation and Designation System

INTENT

Chapter 3: Patient involvement and empowerment (standards 19 to 28)

Patient involvement	
Standard 19	
It is the mission of the cancer centre/institute to encourage patient involvement in services.	
1.	CORE The cancer centre/institute involves patients and patients' voluntary organisations and support groups in the planning and organisation of services.
2.	The standard process of introducing new practices in clinical care ensures that patients are involved.
3.	There is a committee representing patients and serving as a link between the cancer centre/institute and the patients for advice and consultation.

Patient education programmes	
Standard 20	
Patient education programmes are in place.	
1.	There are policies in place for patient education programmes where responsibilities and accountabilities of the staff are stated.
2.	CORE There are patient education programmes that aim at improving patient understanding of their illness, diagnosis, including information on self-care and how to manage multiple aspects of their illness or survivorship.
3.	The cancer centre/institute makes specific provisions for access for individuals with disabilities and special needs (e.g. reduced mobility, visual and hearing difficulties).
4.	CORE An information and support centre is available in the cancer centre/institute and easily accessible for staff, patients, family members and caregivers.
5.	The cancer centre/institute organises public events to showcase advances in cancer research.

Patients' rights and preferences	
Standard 21	
The cancer centre/institute has a policy on patients' preferences.	
1.	The cancer centre/institute has a policy on respecting patients' preferences (religious, cultural, social).

Patient information	
Standard 22	
Information is provided to patients.	
1.	CORE The cancer centre/institute provides information material that is readable, up-to-date, appropriate and available in languages commonly spoken by the population served.
2.	Information about diagnostic and treatment options is provided.
3.	The information includes information about follow-up after treatment.
4.	The information includes information about clinical trials available.
5.	The information includes information about supportive care.
6.	The information includes information about palliative care.
7.	Information on relevant patients' rights is provided to patients and their caregivers.

Informing patients about their care	
Standard 23	
There are procedures for informing patients about the diagnostic results, treatment and follow-up, and survivorship support.	
1.	CORE There are procedures in place which specify how and by whom patients are informed about their diagnostic results, treatment options, follow-up, and survivorship support, which involve shared decision-making.
2.	Expertise and specific training on communicating with patients and their families is available for staff.
3.	The information communicated to the patient is recorded in the patient's record.
4.	If patients are referred to another healthcare provider, they are informed about the continuity of their care.
5.	Patients receive information about their contact person for all matters related to their care.
6.	CORE All patients are given contact information of clinical staff in case of emergency.

Informing patients on admission	
Standard 24	
Cancer patients are informed about the cancer centre/institute admission and welcoming procedures.	
1.	All patients visiting the cancer centre/institute receive general information about the hospital.
2.	Detailed information about the admission procedure is available and communicated to patients.
3.	Information about patients' associations and about self-help and support groups is given to patients and their caregivers.

Discharge procedure, follow-up and survivorship care planning	
Standard 25	
Discharge procedure and related care plans are defined.	
1.	CORE There is a defined discharge procedure including giving information on further treatment, follow-up, re-admission and home care.
2.	The cancer centre/institute has processes to inform the patients' General Practitioner of a transfer of care.
3.	The patient is provided with an individual survivorship plan which is discussed with the patient and includes details of all support services and support groups available.
4.	The patient is provided with an individual plan for end-of-life care, which is discussed with the patient and caregivers.

Patient satisfaction/experience	
Standard 26	
Patients' experience of cancer care is an integrated part of the quality improvement system of the cancer centre/institute.	
1.	CORE The cancer centre/institute has methods to regularly gather patients' experiences during outpatient and inpatient care.
2.	CORE Satisfaction surveys are analysed, reported and acted upon through the line management of the centre.
3.	The cancer centre/institute uses questionnaires to ascertain the perceptions of the patients' health status, level of impairment, disability and health-related quality of life (e.g. Patient-Reported Outcome Measures (PROM)).
4.	The cancer centre/institute uses questionnaires to assess the impact of the process of care on the patient's experience, e.g. communication and timelines of assistance (e.g. Patient-Reported Experience Measures (PREM)).

System for receiving and managing complaints	
Standard 27	
The cancer centre/institute has a complaints procedure.	
1.	The cancer centre/institute has a defined complaints procedure.
2.	CORE The cancer centre/institute has a clearly identified complaints officer or a complaints office.
3.	The actions undertaken by the complaints officer are recorded in a file that is used to produce an annual report.
4.	The complaints officer gives feedback on his/her findings to any member of staff who is the subject of a complaint.

Collaboration with patient organisations	
Standard 28	
The cancer centre/institute collaborates with patient organisations.	
1.	The cancer centre/institute identifies and co-operates with existing patient organisations.





INTENT

Thank you for your attention!

Péter Nagy

peter.nagy@oncol.hu

National Institute of Oncology, Hungary

