Work Package 2 Report

Hungary

Work Package 2: Thick descriptions of

– OnkoNetwork
– Palliative Care Consult Service

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The SELFIE project

SELFIE (Sustainable intEgrated chronic care modeLs for multi-morbidity: delivery, FInancing, and performancE) is a Horizon2020 funded EU project that aims to contribute to the improvement of person-centred care for persons with multi-morbidity by proposing evidence-based, economically sustainable, integrated care programmes that stimulate cooperation across health and social care and are supported by appropriate financing and payment schemes. More specifically, SELFIE aims to:

- Develop a taxonomy of promising integrated care programmes for persons with multi-morbidity;
- Provide evidence-based advice on matching financing/payment schemes with adequate incentives to implement integrated care;
- Provide empirical evidence of the impact of promising integrated care on a wide range of outcomes using Multi-Criteria Decision Analysis;
- Develop implementation and change strategies tailored to different care settings and contexts in Europe, especially Central and Eastern Europe.

SELFIE strands of research and work package (WP) overview
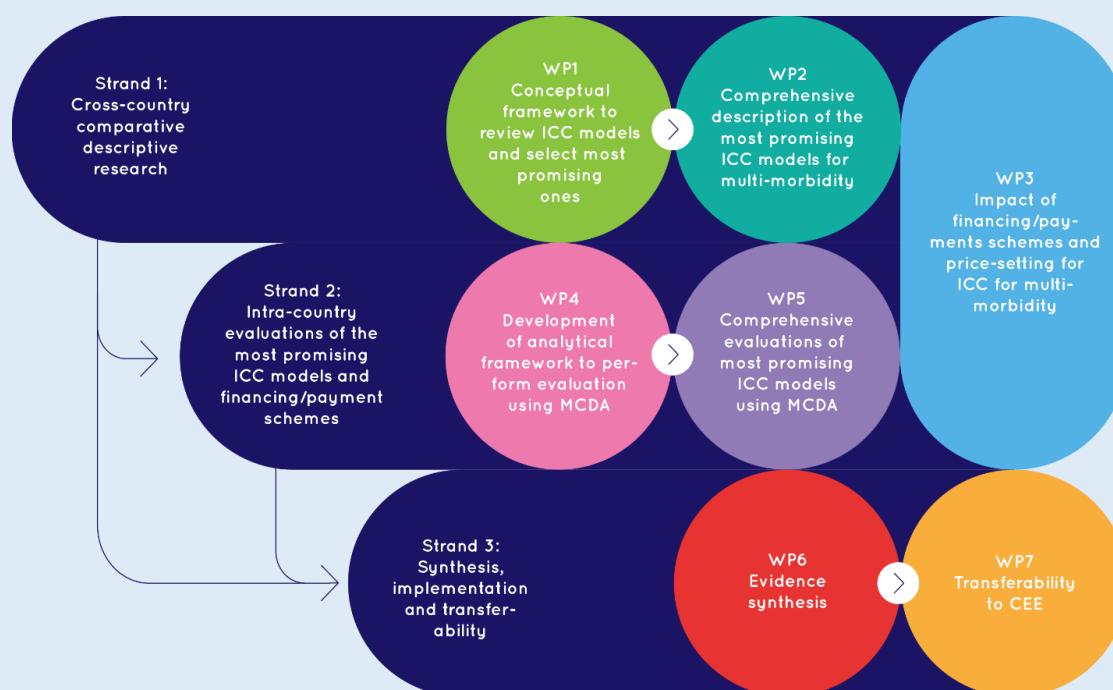
The SELFIE consortium includes eight countries: the Netherlands (coordinator), Austria, Croatia, Germany, Hungary, Norway, Spain, and the UK.

Executive Summary

OnkoNetwork

OnkoNetwork is a local initiative in Somogy county aimed at improving clinical outcomes via timely access to quality assured, unfragmented healthcare.

Service delivery

For patients entering the centre with a suspected diagnosis of a new solid tumour, diagnostics must be completed in 30 days, and therapy must be initiated within a further 2 weeks. The same time goals apply for patients with multi-morbidity, with personalized diagnostics and stabilization of comorbidities in the 30-day window. Individual patient preferences regarding their treatment options are acknowledged. Since this model seeks to improve the severe coordination deficits within the healthcare system in Hungary, other aspects of care e.g. social, physical and mental needs and preferences, do not form part of its focus.

Leadership & governance

The OnkoNetwork is characterised by its strong leadership, who are fully committed to clear goals, in particular timely diagnosis and therapy initiation. Furthermore, accountability is ensured through escalating levels of quality assurance referrals, from technical clarifications to top management interventions.

Workforce

New professional roles have been established within the programme with respect to both physicians and non-physicians. For example, the new role of OnkoNetwork administrators, who have a non-physician assistant or administrator background, has been introduced. These administrators take over administrative tasks from department physicians, allowing the latter to allocate more of their time to professional tasks, including communication with patients. Furthermore, OnkoNetwork ensures that physicians work together as a multidisciplinary team when deciding on the recommended treatment.

Technologies & medical products

A tailored IT system for individual patient path monitoring and management has been developed as part of the OnkoNetwork programme. However, interoperability with other medical IT systems poses a challenge: data transfers across the systems are not fully automated, and have to be supplemented manually by the OnkoNetwork administrators.

Information & research

Due to the relatively short lifetime of the project (started in November 2015), no outcome analyses have been conducted so far. Beyond routine clinical data collection in the hosting institutions, OnkoNetwork specifically collects data on all enrolled patients through its tailored IT system. Data on patient

experience are limited and currently focus on timely and equal access to care. OnkoNetwork does not collect patient-level economic data; this is only done by the national healthcare payer.

Financing

There is no specific coverage or reimbursement for OnkoNetwork services from any external source; the low operational costs are financed from the hospital's budget. Furthermore, there are no specific incentives for the participating professionals. Instead, the staff is motivated by the immaterial values represented by the project.

Palliative Care Consult Service

The Palliative Care Consult Service (PCCS) programme is the first initiative in Hungary to provide palliative care within an acute care hospital (Medical Centre). The programme supports patient pathway management across providers (e.g. between acute care and home care).

Service delivery

The palliative care consultation service process consists of several steps. After a hospital physician requests consultation, an introductory assessment is conducted by the coordinator of the consultation service. Holistic assessment of the patient's need is a core element of the programme, which covers not only clinical information, but also physical and mental status, pain and other symptoms as well as performance status, social, spiritual and cultural aspects. The assessment aims to offer a treatment plan that is in line with the preferences of the patient and his/her family members. Further care is organised based on this treatment plan. The consultation service also includes subsequent patient follow-ups.

Process of service delivery in the Palliative Care Consult Service

Leadership & governance

The multidisciplinary programme team serves as a bridge between the clinical departments, home-based hospice palliative care, institutional hospice care and home-based social care to achieve a higher level of coordination in the palliative care process for seriously ill patients. Furthermore, there is a strong commitment to the programme on the part of the Medical Centre's management. Formalised agreements regarding the cooperation with partners do not as yet exist.

Workforce

The multidisciplinary team consists of a palliative coordinator, a physician and a psychologist; a dietician and a physiotherapist are also available. Cooperation among providers is facilitated by an overlap in

human resources, since the members of the team work for multiple providers in parallel. Furthermore, the PCCS team is involved in under- and postgraduate medical education to support knowledge transfer for future physicians. The programme, however, faces risks with regard to staff retention, due to burnout, low income and the lack of priority in health policy.

Technologies & medical products

As part of the programme, the hospital's electronic referral system has been improved to support consultation requests and to keep record of the electronic documentation.

Information & research

The PCCS programme regularly analyses its activity, including the number of consultations, reasons for referral, time data on entering and leaving the palliative care process and leading symptoms at enrolment. Pain and performance status is also assessed and internal satisfaction surveys of the clinical department are carried out. However, no evaluation of the effects and outcomes has been conducted so far.

Financing

Currently, no direct reimbursement is provided for the operation of palliative consult services. The programme was initially funded by EU grant, which was a great incentive in the early phase. Additionally, an internal financing methodology is used to provide sufficient funding for its operation. The enhancement of the programme will require a dedicated financing method for the reimbursement of palliative consult services.

1. Methodological approach

This report is part of WP2 of the project SELFIE. The WP leader is the *Institute for Advanced Studies* (IHS) in Vienna, the WP co-leader is the *August Pi i Sunyer Biomedical Research Institute* (IDIBAPS) in Barcelona. The stated objective of WP2 is to comprehensively describe the 17 integrated chronic care (ICC) programmes selected in the course of WP1, covering the following features:

- **Barriers to and facilitators of implementation**: how were the most promising ICC models implemented and what were the barriers and facilitators during the implementation phase?
- **Patient centeredness**: how is the delivery of care designed around the patient?
- **Use of modern ICT**: which ICT (information and communications technology) applications are used in the most promising ICC models to support the care process and what are the requirements for implementing them successfully in the treatment of patients with multi-morbidity?
- **Use of self-management interventions**: which self-management interventions are used in the ICC models and how are they adapted to patients from different cultural and socio-demographic groups as well as to distinguish the conditions for their successful implementation?
- **Involvement of new professional roles**: are there new professional roles (e.g. physician assistants, nurse practitioners) involved in the ICC models and what are the barriers and facilitators in their successful introduction?
- **Existing evidence**: what is the existing evidence of the impact of the most promising ICC models?

The methodological approach chosen to achieve this objective is that of a "thick description". For each of the eight countries participating in SELFIE, this report contains at least two[1] thick descriptions of the programmes selected in the respective country, resulting in a total of 17 thick descriptions.

The method of thick description is a well-established qualitative empirical approach. The basic idea was first introduced by the philosopher Gilbert Ryle [1]. In the 1970s, it was established as a qualitative method to investigate implicit social practices in their specific contexts by the anthropologist Clifford Geertz [2]. Geertz himself does not provide an explicit definition of this scientific approach. Studying thick descriptions by Geertz himself as well as other scholars, however, makes it possible to deduce the main aspects of the method. In the following quote, Geertz outlines the aims of the method:

> *"Setting down the meaning particular social actions have for the actors whose actions they are, and stating, as explicitly as we can manage, what the knowledge thus attained demonstrates*

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[1] Three in the case of the Netherlands.

about the society in which it is found and, beyond that, about social life as such. Our double task is to uncover the conceptual structures that inform our subjects' acts, the 'said' of social discourse, and to construct a system of analysis in whose terms what is generic to those structures, what belongs to them because they are what they are, will stand out against the other determinants of human behavior. […] provide a vocabulary in which what symbolic action has to say about […] the role of culture in human life can be expressed." [2]

In recent decades, Geertz' methodological and conceptual work has influenced empirical research in several disciplines [3]. In sociology, it is widely used in a variety of research fields, including research of care practices [4].

As shown in Figure 1, a thick description covers several levels of depth of analysis. The starting point is a formal description, which provides information on the surface of the studied phenomenon.

Figure 1: Levels of the programme description. Source: IHS (2015).

In the specific context of the SELFIE project, this formal description pertains to the general organisational structure of the programme and formal relations of the involved stakeholders. The formal description is valuable in itself, because it gives an overview of the domains and levels of integration, the individuals and organisations involved, the tools used and the processes employed. In particular, the formal description includes the following information:

- Name of the programme
- Contact details of the programme management
- Starting date of the programme
- Geographical scope of the programme
- Target group of the programme (type of individuals/scope/included combinations of morbidities)

- Number of persons treated in the programme (total and development over time)
- Aim of the programme
- Definition/understanding of "integrated care" (as far as described in documents)
- Definition/understanding of "multi-morbidity" (as far as described in documents)
- Definition/understanding of "person centredness" (as far as described in documents)
- Definition/understanding of "self-management" (as far as described in documents)
- Organisational form and ownership of the programme (including legal form)
- Involved partner organisations (payer(s), medical and social service providers), including subdivisions (e.g. departments of a hospital)
- Involved disciplines and professions

The formal description is mainly based on available literature, a variety of documents (e.g. official documents of the programme, grey literature) and expert information. A document analysis was performed on these materials, which comprise the first source of information and the basis for obtaining "hard facts" on the respective programme.

However, written documents are in general not suitable to give a deeper understanding of what actually constitutes the programme below its surface when put into practice. These substructures are, however, essential for the functioning of the programme. In addition to the formal description, the method of thick description therefore aims to gain insights on what lies beneath the surface of the studied phenomenon (see Figure 1).

For the purpose of gathering the necessary information, interviews were conducted with different stakeholders involved in the programme. These served as the second source of information. While the interviews were also used to complement the "hard facts" gathered in the course of the document analysis, their main aim was to obtain "soft facts" about the substructure of the programmes. Therefore, questions of "how" and "why" were at the centre of the interviews and the subsequent analysis of their contents. This comprehensive approach allows for a deeper understanding of what daily practice in the programme looks like and in which way multi-morbidity is addressed in the specific context of the programme.

A set of stakeholder types to be interviewed was defined in advance. This set consisted of the following stakeholder types:

A. **Manager(s) of the programme**
B. **Initiator(s) of the programme**: individuals or representatives of institutions that participated in initiating, conceptualising and planning the programme (e.g. representatives of sickness funds, physicians, etc…)
C. **Representative(s) of sponsor/payer organisations:** individuals or representatives of institutions that fund the programme on a project basis or on a regular basis (e.g. representatives of sickness funds, representatives of municipalities, representatives of associations, etc…)

D. **Medical and social staff**
   D1: physician(s)
   D2: non-physician medical staff (e.g. nurses), social staff, new professional groups (if applicable)
E. **Informal caregivers** (e.g. relatives, neighbours, volunteers)
F. **Clients or their representatives** (e.g. clients or persons in their close environment, representatives of self-help groups)
G. **Other stakeholder(s)**: individuals or representatives of institutions, who turn out to be of specific relevance for the respective programme and do not fit in the categories A.-F.

For each stakeholder type, the WP leader set a minimum number of persons to be interviewed. However, considering that the 17 selected programmes involve very different kinds of stakeholders, a specific sample of interviewees was developed for each individual programme. The partners discussed these samples with the WP leader, in order to ensure a balanced sample structure in each programme.

For each of these stakeholder types, thematic focus areas were defined. Based on these focus areas, a set of interview protocols was prepared by the WP leader. The protocols accounted for the different backgrounds and relevant themes of the individual stakeholder types. This served the purpose of gaining insights into the programme from various perspectives. The included questions concerned, for example, the stakeholders' perceptions of delivery of care for persons with multiple chronic conditions, their roles and relationships in the programme, their specific problems and their personal views.

In general, all interview protocols were structured according to the following outline:

- A Brief introduction about SELFIE and the interviewer as well as clear information about the goal of the interview
- Signing and exchanging the anonymity agreement and the declaration of consent for recording
- First question: Regarding the person's qualification and position in the programme
- Next question: Regarding the main work of the interviewee and his/her specific role in the programme
- 1-2 main questions: Regarding the work in the programme (covering selected focus area of respective stakeholder type)
- (Direct and indirect follow-up questions)
- Last question: valuation of an important aspect of the programme

The interview protocols were adapted by the partners according to the specific context of each programme and interviewee, using prior knowledge obtained from the document analysis and from previous interviews. The interviews were carried out face-to-face and the interview duration was between 30 and 90 minutes. The interviews were recorded and transcribed. The resulting transcripts

were analysed using the method of content analysis developed by Mayring [5]. This method involves the following steps of abductive interpretation[2]:

- Selecting units of analysis
- Paraphrasing these units of analysis
- Transforming the paraphrases to short forms
- Constructing categories, where possible

The thick descriptions are structured according to the elements of the conceptual framework developed in the course of WP1. The model is depicted in Figure 2.

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[2] Timmermans and Tavory [6] define abduction as a "creative inferential process aimed at producing new hypotheses and theories based on surprising research evidence."

Figure 2: Conceptual framework for the delivery of care for persons with multiple chronic conditions. Source: [7]
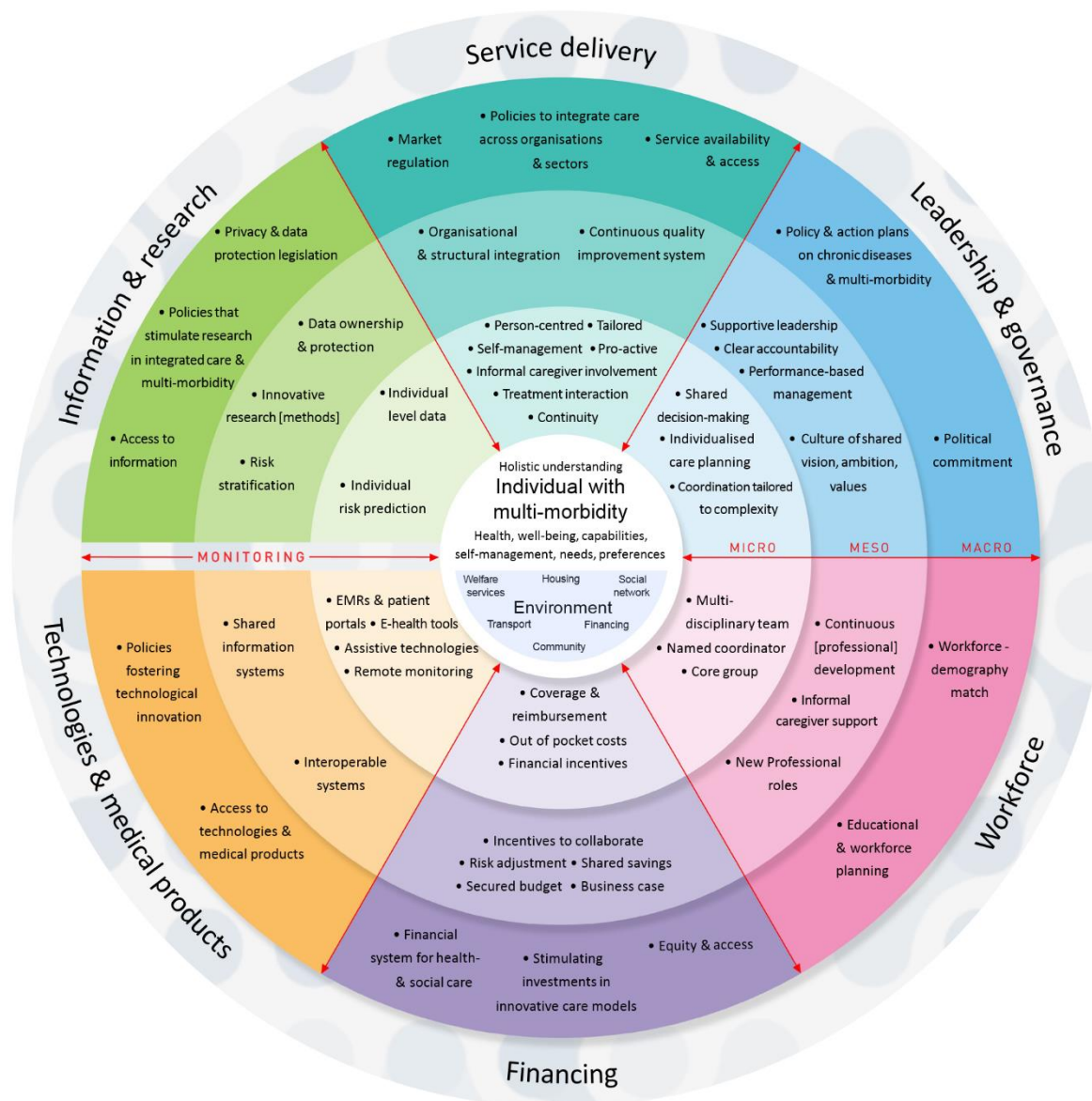
Simultaneously, each thick description covers the eight tasks of WP2 set out in the SELFIE proposal, as well as one supplementary task (denoted by TS), which was agreed on by the project consortium at the kick-off meeting and actually belonging to WP3:

- **Task 1:** To develop the approach for the qualitative analysis of ICC programmes
- **Task 2:** To investigate how the most promising ICC programmes were implemented as well as to identify barriers and facilitators during the implementation phase
- **Task 3:** To analyse how the delivery of care is designed around the patient in the most promising ICC programmes

- **Task 4:** To analyse the relationship with long term care, social care and other partners beyond the healthcare system
- **Task 5:** To investigate which ICT applications are used in the most promising ICC programmes to support the care process as well as to explore the requirements for implementing them successfully in the treatment of patients with multi-morbidity
- **Task 6:** To analyse which self-management interventions are used in the most promising ICC programmes and how they were adapted to patients with multi-morbidity from different cultural and socio-demographic groups as well as to distinguish the conditions for their successful implementation
- **Task 7:** To explore new professional roles (e.g. physician assistants, nurse practitioners) involved in the ICC programmes as well as to identify barriers and facilitators in their successful introduction
- **Task 8:** To review existing evidence on the impact of the most promising ICC programmes
- **Task TS:** To explore the experiences of the stakeholders regarding financing and payment schemes

The WP leader provided the partners with continuous guidance in order to ensure that all partners are able to follow the methodological approach described above. This guidance mainly consisted in three parts. First, in the preparatory phase of WP2, methodological guidance materials were developed by the WP leader for all partners. These materials were presented to the partners in the course of the 2nd steering committee meeting in Vienna on January 25th and 26th 2016. Second, a special training course was held at IHS Vienna for researchers directly involved in the thick description on April 14th 2016. Third, all 17 thick descriptions were reviewed in order to ensure that they are harmonised to a certain degree. In this third part, the WP leader received support from the WP co-leader. The review process was divided as follows:

- **WP leader:** Germany, Netherlands, Norway and Spain
- **WP co-leader:** Austria, Croatia, Hungary and United Kingdom

However, it is part of the method that thick descriptions are not standardized but instead should be guided by what the prominent features of the individual studied phenomenon are. Therefore, the diversity in the thick descriptions reflects different topicalities, approaches, challenges and solutions.

As mentioned above, the method of thick description allows for a deep understanding of the implicit structures of the investigated programmes. This is of utmost importance also as a basis for further work packages of the SELFIE project. In the context of WP3, this deep knowledge can help to understand incentives of payment methods better and thus help to develop a comprehensive guide to financial and payment schemes that facilitate the provision of ICC to multi-morbid patients, as well as a guide to pricing of ICC programmes. In the context of WP4, this knowledge it can help to identify the relevant indicators to measure outcomes of ICC programmes. In the context of WP5, it can help to gain ideas

regarding how to set up a suitable empirical evaluation of these programmes. Furthermore, it may help to better understand and explain the outcomes of the empirical evaluation.

Each report is structured in the following way: After the methods chapter, chapter 2 provides general information on the national health and social care system with a special focus on integrated chronic care for persons with multi-morbidity. This chapter covers the macro level of the conceptual framework and has the purpose of giving insight into the specific context the two selected programmes are embedded in. The programmes are subsequently described in detail in chapters 3 and 4, respectively. The descriptions present important findings obtained from the document analyses as well as the interview analyses. After a short overview of basic information about the programme, the findings are structured according to the six segments of the conceptual framework: service delivery, leadership and governance, workforce, technologies and medical products, information and research/monitoring and financing. Furthermore, the implementation process is described in an additional section. The descriptions conclude with a discussion of the respective programme. The discussion summarises the distinctive features of the programme and puts the empirical findings in context of the conceptual framework.

The report includes several quotations from the interviews. These are intended to present the stakeholders' perspectives in their own words. They were selected in the process of "abduction" and are used as a source of, e.g., typical forms of care practices, cooperation forms and motivations for participating in the programme. All quotations are anonymised and translated into English. In the appendix, however, they can be found in the respective original language.

1.1.   References

[1] Ryle, G. (1949). The concept of mind. Prescott: Peregrine Books.

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[4] Maloney-Krichmar, D., Preece, J. (2005). A multilevel analysis of sociability, usability, and community dynamics in an online health community. ACM Transactions on Computer-Human Interaction (TOCHI), 12(2): 201-232.

[5] Mayring, P. (2001). Combination and integration of qualitative and quantitative analysis. Forum: Qualitative Social Research, 2(1).

[6] Timmermans, S., Tavory, I. (2012). Theory construction in qualitative research from grounded theory to abductive analysis. Sociological Theory, 30(3): 167-186.

[7] Leijten, F., Struckmann, V., van Ginneken, E., Czypionka, T., Kraus, M., Reiss, M., Tsiachristas, A., Boland, M., de Bont, A., Bal, R., Busse, R., Rutten-van Mölken, M. on behalf of the SELFIE consortium (2016). The SELFIE Framework for Integrated Care for Multi-Morbidity: development and description. Manuscript submitted for publication to Health Policy.

2. Macro level

Figure 3: Hungary. Source: World Health Organization - Noncommunicable Diseases (NCD) Country Profiles, 2014.
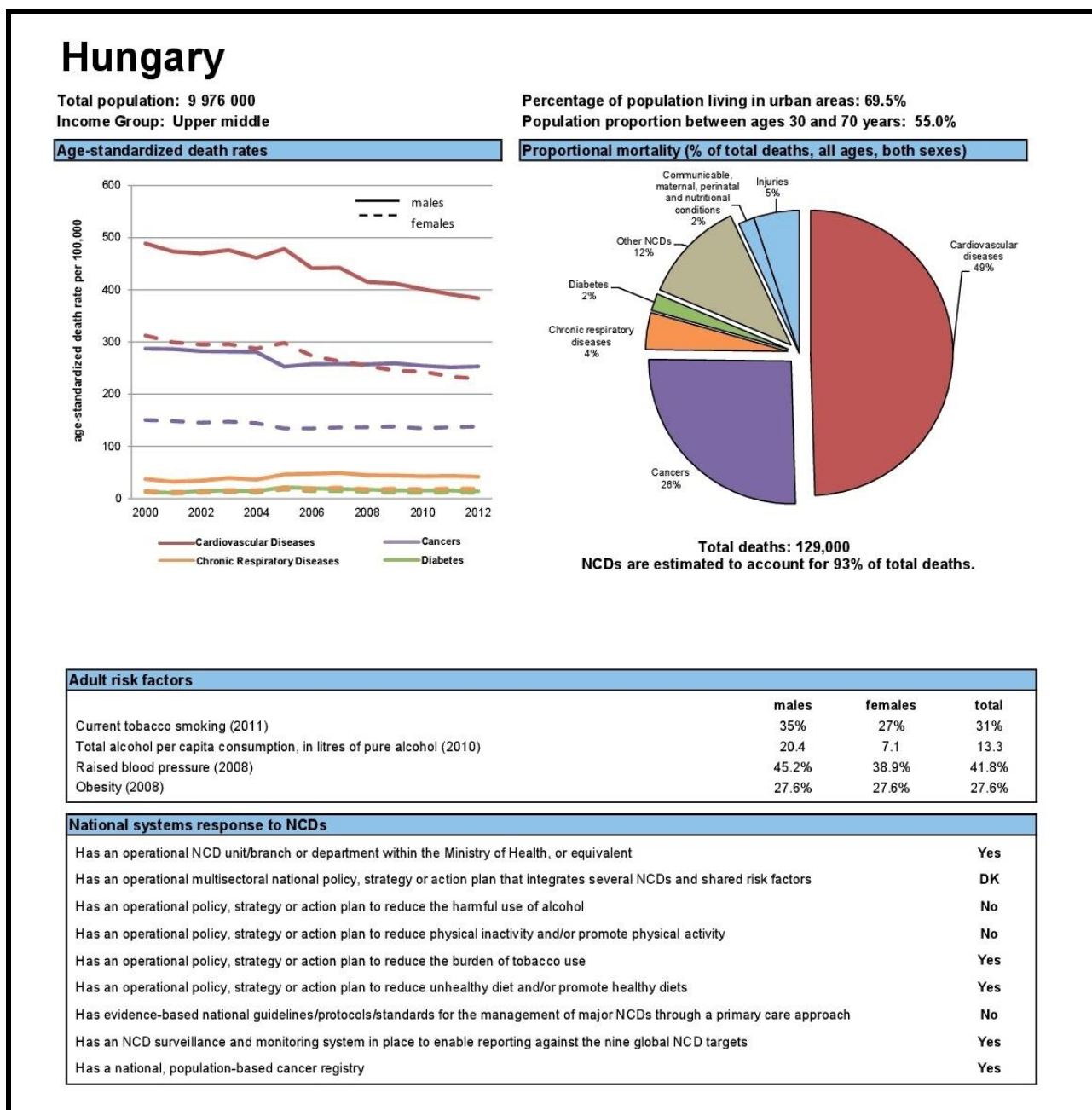
Table 1: Key facts and figures

	Hungary
Key facts and figures	
Population	9 830 485 million (2016) Source: KSH*
Population ≥ 64 yrs (%)	17.5 (2014) Source: KSH*
Model of care	Bismarck
Life expectancy (yrs)	72,09 Male & 78,61Female (2015) Source: KSH*
Birth rate	10 per 1000 inhabitants (2014) Source: Worldbank
Gross mortality rate	13.4 per 1000 (2015) Source: KSH*
Infant mortality	5 per 1000 live births (2013) Source: OECD
Healthcare expenditure % GDP	7.4 % (public: 66% of the total) (2014) Source: Worldbank
Healthcare expenditure per capita €/year	Health: 777 EUR (2012) Source: Eurostat / Health: 1037 USD (2014) Source: World Bank
Coverage (% population) (paid by taxes)	~100%
Public Payer	One Public Payer (National Health Insurance Fund)
Suppl. private insurance (% population)	Private health insurance in Hungary is negligible**
Number of physicians per 10,000 population	3.08 (2012) Source: WHO
Number of hospital beds per 10,000 population	69.84 (2014) Source: WHO

* Hungarian Central Statistical Office

** OECD Health Statistics 2016, Definitions, Sources and Methods, Private health insurance

Figure 4: Geographical location of OnkoNetwork, Palliative Care Consult Service and Syreon Research Institute

OnkoNetwork – *Kaposvár* , Outpatient cancer care clinics in *Siófok, Marcali, Nagyatád, Mosdós*

Palliative Care Consulting Service (Mobile) Team- *Pécs*

Syreon Research Institute - *Budapest*
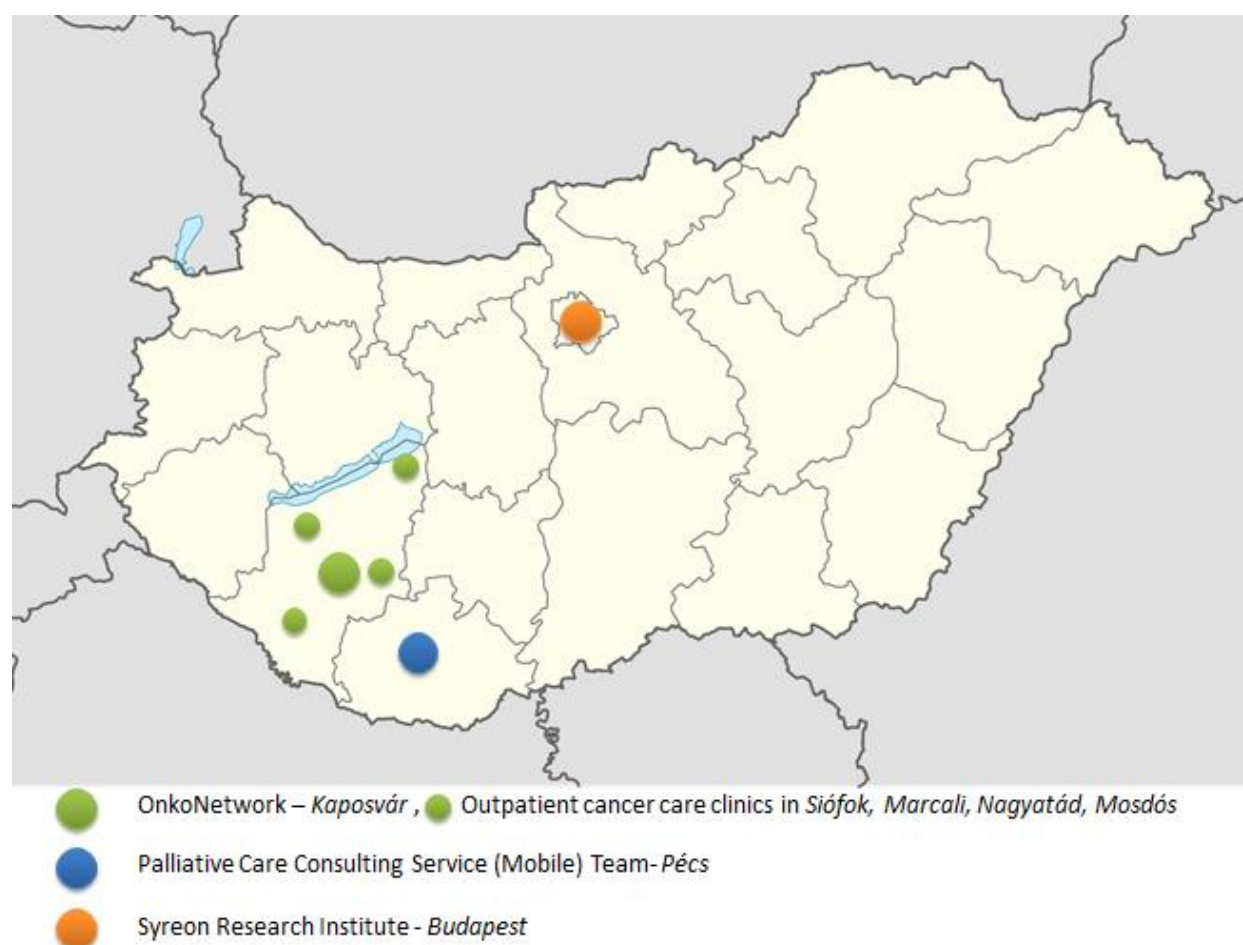
2.1.   Service delivery

2.1.1.   Description of main policies and regulations shaping the health and social care system

Most important regulations of healthcare in Hungary are the Law on healthcare (law CLIV in 1997) and the Law on obligatory health insurance services (Law LXXXIII in 1997). Central government has almost exclusive power to formulate strategic directions and to issue and enforce regulations regarding healthcare [1]. Following major national level plans and policy recommendations were published in recent years:

- Healthy Hungary 2014-2020 - Healthcare Sector Strategy [2] Published in 2014 December. Prepared by Secretary of State for Health. Objectives and future plans are introduced in the document. Priority areas of public health in Hungary were defined and integration in healthcare was mentioned focusing on the role of primary care.

- Semmelweis Plan to save healthcare – Reviving healthcare [3] Published in 2010 October. Prepared by Secretary of State for Health. The document identified structural and functional problems of healthcare and set up future development areas and priorities. Within primary care, 1) strengthening the collaboration among GPs and 2) the importance of integrating home care and social care services delivered by civil or religion organizations was highlighted.

Note that the two documents are related to each other. Healthy Hungary 2014-2020 attempted to consider and build on the experiences from Semmelweis Plan.

2.1.2. *Description of clear and well-designed national/regional policies/plans and programmes supporting integrated care for chronic patients with multi-morbid condition/complex care needs*

The Health Promotion Offices programme (based on an antecedent model at Kaposvár) focuses on approx. 60 micro-regions. Programme is coordinated by National Public Health Institute since 2014. Offices aim to harmonize health promotion programmes and local level activities. They connect primary and outpatient care with health promotion programmes. Individual risk assessments, healthy lifestyle promotion, and monitoring of changes in risk and health status are conducted [4].

Primary Care Development Model Programme started in 2013 and aims to expand preventive services of primary care to eradicate inequalities in access to care. 24 local GP practices in 16 rural settlements created 4 GP clusters. Nutritionists, physiotherapists, nurses responsible for health state evaluations, health psychologists and assistant health mediators are involved [5].

TÁMOP 6.2.5/13/1 – "Improving organizational efficiency of the national healthcare system" was focusing on 1) development of multidisciplinary healthcare guidelines 2) expand the focus of primary care to primary prevention and health management. It was completed in Q4 2015. Methodological recommendations were prepared; however their implementation was highly limited [6].

Complex renewal of primary care is in pre-launch stage with expected start in Q3 2016 the earliest. It aims to integrate 250 primary care practices in Hungary. More detailed information is currently not available yet [7].

2.1.3. *Description of specific policies for integration of social and healthcare programmes for management of patients with multi-morbidity with current or potential social needs?*

Establishment of Mental Health Centers is currently under development. A pilot project of establishing 6 centers was initiated in 2016 May. These centers will be established in places with well-functioning Health Promotion Offices therefore strong collaboration among them will be ensured. Mental Health Centers will focus on social determinants and prevention of mental illnesses such as depression. Currently methodological and structural planning procedures are ongoing. The programme is coordinated by the Office of the Chief Medical Officer [8].

There are efforts to separate chronic healthcare from social care in Hungary, since a significant part of chronic beds are utilized for social purposes (i.e. for nursing of patients without need for medical supervision). The transfer of 10,000 chronic beds from healthcare to social care is planned in the upcoming 3 years [25].

2.2. Leadership & Governance

2.2.1. Governance structure of the health and social care system

Ministry of Human Capacities is responsible for the functioning of the national healthcare and welfare system in Hungary among many other areas (e.g. education, pensions-policy). It oversees the provision of equal rights, efforts to integrate Roma communities into mainstream society, the development of links with civil and social groups, and the harmonization of social policy. Within the ministry three state secretariats are relevant for health and social care system:

- State Secretariat for Healthcare - Responsible for determining the policy related to healthcare provision, and the preparation of legislation related to the direction of healthcare provision on a national level and in institutions of higher education. It regulates national public healthcare tasks.
- State Secretariat for Social and Family Affairs - Responsibilities cover four large areas: family and welfare services; promotion of the rights of young people; promotion of the rights of pensioners and the elderly; promotion of the rights of people suffering from mental impairment. Other high-priority tasks are the regulation and supervision of the system of social security transfer payments.
- State Secretariat for Social Inclusion – Focuses on individuals and groups in disadvantaged positions. It promotes that they should have access to their fair share of the expanding opportunities available. [9].

2.2.2. Governance structure of the integrated care initiatives/programmes

Three institutes/organizations are generally involved in development, implementation and coordination of integrated care initiatives:

- National Healthcare Services Center - The Institute is practicing state ownership rights at 102 Hungarian hospitals, to provide good-quality, high-level, accessible and efficient healthcare services to Hungarian population. They help hospitals to operate efficiently, focusing on patient needs. [10].
- The Office of the Chief Medical Officer (OCMO) - The Office functions as a central budgetary authority being a central agency under the direction of the Minister responsible for public health. OCMO has national competence within its scope of activities. In order to fulfil the public health goals OCMO performs managing, coordinating and supervising activities related to public

health (especially environmental and settlement health, food and nutritional health, child and young health, radiohygiene and chemical safety), epidemiology, health development, public health administration and supervision of healthcare provision [11].

- National Institute for Health Development (NIHD) – The Institute aims to improve the health of the Hungarian population, to develop disease prevention and to promote healthy lifestyles. NIHD is a methodological institute that ensures the methodological background for national policies, it is also the national coordinator of public health programmes [12].

2.3. Workforce

2.3.1. Workforce preparation for and involvement in the transitions and scale-up of integrated care

There are several universities in Hungary where healthcare workers such as nurses, midwives, healthcare managers and coordinators are trained – typically not in the medical but in a separate faculty [13, 14]. An example for integrated social care and healthcare education is the University of Debrecen, Faculty of Public Health. An important aim of the faculty's programmes is to train professionals with knowledge and methods gained about the fields of health and social sciences in order to tackle both health and social related problems by performing professional, social and intersectoral cooperation [15].

Healthcare professionals' education include training on the use of EESZT, a national harmonized IT system for e-health, from 2015. However, it is still in a development phase and the system will be launched in March 2017 [26].

2.3.2. New professional roles in integrated care

Beyond the investigated models, the following examples of new professional roles were identified:

- Within Health Promotion Offices generally there are two positions which are new professional roles: Office manager, who has a qualification from health promotion or health administration and a leading professional who is a physician or nurse delivering health related services [16].
- In order to increase the efficiency of cervical screening, a model programme involving 110 public health nurses from 168 small settlements was launched by the Office of the Chief Medical Officer, in 2009. After three months training, the public health nurses were able to collect cervix smears. This new professional role of nurses focuses on the population of deprived areas in Hungary with limited access to healthcare [17].
- Within Primary Care Development Model Programme, the position of GP cluster coordinator was defined. This role is taken by an experienced GP from each of the selected regions [5].
- Within the Mental Health Centers, special positions will be defined in order to promote and implement activities related to health promotion, social care and prevention of mental diseases. For such position, background in psychology is expected to be a requirement, however more detailed information is currently not available [8].

2.4. Financing

2.4.1. Funding system for the health and social care sector

The Hungarian health system is a solidarity-based health insurance system with compulsory participation for every citizen. National Health Insurance Fund Administration (NHIFA) in the only public purchaser. Employers and employees pay mandatory health insurance premium which is complemented by tax revenues through transfers from state budget [18]. NHIFA receives revenues from a recently introduced public health taxation on unhealthy products and from pharmaceutical companies through clawback and payback.

There are separated funding schemes for primary care, hospital care, long-term care facilities, mental health and social care and retail pharmaceutical services [1]. Service contract with NHIFA is a prerequisite for any payment made to providers. Most of the revenues of GPs come from capitation fee. For outpatient care, a fee-for-service payment system is used. Since 1993, acute inpatient care has been paid by a diagnosis related group (DRG) system [18].

Performance-based financing of GPs is an additional payment and include 16 indicators; 3 indicators can be linked to integrated care [19]:

- Diabetes care - Participation at annual eye examination of diabetes patients is monitored.
- COPD care - Participation at annual pulmonary function tests of COPD patients is monitored.
- Referral practices - GPs' referral rates to outpatient healthcare facilities are monitored.

2.4.2. Sustainability of funding for integrated care programmes

Financing integrated care models is typically transient, which is a bottleneck for sustainable operation. Most integrated care programmes are highly dependent on external financing (EU Funds or Non-EU European countries' contribution):

- Primary Care Development Model Programme - 85 percent of funding was provided by Swiss Contribution and remaining 15 percent was provided from central budget. Swiss Contribution is expected to be terminated in 2016 [5]. Future sustainability of the programme is not clear.
- Mental Health Centers - The programme is funded through the Norwegian Contribution. Available funds: approx. 3,8 - 4 million EUR [8].

Several EU funded projects were initiated, are in progress or are in planning stage. Most notably TÁMOP 6.2.5/13/1 project was completed last year. This project was stopped when the external financing ended.

Positive exception for sustainable central funding is the performance-based financing of GPs. This additional payment consists approx. 15% of the monthly revenue of GPs. It seems to be sustainable and the budget for payment is defined centrally every year.

Interestingly, sustainability of local initiatives can be better as long as the long-term commitment of regional/local stakeholders can be maintained and the model concept is economically viable. An example for that is OncoNetwork.

2.5.   Technologies & medical products

2.5.1.   National/regional policies to promote the use of ICT to support integrated care

Programmes to improve the use of ICT application in healthcare are financed by contributions of both EU and Hungarian government:

- Regional Healthcare Informatics within Social Infrastructure Operational Programme was focusing on development of local infrastructure of integrated information systems [20]. As an example, this programme supported the development of IT solution for OncoNetwork.
- National Healthcare Informatics within the Social Infrastructure Operational Programme was focusing on the development of IT systems for centralized, inter-institutional data transfer and a single national IT solution for medical records [21].
- EESZT is a national e-health system aiming to introduce national coding standards and to establish safe medical data transfer across providers. Developments will include detailed information on patients such as e-anamnesis, e-prescriptions, remote access to radiology images. It is expected to be launched in Q1 2017 [26].

GPs use several medical IT systems. Unfortunately these systems are not compatible, although each programme must have the same reporting format towards NHIFA. Records are limited to medication history and performed examinations. Results of examinations and other detailed medical information are not available electronically. Some IT companies provide electronical availability of detailed medical data but these are usually costly and they are not supported by national/regional programmes.

2.5.2.   National/regional policies stimulating e-health applications and assistive devices

The eHealth policy in Hungary is the responsibility of the State Secretariat for Healthcare, together with the Prime Minister's Office, and the National Office for Research and Technology. In practice, the State Secretariat for Healthcare develops and supervises the national eHealth programme under general guidelines defined by the eGovernment Centre of the Prime Minister's Office. A basic principle is that the national programme aims to comply with the European Commission's eHealth Action plan [22].

Implementation of the eHealth Programme started in January 2004. The Programme identified eleven activity groups which cover about 25 initiated projects that comply with the Programme. eHealth is a

major policy initiative underlying both the National Health Strategy and the Convergence Programme. It is planned to expand the health professional portal, to include ePrescription and other electronic transactions and ultimately to merge it with the portal for citizens.

Outcome of the eHealth Programme in terms of nationally or regionally implemented e-health applications and assistive devices was not found.

2.6. Information & research

2.6.1. Legislative framework on data privacy

Act XLVII of 1997 relates to handling and protection of health data and related personal data. From 2011, GPs have access to their patients' data of healthcare provided under statutory health insurance through electronic data query from the National Health Insurance Fund. From 2013, the legislation allows also the pharmacist to have access to medication data of the patient redeeming a prescription provided under the statutory health insurance within one year. Insured persons, following specific procedures, can directly access their own healthcare related data [23].

2.6.2. Specific national/regional research programmes for integrated care and/or multi-morbidity

No such research programme was initiated in Hungary.

2.6.3. Cooperation with larger (European-wide) innovation & research platforms for integrated care

Hungary was involved in the European eHealth Governance Initiative (eHGI) that supports cooperation between Member States at Political Governance levels and eHealth Stakeholders [24]. The European eHealth Governance Initiative ultimately aims at improving the health status of European citizens, quality and continuity of care and sustainability of European health systems.

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3. Progamme 1: OnkoNetwork

3.1. Basic information

The first evaluated Hungarian integrated chronic care (ICC) programme is called OnkoNetwork. The initial concept of this programme was raised in June 2014, followed by a 17-month planning and development phase [7]. A supporting custom IT system was launched in the beginning of October 2015 as a test version, and all OnkoNetwork activities became fully functional on 1st of November 2015 [7, 9].

The geographical scope of this programme is the catchment area of the Kaposvár Complex Oncology Centre, with a population of ~500,000 inhabitants [5, 9]. The centre consists of the Móritz Kaposi General Hospital and the Kaposvár University Health Center, the latter is responsible for CT, MR, PET CT, PET MR diagnostics and also for radiotherapy [9]. Outpatient cancer care departments of the Hospital in other locations (Siófok, Nagyatád, Marcali), and a radiotherapy unit in Mosdós also participate in this collaboration [9].

Ownership of the programme is at the Hospital management, with a licence for the developed IT application (OncoLogistic). Ownership of this IT tool is at the co-initiator IT development vendor (IP12_1).

Hospital departments participating in OnkoNetwork include all organ-specific departments e.g. Dermatology, Endocrinology, Gastroenterology, Gynecology, Neurology and neurosurgery, Otorhinolaryngology, Pulmonology, Stomatology, and Surgery departments, beyond the Oncology department. The corresponding disciplines are all involved in the programme, in addition to non-organ specific diagnostic and cancer treatment specialists [9]. Non-medical professionals also play an important role in OnkoNetwork, e.g. as patient path managers and IT system administrators. Participation of other non-medical professions such as psychologist, physiotherapist, nutritional specialists is part of the routine practice in the hospital and has not changed by the introduction of OnkoNetwork, with a single exception: from 15th June 2016, all newly identified head and neck tumour patients undergo nutritional status assessment before therapy initiation as part of the OnkoNetwork programme.

The target group of OnkoNetwork is comprised of adult patients with new suspect or new diagnosis of solid tumours in the catchment area of the Complex Oncology Centre [5]. Onco-haematology and paediatric oncology care is not integrated into OnkoNetwork. Eye and bone/connective tissue tumours are also exceptions: patients with these rare conditions are forwarded to specialized institutes [5]. OnkoNetwork has no enrolment criteria on the existence or absence of chronic comorbidities. However, cancer typically affects multiple organ systems, and comorbidities which are not complications of cancer, but frequently occur in the typical age of oncology patients [5]. Proportion of patients with prevalent chronic comorbidities from a sample of 961 enrolled OnkoNetwork patients are shown in Table 3 by decreasing co-morbidity frequencies [3]. Accordingly, the most frequent chronic

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comorbidities in the OnkoNetwork population are cardiovascular diseases and hypertension. Note that cardiovascular comorbidities modulate the patient tolerance to chemotherapy and radiotherapy, potentially resulting in contraindication or discontinuation of some sort of cancer therapies. In OncoNertwork patients with cardiovascular co-morbidities, cardiovascular status is checked before each chemotherapy session by ECG and cardiac ultrasound examinations, and patient anamnesis is also considered at therapy initiation [11]. Ejection fraction below 45-50% is an indicator of high risk, although other criteria must also be present for chemotherapy contraindication, e.g. left ventricle function, cardiomyopathies (these conditions typically contraindicate chemotherapy), AMI in history (depending on date, severity, and residual symptoms), angina or coronary sclerosis (5-FU based chemotherapy is contraindicated), severe heart valve conditions leading to cardiac insufficiency, and atherosclerosis. Note that cisplatin based chemotherapy regimens have kidney toxicity, therefore they are administered with intravenous blood dilution to protect the kidneys – and this extra fluid intake may lead to cardiac decompensation in predisposed patients [11]. These examples demonstrate that the integrated care of cancer and cardiovascular comorbidities is an implicit but important feature of OnkoNetwork.

The number of enrolled patients in OnkoNetwork was 337 after the 1-month test period, 1631 at the 5th of April 2016 [9], and more than 2000 after 7 months of the project [IP05_1]. Accordingly, the rate of monthly new cases is about 300.

Table 2: Frequency of prevalent chronic comorbidities in a sample of 961 enrolled patients. Source: [3].

Disease	Percentage of patients
Cardiovascular disease	48.6%
Hypertension	25.7%
Diabetes	10.9%
Kidney disorders or urinary tract infections	6.7%
Musculoskeletal disorders	4.5%
Psychiatric disorders	2.7%
Mental disorders	2.7%
Chronic liver disorders	2.2%
Endocrine disorders	2.0%
Immunological diseases	1.1%

The overall aim of OnkoNetwork is to improve clinical outcomes in the target patient group using patient path management tools [1, 2]. The clinical benefit is intended to be achieved through the following improvements in the healthcare process:

- Timely access to care: Tumour Board decision should be made in 30 days from initial indicative diagnosis of cancer recorded in the hospital system, and then the treatment should be started in 14 days [9];

- Quality of care, equal access to care: diagnostic protocols, no treatment initiation without Tumor Board decision [5];
- Continuity of care across the various specialities, to avoid the loss of patient among departments [9];
- A specific IT system for patient path management of the target patients, with patient documentation stored separately on a parallel server [1, 2].

To achieve these aims, harmonized diagnostic protocols were created across departments, to allow the subsequent development of a custom IT application for patient path monitoring. Target patients receive top priority status across all hospital departments, with clear identification of their responsible therapist. Patient paths are closely monitored by OnkoNetwork Office administrators and supervisor physicians (new professional roles) on a daily basis using a customized IT system (OncoLogistic).

For OnkoNetwork patients with chronic comorbidities, the same ambitious goals are targeted as in the general OnkoNetwork population. For multi-morbid persons, it is even more challenging to achieve timely diagnosis and treatment initiation, due to the increasing complexity of diagnostics and treatment selection – which must be achieved by the integrated care of cancer and comorbidities.

There are no formal definitions for multi-morbidity, integrated care, person centeredness, or self-management in the documentation of OnkoNetwork. However, quality assured, protocol-based but flexible integrated care of the target patients (including a significant number of multi-morbid patients) across the multidisciplinary diagnostic and treatment process is a core feature of OnkoNetwork [9].

Documents

The documents used for the document analysis can be found in the references section.

Interviews

For an in-depth understanding of OnkoNetwork, all together 20 interviews were conducted with members of various stakeholder groups: patients, family members, primary care physicians, hospital department physicians, hospital department assistants / nurses / administrators, OnkoNetwork Office administrators, supervisor physicians, psychologists, as well as initiators, hospital managers and hospital financial management. For the listing of interview partner IDs, stakeholder groups and interview dates, please see Appendix 1.

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3.2.   Service delivery

3.2.1.   Design of delivery of care

OnkoNetwork is a local initiative of the Kaposvár Complex Oncology Centre, and is deeply embedded into the structure of the relevant healthcare organizations (Móritz Kaposi General Hospital and the Kaposvár University Health Center) [9]. OnkoNetwork was initiated, planned, and implemented by the hospital management with negligible external support (a nominal support for the development of the OncoLogistic IT system was received from an EU fund).

The Móritz Kaposi General Hospital (referred to as "Hospital" hereafter) was established 170 years ago, and during several decades, additional buildings for the various departments were attached to the hospital, without an overarching engineering concept. Recently, significant European and Hungarian funds were granted to the Hospital in the last EU funding period to improve the infrastructure of oncological care and all related professions at Kaposvár [9]. In total, the Hospital received almost 53 million EUR and the Kaposvár University Health Centre received 5 billion HUF in an EU grant entitled "The complex infrastructural development of the focal Kaposi Mór Teaching Hospital for the benefit of the integrated Somogy County and Balaton region healthcare system" for infrastructural developments. As a result, the Complex Oncological Centre was established and new technologies related to diagnostics (e.g. PET CT) and modern radiotherapy were brought to Kaposvár. The intensive development of radiology diagnostics in this Centre is illustrated by the fact that it was the first healthcare organization in Hungary to hosts a PET MR clinical imaging device [9]. In addition, the architecture of the entire hospital was reconsidered and new, more appropriate buildings were erected.

In parallel with these large-scale infrastructural developments, the Hospital management envisioned to identify additional tools to improve the clinical outcomes in cancer patients. Note that the Hungarian standardized morbidity and mortality rates of lung cancer and colorectal cancer are among highest ones in the world [9]. The Hospital management started to analyse patient paths in the hospital and found that the diagnostic procedure of cancer patients occasionally may take 6 months or even longer (see Figure 5). In addition, the time from Tumour Board meeting to the first day of therapy also showed high variability, even with a couple of month delay in some patients (see Figure 6). In addition to these quantitative metrics, the management felt that Tumour Board meetings were not sufficiently effective due to incomplete diagnostics or inaccessible results of diagnostics in many cases [9]. For a more detailed description of programme rationale and the implementation process, please see section 3.8.

Accordingly, the main concept of OnkoNetwork was to set up a patient path management system ensuring the quality assured, equal access of cancer patients to timely cancer diagnosis and treatment initiation along evidence based clinical protocols and efficient continuum of care. The need for integrated care is very high in Hungary considering either the vertical (organizations with various competence levels) or the horizontal (departments of the same organization) dimensions [9]. OnkoNetwork is a pioneering initiative in this respect, as such a patient path management system is unprecedented in Hungary [9].

It is apparent that OnkoNetwork is not limited to patients with multi-morbidity, although about half of the enrolled patients have cardiovascular comorbidities [3]. The integrated care of cancer and cardiovascular comorbidities is an implicit but important feature of OnkoNetwork [11] as detailed in Section 3.1.

Figure 5: Time from first indicative diagnosis of cancer ("C" or "D" diagnosis code) to Tumor Board meeting in the Hospital in H1 2014. Horizontal axis, time in months. Vertical axis, number of cases in the first half of 2014. Source: [1, 2]
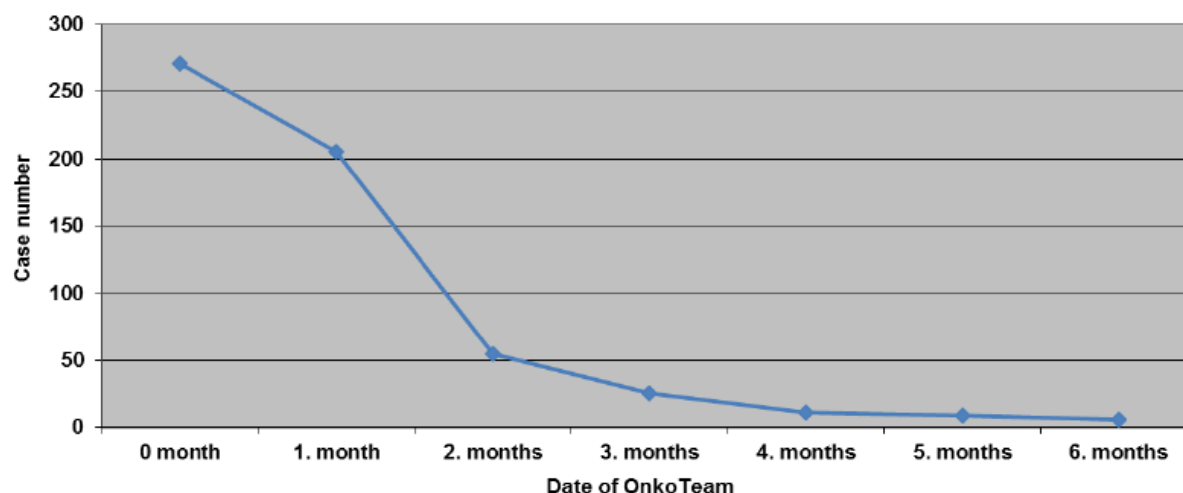
The care process in OnkoNetwork starts when a target patient is referred to any department or outpatient service provider belonging to the Complex Oncology Care Centre with an indicative diagnosis of cancer (a disease code starting with "C" or "D"). This follows the suspect phase which is typically raised by the primary care physician [5, 9]. At this entry point, the key features of the OnkoNetwork model are explained to the patient and the enrolment is offered upon signing the informed consent form [12]. Enrolment has been accepted by all invited patients but only a few exceptions so far [IP10_1]. For the enrolled patients, first a standardized questionnaire is filled in on patient anamnesis, risk factors, comorbidities, and current medications [12], typically with the support of non-physician team members who must not perform physical examinations [7; IP06_1]. Phone or email availability of the patient is also recorded [5].

Relevant comorbidities are identified either from the completed OnkoNetwork entry questionnaire [12] or at a physician visit, or even by an IT-assisted retrospective analysis of the Hospital's medical system searching for medical codes of relevant comorbidities in the last 6 months [11]. The necessary diagnostics of cancer and its comorbidities are driven by organ-specific and general oncology protocols [1,2,5,9], the latter requests additional examinations e.g. cardiology consultation before cardio-toxic chemotherapy; anaesthesiology consultation for surgery feasibility assessment; dentist consultation before radiotherapy of head and neck tumours or starting bisphosphonate therapy; haematology consultation in case of thromboembolic event in anamnesis; diabetologist consultation in case of elevated blood sugar levels; gastroenterology consultation if tube feeding is needed; and gamete cryopreservation in patients of fertile age before cancer treatment initiation, to mention a few [5]. The preventive nutritional status assessment of OnkoNetwork patients with head and neck tumours has been introduced recently, on 15th June 2016 [IP09_1].

To all enrolled patients, a named responsible therapist is allocated in each phase of the care process [IP08_1]. In the diagnostic phase, the responsible therapist is typically a physician from the relevant organ-specific department of the Hospital [IP10_1]. The responsible therapist can deviate from the diagnostic protocols in justified cases (e.g. if results are available from an earlier investigation, or if there is a need for additional diagnostics in the specific case) [IP01_1, IP05_1].

OnkoNetwork patients have top priority status across all departments and outpatient care providers belonging to the Complex Oncology Care Centre [1,7,9], allowing the timely completion of their multidisciplinary diagnostics and diagnosis. This priority is also valid for the investigation / stabilization of relevant comorbidities [IP05_1, IP07_1]: since these patients need rapid initiation of cancer therapy, there is no time for the usual 2-3 months of waitlist period in the corresponding departments [IP03_1]. In the OnkoNetwork model, all necessary diagnostics must be completed and the patient must be referred to a Tumour Board meeting with complete documentation within 30 days of entering OnkoNetwork [9]. Tumour Board meetings are held weekly, on the same day of the week by tumour organs [5; IP04_1]. After the decision of the Tumour Board meeting, the selected therapy must be initiated within 14 days [7,9]. Any delay in referring a patient to the Tumour Board or in therapy initiation must be justified by the responsible therapist. To ensure that the patient is treated along a multidisciplinary consensus, it is not allowed to start any modality of cancer therapy without Tumour Board decision [7,9]. Treatment or stabilization of relevant comorbidities does not have to wait for the Tumour Board decision but is the responsibility of the relevant hospital department(s) [IP04_1]. Prioritization of patients with suspected cancer is well accepted across physicians and other patient groups [IP10_1], without an apparent increase in the waiting times for non-OnkoNetwork patients of the Centre [IP05_1]. Acute interventions of non-OnkoNetwork patients are done within 24 hours and emergency examinations are done within 48 hours [IP18_1].

Selected non-physician staff members, typically assistants and administrators were trained and empowered in all departments of the Centre to schedule the necessary diagnostics for the enrolled patients, and to record the relevant data in the custom IT system (OncoLogistic). The list of obligatory diagnostics is integrated into OncoLogistic along revised organ-specific guidelines adapted to the Centre, so that OnkoNetwork administrators can immediately start to arrange these without a specific request from physicians [IP05_1]. Apart from the protocol-driven diagnostics, additional examinations can be requested by the responsible therapist [IP01_1, IP05_1]. Patient consent is a prerequisite for all examinations, even if the same examination is repeated for some reason [IP02_1]. Arrangement of patient diagnostics was previously a huge burden on department physicians, requiring a lot of inefficient phone calls and fighting for early dates. By the introduction of OnkoNetwork and the declaration of top priority status of cancer patients, early dates became continuously available, and can be booked easily through a web application or phone by OnkoNetwork administrators [IP04_1, IP06_1, IP10_1]. Before OnkoNetwork, the waiting time for a CT scan was two or more weeks, now it reduced to a few days by allocating the necessary capacity to oncology patients [IP04_1, IP06_1, IP09_1]. Department physicians may utilize their spared worktime allocating more time for their patient communication [IP04_1, IP07_1,

IP185_1], treating more patients in a day [IP10_1], or increasing their involvement in other professional tasks. Within the allowed 30-day timeframe, OnkoNetwork administrators try to adjust the dates of the planned diagnostics to the patient's individual preferences, preferably scheduling multiple diagnostics of the patient to the same calendar day(s) to decrease unnecessary travel or transport of the patient [IP06_1; IP09_1]. The patient is typically provided at his/her first visit with all referral documents necessary for the scheduled diagnostics, so there is no need for repeated hospital visits merely to organize the diagnostics [IP01_1].

All diagnostic findings arriving from Hospital departments, from the University Health Centre, or from any external provider are collected in the custom IT system (OncoLogistic) in a semi-automated way. For a detailed description of the underlying IT development, please see Section 3.5. When all relevant results are collected, the case is referred to the next Tumour Board meeting where the recommended treatment option(s) is/are selected based on multidisciplinary considerations of the participants (chief oncologist, chief pathologist, chief radiologist, chief radiotherapist, head of central laboratory, head of nuclear medicine department, head of the relevant organ-specific department, representatives of onco-surgery, Tumour Board organizer, and further optional members without vote including the responsible therapists) [7]. OnkoNetwork did not change the composition or frequency of Tumour Boards [IP04_1], but contributes to more effective discussions since all relevant diagnostics are completed with available results in due time from OncoLogistic [9]. In addition, an important aim of OnkoNetwork is that the patient should be referred to the Tumour Board in an earlier stage of cancer, with a higher chance for effective curative treatment [1].

Patients and/or family members theoretically may also participate in Tumour Board meetings discussing their personal case, but they do so only in exceptional cases [IP04_1, IP07_1] and due to time pressure it would not be technically feasible as a common practice [IP04_1]. Instead, the recommendations of the Tumour Board are usually explained to the patient by the responsible therapist in a face to face visit following the Tumour Board decision. In many cases, the patient can select from two different treatment options [IP07_1]. Patients must not be informed about their disease and prognosis by non-physician members of the staff [5,7]. The amount of information provided to family members and informal caregivers is based on the permission of the patient [IP06_1]. Ultimately, it is the patient's right to accept or reject the proposed treatment or selected parts of it [IP01_1, IP02_1, IP04_1, IP06_1], although professional aspects must also be followed when specific elements of therapy are refused [IP04_1]. For OnkoNetwork patients, the agreed treatment must be initiated within 14 days after the Tumour Board meeting, unless the delay is justified [5,7,9].

Cancer treatment may consist of surgery, chemotherapy, radiotherapy, hormone or immune therapy, or any combination of these modalities. The responsible therapist is typically a surgeon in the perioperative phase, and an oncologist during chemo- or radiotherapy episodes [IP05_1]. Cancer treatment protocols are planned to be integrated into OncoLogistic to support more detailed patient path monitoring also in this phase [IP04_1, IP07_1, IP08_1, IP09_1, IP12_1].

After the completed multimodal treatment phase, the patient is re-staged and a follow-up plan is agreed with regular control diagnostics [5,7]. OnkoNetwork Office administrators trace and call those patients who did not appear at the control events [9]. The first enrolled patients of OnkoNetwork are entering the follow-up phase in the time period of writing this document [IP01_1, IP18_1].

To monitor the smooth operation of the above described care process in OnkoNetwork, a dedicated monitoring unit called "OnkoNetwork Office" was established in the hospital with 4 full-time employees and the office leader [5,9] and with new professional roles for non-physicians and physicians as detailed in Section 3.4. OnkoNetwork Office administrators perform daily searches in the Hospital's medical system (MedSol) for candidate patients to be enrolled; they monitor the patient paths in OncoLogistic identifying protocol deviations or delays in diagnostics and therapy initiation; they look for recorded justifications in OncoLogistic and in MedSol, and contact the OnkoNetwork administrators in the relevant departments of the Centre for further clarification if needed [5]. They may also contact the patient and his/her primary physician when necessary [IP09_1]. Supervisor physicians can fix some open issues on their own, or can efficiently translate the requests of OnkoNetwork administrators to department physicians and achieve their cooperation [IP09_1]. Unsolved issues, e.g. missing CT results after 72 hours are reported to the Strategic Director of the Hospital every week [IP04_1, IP09_1]. Hence, the operation of OnkoNetwork Office is a robust quality assurance tool in OnkoNetwork, contributing to good physician compliance with the diagnostic protocols, improved patient equity, and timely access to and continuity of care.

For cancer patients with comorbidities the same principles apply, supplemented with the additional diagnostics and therapies related to comorbidities. As a general rule, the investigation and stabilization of comorbidities must comply with the established timelines for cancer diagnostics and start of cancer therapy [IP05_1]. The oncology diagnostic protocol requests a set of additional diagnostics for specific comorbidities as detailed above. However, the consideration of comorbidities is typically personalized and it ultimately belongs to the department physicians' competence, rather than to the rigid application of any comorbidity-specific clinical guideline [IP05_1]. A few examples for personalized consideration of comorbidities:

- *"It frequently occurs that patients with recent coronary stent implantation arrive to colonoscopy because of occult blood in their faeces, and a colon tumour is found. From the cardiologist's perspective, triple anticoagulant therapy is obligatory for 6 months after coronary stent implantation and it can't be discontinued. On the other hand, the treatment of colon tumour should not wait for 6 months and albeit surgical removal is contraindicated by the triple anticoagulant therapy. Another example was when multiple gastric ulcers with an in situ carcinoma were found in a patient after a recent coronary stent implantation. How to solve the conflict between obligatory 6-month triple anticoagulant therapy, and complete gastrectomy recommended by the oncology team? If the triple anticoagulant therapy is prematurely*

> *discontinued, the coronary stent may get blocked. But if we wait for six months, the in situ carcinoma may shift to invasive carcinoma with worsened prognosis." [IP02_1, non-physician]*

- *"Comorbidities are checked in a redundant way, at the anamnesis interview with the responsible therapist and also by the standardized OnkoNetwork entry questionnaire. (…) At endoscopic interventions, patients with pacemaker need special care. The pacemaker must be switched off or removed, to avoid its damage or dysfunction during high-frequency ablation." [IP02_1, non-physician]*

- *"Cancer patients are typically middle-aged or elderly with frequent comorbidities. In case of hypertension or diabetes, we ask them to schedule control visit(s) at the corresponding specialist or primary care physicians and to adapt their treatment medications if necessary. We must cooperate with internal medicine specialists and general practitioners in these cases." [IP06_1, non-physician]*

- *"Several chemotherapy agents are cardio-toxic. Patients with cardiology disease in their anamnesis undergo additional cardiologic diagnostics to select their optimal therapy regimen. … Cardiologic examinations before chemotherapy were required even before OnkoNetwork. However, OnkoNetwork makes the diagnostics and their results easily accessible and transparent, assuring that everybody is complying with these rules." [IP09_1, non-physician]*

- *"Comorbidities are important in oncology care, e.g. metformin treatment in diabetes must be discontinued for three days before CT investigation, to avoid kidney damage." [IP10_1, non-physician]*

- *"The whole individual is treated and not only the cancer disease." [IP10_1, non-physician]*

3.2.2. *Self-management interventions*

OnkoNetwork primarily aims to integrate outpatient and inpatient care, and does not put too much emphasis on patient self-management [IP09_1]. Nevertheless, some elements of the model are worth mentioning in this respect, and there are also good practices in the Hospital.

OnkoNetwork established a new contact point for patients, the OnkoNetwork Office. Patients can turn proactively to the Office with their questions on technical issues, e.g. availability of test results, or re-arrangement or pre-scheduled diagnostics [IP01_1, IP02_1]. OnkoNetwork administrators may also be contacted in case of experiencing adverse events at home, e.g. with an implanted gastrostoma [IP02_1].

OnkoNetwork did not alter the way of patient participation in therapeutic decision-making in the Hospital [IP09_1]. Patients rarely attend the Tumour Board meetings discussing their case, although these are theoretically open for them [IP03_1, IP04_1]. On the other side, the meetings took unfeasibly long if all patients would attend their meetings [IP04]. Provision of medical information to patients and family members / caregivers is the privilege of department physicians [5,7]. Some physicians argue that the pieces of information provided to patients must be simplified for optimal understanding and prevent unnecessary stress, while others express that the depth of information should be adapted to patient characteristics, e.g. mental health status; or believe that the patients would need more detailed

information for their thorough decision on therapeutic plan approval in general. Family members are never informed about the patient's condition or prognosis without the patient's prior approval [IP06_1]. The developed custom IT system (OncoLogistic) would be capable to provide remote access for patients to review their personal records real-time from their home. Based on the individual records, tailored prognosis and lifestyle recommendations could be generated and presented to the patients. These functionalities have not been implemented in practice yet and would require significant investments in terms of development work in the IT system and adaptations of Hospital regulations [IP12_1].

Patients have the ultimate right to decide on accepting the therapy, as long as they are not under psychiatric care or guardianship [7; IP01_1, IP02_1, IP04_1, IP06_1, IP08_1, IP09_1] although their right to decide is still not consistently approved by all physicians in Hungary [IP09_1]. Their refusal for some parts of therapy is registered in OncoLogistic [7; IP04_1], and should not compromise the medical rationale of the approved treatment plan [IP04_1].

Importantly, all inpatients in the Hospital are routinely trained for certain self-management activities before discharge, i.e. the self-administration of subcutaneous injections if needed (e.g. for thrombus prophylaxis) [IP06_1, IP07_1, IP10_1]. Training of patients for self-care is a nursing competence, documented in all departments' nursing diary (date of training, date of first self-administration with supervision) [IP09_1]. Family members can also be involved in this training if needed e.g. when the patient is unable or scared to do so [IP02_1, IP08_1, IP09_1].

Other supported self-management activities of patients at home beyond the self-administration of subcutaneous injections (and oral medicines) include wound care, stoma bag replacement, laryngeal tube cleaning; and early notice of alarming symptoms during chemotherapy [IP01_1, IP09_1]. Training of patients with new stoma is important, one of the stoma nurses is available in 24 hours and visit the patient on the first day after stoma implantation [IP10_1]. Enteral nutrition or home feeding through a percutaneous gastrostoma need to be arranged for patients with oesophagus or larynx tumours [IP02_1]. In addition, OnkoNetwork has recently introduced the obligatory nutritional status assessment of new patients with head or neck tumours, before starting their therapy [IP09_1]. From that time, OnkoNetwork patients with poor nutritional status or high risk of worsening have an increased chance to receive preventive supportive devices (e.g. feeding tube or percutaneous gastrostoma), together with the corresponding trainings for their proper use at home [IP02_1]. It was observed that male patients refuse their participation in gastrostoma hygiene related self-management activities more frequently than female patients [IP09_1]. An efficient facilitator to break through this negative attitude of patients was when they were faced with other patients successfully coping with the same situation, with the opportunity to learn from them directly [IP09_1].

The Hospital psychologist recommends the patients to write authorizations for selected family members to manage bank issues, electricity and heating bills, etc in the household - because in some stage of therapy the patient may not be able to stand in a queue for an hour and to manage these businesses in

person. However, family members frequently interpret the proposed preventive approach as accepting an approaching tragedy, hence refuse to do so [IP11_1].

From a psychologist perspective it was also noted that cancer is a serious disease with a high emotional stress not only on the patients but also on their family members. Even if family members are not involved in the treatment decision, their aspects need to be considered there. Patient survival is not the only objective, but the personal relationships of patients also need to be maintained in this stressful period. Accordingly, self-management in a wider context need to be interpreted also at the family level [IP11_01].

Illustrations to self-management at OnkoNetwork from the conducted interviews:

- *"It happens that patients contact the OnkoNetwork Office and ask questions on the availability of their computer tomography findings or laboratory results. OnkoNetwork Office can also help them in scheduling an investigation, or can inform them on the agreed date if the patient forgot it." [IP01_1, non-physician]*

- *"About patient participation: many patients are trained to self-administer subcutaneous injections. Those not trained before are trained in the Hospital to self-administer it before their discharge. Training of patients with new stoma is important, one of our stoma nurses is non-stop available and visit the patient on the first day after stoma implantation. Training of patients and family members for self-management is part of normal routine of the hospital, not changed by OnkoNetwork." [IP10_1, non-physician]*

- *I encourage the patients to write legal authorizations for selected family members to manage their bank accounts, electricity and heating invoices in the household - because in some stage of therapy the patient will not be able to stand in a queue for an hour and will not be interested in the day-to-day management of these issues. However, family members are worried about losing the patient and interpret this recommendation as the acceptance of an approaching tragedy, therefore they frequently refuse to do so. Patients frequently do not ask questions because they are afraid of answers." [IP11_1, non-physician]*

3.3. Leadership & governance

The management of the Complex Oncology Care Centre at Kaposvár played a proactive and leading role in the conceptual development and planning of OnkoNetwork. In the implementation phase the management role was also formalized, the Hospital General Director delegated the OnkoNetwork upper management responsibility to the co-initiator Strategic Director of the Hospital, who also acts as a professor at the Kaposvár University Health Centre [9]. The Strategic Director does not have to be involved in OnkoNetwork operation on a daily basis, but is informed every week on all patients with

delays, and can solve any situation in the Centre very effectively if needed. His unique leadership position and strong commitment to OnkoNetwork are important facilitators for implementation, permanent operation and future development of the model [IP09_1, IP18_1]. Ultimately, the Hospital General Director may also intervene in the rare escalated cases, e.g. when systemic noncompliance is identified at a department level [IP05_1].

Partnerships beyond the healthcare system are hardly approached in the OnkoNetwork model. The standard practices in Hungary and in the hosting Hospital are described below with some recent achievements in this respect, based on the collected information from stakeholder interviews.

In Hungary, physicians play a dominant role in the holistic care process. Patient access to physiotherapy, nutritional and psychologic support strongly relies on recommendations of the responsible therapists [IP11_1]. It is not uncommon that physicians underestimate the relevance of physiotherapy, nutritional or psychologic care because these modalities are provided by non-physician specialists. A better collaboration is observed across these care sectors in rehabilitation departments where the added value of non-medical modalities is more easily observable [IP11_1]. The true nature and value of social support services is not always clear to physicians, although patients with fixed social support issues would be more relaxed and that would be a benefit for physicians as well [IP11_1].

Initiators and managers of OnkoNetwork believe that OnkoNetwork need to be extended to cover the holistic needs of the enrolled patients, e.g. for psychologic and emotional support, physiotherapy, and dietary advice [IP05_1, IP18_1], since it is always better to recognize and manage these patient needs in a preventive way than to face severe situations later, blocking the continuation of therapy [IP18_1]. The reason that OnkoNetwork did not cover these aspects of holistic care from the beginning was a prioritization decision: because all problems can't be solved at the same time, first the programme focused on the integration of medical care itself [IP03_1].

However, some steps have been taken by OnkoNetwork in this direction. A recent and significant addition to OnkoNetwork was the introduction of nutritional status assessment and education before medical treatment initiation in OnkoNetwork patients with new head or neck tumours, from the 15th of June 2016 [IP09_1, IP10_1]. Dietetic consultations were previously organised for patients with gastric surgery, stoma, or poor physical status in the Hospital, but only after therapy initiation in about 90% of the cases [IP09_1]. Now it is systematically organized for all OnkoNetwork patients with head / neck tumour before the initiation of their cancer therapy [IP10_1]. Patients are investigated in a dedicated room in scheduled 30-minute visits, and educated on their optimal diet with specific attention to the expected effects of chemotherapy (e.g. reduced/abnormal tasting and dysphagia predispose to undernutrition; nausea and vomiting can be ameliorated by less intake of carbonated drinks and fatty food) [IP09_1]. Patients generally appreciate that this service is provided not by nurses but by nutrition specialists [IP09_1].

In the Centre giving home to the OnkoNetwork model, psychologic support is available with a long tradition but with limited resources [IP09_1, IP11_1]. Psychology care is typically endorsed by physicians to those patients who are thinking and arguing with them, although these patients show active coping and are not really in need of psychologic support. Instead, passive and "well socialized" patients internalizing the aspects of their doctors have much more need for a psychologist but are less likely to be referred to such service [IP11_1]. Psychologic care is currently not integrated into OnkoNetwork [IP07_1]. Volunteers and also the representatives of Churches take an active role in emotional and spiritual support to inpatients in the Hospital.

Physiotherapy is also available and it is recorded in OncoLogistic if a patient receives such service [IP09_1].

Home care and hospice care are organized by hospital departments, not by the OnkoNetwork model [IP01_1]. For patients with poor physical status, home care may be proposed by the responsible therapist to reduce their unnecessary travel/transport [IP06_1]. Considering the suggestion of the responsible therapist, the arrangement of home care is the responsibility of the primary care physician [IP09_1]. There is a huge inequality in patient access to home care since relevant services are hardly available in small villages [IP09_1]. OnkoNetwork administrators contact the homecare and palliative care provider organizations to clarify the patient's status from time to time [IP09_1].

Many patients are not adequately informed about their opportunities for accessing social support services. Such patients occasionally identified in various departments are directed for detailed guidance to a social worker who has a specific education on social care administration requirements and helps in these cases. Good personal connections between this social worker and healthcare personnel are important facilitators in this process [IP11_1]. OnkoNetwork did not add to the provision of social care [IP02_1, IP07_1].

- *"Psychology, physiotherapy, and dietary advice have not been integrated into OnkoNetwork so far. Their integration is planned, since it is better to prevent such problems than to face with them when they are severe and block the continuation of therapy." [IP18_1, initiator]*
- *"It was the largest change in the scope of OnkoNetwork from its initiation when nutritional assessment has been introduced." [IP09_1, non-physician]*
- *"Home care, hospice care, and psychologic support are organized at the hospital department level, not by OnkoNetwork administrators." [IP01_1, non-physician]*

3.4. Workforce

OnkoNetwork pioneered to introduce new professional roles in Hungary and also reshaped some existing ones in the Centre. Since no relevant prior experience could be identified in the Hungarian

healthcare system by the management of OnkoNetwork, these changes were based on a thorough planning and discussion phase as part of the model concept development [IP04_1, IP12_1].

- *"The new roles were composed by scratch, without precedent cases to learn from. There was a need for administrators who overview the full care process, with a supportive role but also with some power; and it became evident early that communication between non-physicians and physicians is not ideal in this context, so we need a supervisor physician role also." [IP12_1, initiator]*

3.4.1. Change in the roles of department physicians

Before OnkoNetwork, scheduling the necessary diagnostics was a time consuming and stressful everyday experience for department physicians, requiring several phone calls and fighting for early dates. The introduction of OnkoNetwork altered this practice, passing the coordination of diagnostics to OnkoNetwork administrators of the departments [IP04_1, IP06_1, IP10_1]. Physicians hence may allocate 5-10 more minutes for patient-physician communication [IP04_1].

On the other hand, the programme limits the independence of department physicians and press them to collaborate with other medical professions. Unlike the practice before OnkoNetwork, surgeons or other specialists can't make decisions alone on therapy but have to work together with other physicians as a team, along the personalized and patient-approved Tumour Board decisions [1,9; IP03_1, IP08_1]. This rule also applies for the surgical treatment of comorbidities, except for emergency situations e.g. in neurosurgery, urology, or gynaecology where a posterior notification of the Tumour Board is sufficient [7].

At implementation, there was a chance that some physicians do not want to cooperate and consequently not all target patients can be accessed by the model. However, all physicians accepted the new system and it works now [IP03_1, IP08_1].

In OnkoNetwork, all enrolled patients have a named "responsible therapist" throughout the complex interdisciplinary diagnosis and treatment process [IP08_1] to ensure the continuity of care. This dedicated physician is competent to decide on diagnostics and is responsible for any delay in diagnosis and in therapy initiation [IP04_1]. The person of the responsible therapist changes along the patient path, it is typically a physician from the relevant organ-specific department of the Hospital, a surgeon, and an oncologist in the diagnostic phase, in the perioperative stage, and during chemo- and radiotherapy episodes, respectively [IP05_1, IP10_1]. The responsible therapist must be available for discussions with supervisor physicians, but should not be directly contacted by OnkoNetwork Office administrators [IP07_1] (for details, please see the description of these new roles below).

- *"In the Hungarian healthcare system, physicians and non-physicians are far from each other in their societal status, and it helps a lot if physicians are contacted by physicians and not by office administrators." [IP08_1, non-physician].*

Importantly, the cooperation of department physicians with OnkoNetwork administrators of their own departments is good, and sometimes symmetric, e.g. they fill in the standardized OnkoNetwork questionnaire while the administrator asks the relevant questions from the patient [IP06_1].

3.4.2. OnkoNetwork administrators of the departments

One to three candidates were selected from employed non-physician assistants or administrators to become OnkoNetwork administrators in all relevant departments of the Centre [IP02_1], followed by their personal appointment by the top management [IP09_1], and tailored training [IP02_1]. In total, 41 OnkoNetwork administrators were appointed in the various departments [IP09_1]. Their related tasks are 1) initial patient interview and filling in the standardized OnkoNetwork questionnaire at programme entry; 2) scheduling all protocol-driven diagnostics, together with any additional diagnostics requested by the responsible therapist; and 3) recording of all relevant medical data (e.g. suspect diagnosis, anamnesis and comorbidities, scheduled dates and results of diagnostics) in the custom IT system of OnkoNetwork (OncoLogistic), together with the responsible therapist's explanation for any delay or deviation from the protocol [1,2; IP01_1, IP02_1]; and 4) and monitoring therapy initiation after Tumour Board decision [IP02_1]. Accordingly, OnkoNetwork administrators of the departments have the same level in OncoLogistic data access as physicians [IP02_1], and they work in two IT systems in parallel: in the medical system of their department, and in OncoLogistic, with significant need for parallel data entry due to suboptimal communication of these systems [IP12_1]. OnkoNetwork administrators of the departments usually focus on data entry into the medical system, while OnkoNetwork Office administrators (see later) focus on OncoLogistic entries and negotiate with department assistants in case of invalid / missing data [IP06_1]. Although both office administrators and department administrators are authorized to enter new data into the OncoLogistic system, it is desirable that the missing pieces of data are entered by OnkoNetwork administrators of the relevant departments [IP01_1].

OnkoNetwork administrators of the departments are in close collaboration both with OnkoNetwork Office administrators (see below) and with responsible therapists in their department [IP01_1, IP02_1, IP06_1].

The selected OnkoNetwork administrators of the departments typically received their new role on top of their existing assistant or administrator responsibilities and tasks [IP02_1, IP06_1, IP10_1]. Nonetheless, in departments with high OnkoNetwork administration workload the OnkoNetwork administrator function can be a full-time position [IP02_1].

3.4.3. OnkoNetwork Office administrators (Conductors)

The OnkoNetwork Office was established a few months before the implementation of OnkoNetwork, in July 2015 [IP01_1]. It is settled in two connected rooms on the first floor of the central building of the Hospital, with 4 full-time administrators [IP01_1] led by the Office Manager directly reporting to the Strategic Director of the Hospital [5]. The majority of conductors were recruited outside from the hospital, without prior healthcare background – except for one of the conductors and the Office Manager [IP08_1].

Tasks of the conductors include 1) the management of all OnkoNetwork processes; 2) patient path management and monitoring directly and through OnkoNetwork administrators of the departments, assuring that the diagnostic phase is completed within 30 calendar days; 3) collection and overview of documents to the Tumour Board; 4) continued patient path management after Tumour Board decision, assuring that the therapy is started in 14 calendar days; and 5) patient follow-up for years [5,9].

In the everyday practice, OnkoNetwork Office administrators search for new patients with a C or D disease code every morning in the Hospital system for OnkoNetwork candidate patients, and check whether all of them have been invited and enrolled into OnkoNetwork; and if not, why not [5]. On a typical day, the status of about 40-50 OnkoNetwork candidate patients is checked by the team [IP01_1]. The conductors also look after all enrolled OnkoNetwork patients with a delay of diagnostics, Tumour Board meeting, therapy initiation, or control visits on a daily basis [IP01_1], using the OncoLogistic tool (see details in Section 3.5). Finding a patient with invalid data entry or apparent delay, first they check the available documentation in the medical IT system of the Hospital (MedSol) and clarify whether a data export-import issue explains the identified anomaly. If not, they contact with OnkoNetwork administrators of the relevant department for further clarification [IP01_1, IP08_1, IP09_1, IP10_1]. They do not question the justification stated by the department for any delay or protocol deviation, but ensure that it is recorded in the system [IP01_1, IP08_1]. If no solution is found, the conductors notify the supervisor physicians who solves the situation (see below) [IP01_1, IP08_1]. The head of the OnkoNetwork Office works very close to the conductors and is also continuously available to help them to deal with any professional or communication-related issue [IP01_1]. In cases where the patient did not come to a diagnostic visit, the conductors may call the patient and schedule an alternative visit [IP01_1, IP08_1]. The conductors do their best to achieve that Tumour Board documentation is completed and available in OncoLogistic online within 30 days of OnkoNetwork enrolment [IP09_1]. If all documents are ready, they notify the department of the responsible therapist that the control visit can be rescheduled to an earlier day than planned [IP09_1].

- *"The new roles in OnkoNetwork are about organization: the establishment of a coordinative role for patient path management and monitoring, who can contact with the patients directly when necessary. An IT development alone is insufficient, there is a strong parallel need for a dedicated staff with the corresponding task descriptions and responsibilities, i.e. the IT system users / administrators."* [IP03_1, physician].

- *"OnkoNetwork Office administrators monitor the patient paths of all enrolled subjects on a daily basis, and proactively contact with patients at risk of discontinued care." [9]*

3.4.4. Supervisor Physicians

Two supervisor physicians have been invited and appointed by the top management, one working at the Hospital and another one working at the University [IP01_1, IP04_1]. The key role of supervisor physicians is to negotiate by phone or in person [IP04_1] with department physicians on OnkoNetwork related issues that could not be solved by OnkoNetwork administrators, and to refer the remaining unsolved situations to the Strategic Director of the Hospital [9]. The supervisor physician may request clarification and justification for missing or delayed diagnostics, but should not interfere with medical decisions of department physicians [IP04_1]. Tumour Board decisions are almost obligatory and evidently can't be changed by the supervisor physician, but only by the responsible therapist in exceptional, justified cases (e.g. worsening of patient fitness, the cancer turned to be inoperable) [IP04_1]. Supervisor physicians can decide on their own on specific OnkoNetwork-related issues, e.g. whether to invite a terminal stage patient, or a patient with a second primary tumour into OnkoNetwork [IP01_1, IP04_1]. The ultimate aim of their supervision is to achieve that the clinical protocols are followed in a timely manner whenever relevant [IP04_1].

The selected supervisors have a personality that decreases the psychologic stress on office administrators. It is important that they are helpful and calm, making others calm, too [IP01_1]; and they are accepted as partners by department physicians because they are also doctors [IP09_1].

3.4.5. Barriers and facilitators for new roles

Barriers and facilitators for the establishment of new professional roles are briefly described below. For barriers and facilitators of OnkoNetwork implementation in general, please see section 3.8.

The first barrier to tackle with regarding the new roles was that no relevant prior experience could be identified in Hungary, therefore the workflow description and the definition of new professional roles were started from scratch. Thorough discussions with all stakeholders, organized throughout the model concept development were important facilitators in this phase [IP04_1, IP12_1].

- *"At implementation, it was an important facilitator that first we described the full care process and clarified the roles. Then we selected the staff and allocated the necessary infrastructure." [IP12_1, initiator]*

Hospital regulations were adapted to the planned changes in roles, responsibilities, and hierarchy [7,9; IP12_1]. To ensure that the changes in roles and workflows will be implemented smoothly across all departments of the Centre, consensus agreements of department heads and hospital management were achieved, followed by the development and implementation of harmonized operational procedures covering all relevant departments of the Centre [9]. The establishment of OnkoNetwork Office was also

a facilitator tool, allocating a dedicated staff supporting and monitoring the implementation and permanent operation of the new model [9]. The implementation was decided by the Board of Directors, and was announced by the General Director of the Hospital [7,9]. The availability of all necessary diagnostic and treatment modalities necessary for a complex oncology care centre, as well as the underlying infrastructural developments and the consistent development strategy of the Hospital to provide cutting edge oncology care in the last 10-15 years were strong facilitators at Kaposvár [IP18_1].

The developed custom IT application (OncoLogistic) was also a strong facilitator, providing tailored IT support for patient path monitoring and for the organization of the related documentation [1,2]. The IT application was developed with marginal external support (a nominal support for the development of the OncoLogistic IT system was received from an EU fund). On the other hand, the connection of OncoLogistic to the two medical systems of the Centre is suboptimal, with manual searches and copy-paste steps which requires additional efforts from OnkoNetwork administrators and are subject to further IT development [IP01_1, IP04_1, IP05_1, IP06_1, IP07_1, IP09_1, IP14_1]. For more details on IT support, please see Section 3.5.

There were no available external funds to financially compensate OnkoNetwork administrators and supervisor physicians, who took the new roles typically on top of their existing responsibilities [IP02_1, IP06_1, IP10_1]. In fact, it was not a true barrier since all invited OnkoNetwork administrators and supervisor physicians were pleased to contribute to the planned pioneering exercise, were motivated by the opportunity to improve the complex oncology care in the region, and appreciated that they were invited personally by the top management of the Centre [IP09_1].

The new roles required appropriate education and training, which was accomplished as plenary lectures to explain the concept of the model, together with practice oriented technical presentations. OncoLogistic users also received a written description which was in a not sufficiently plain language to be understood by all administrators. Training events took for 1-2 hours in every 1-3 weeks in the planning and developing phase, these were interactive, any feedback was seriously considered, and all changes in the planned model were instantly communicated. These regular trainings facilitated the breakthrough of initial resistance. However, OnkoNetwork administrators could not fully familiarize themselves with the IT software by these meetings, and a few months of learning by doing experience was also necessary for them to get fluent in the use of OncoLogistic [IP01_1, IP02_1, IP04_1, IP07_1]. The selection of OnkoNetwork administrators was guided by their skills, and preferably those non-physician colleagues with strong computer skills and/or complex oversight of the care process were selected [IP01_1, IP06_1, IP10_1].

At implementation, some physicians, especially surgeons were irritated as they could not make decisions on the treatment alone (e.g. when to take a histology sample). Facilitators to overcome this resistance included the consensus agreements with department heads, the strong commitment of the management, and the experienced early benefits of the model, e.g. the organization of diagnostics by OnkoNetwork administrators [IP07_1].

A further barrier came from the culture of many physicians [IP01_1, IP07_1], as illustrated below:

- *"At the beginning, administrators asked for clarifications / corrections from chief physicians and it was not really accepted / tolerated. Supervisor physicians are much more accepted as partners by department physicians. I know that teamwork of physicians and non-physicians is the standard practice in Western Europe and in the US, but it does not work in Eastern Europe, where it is better to negotiate with physicians by other physicians. OnkoNetwork did not change the attitude of department physicians, but circumvented this situation by the establishment of the supervisor physician role in the model." [IP07_1, physician]*

OnkoNetwork administrators are motivated by the supportive work environment, by the availability of the necessary infrastructure (e.g. new buildings with modern facilities, dedicated workstations with personal computers), by the open communication at meetings, by the personality of the supervisor physicians, by informal social events e.g. birthday parties, and by the observed successes in individual patient paths. On the contrary, their oversight of patient paths with negative outcomes may put an emotional burden on them [IP01_1, IP06_1, IP08_1, IP09_1].

The importance and the value of the work done at OnkoNetwork were recognized by the Ministry of Human Capacities, which is responsible for healthcare in Hungary. The OnkoNetwork team received a Ministerial award from the Minister of Human Capacities for their exemplary professional work in healthcare. Such recognition refers to the OncoNetwork Office and for OnkoNetwork administrators working at different departments as well [10]. This positive political feedback was also reinforcing for OnkoNetwork personnel.

3.5.   Technologies & medical products

Before OnkoNetwork, a range of ICT applications have been already implemented in the hosting institutions. The Móritz Kaposi General Hospital used eMedSol, a hospital information system which collects, monitors and stores patient level data at the institution [8,9]. The Kaposvár University Health Center used Softic as a medical IT system [9; IP04_1, IP14_1]. The hospital applied an additional IT system to manage chemotherapy and radiotherapy protocols / dose selection (Cato system) [IP07_1]. Cato includes all the chemo- and radiotherapy protocols from which a physician can select. The Cato system considers the comorbidities and the polypharmacy as well, and the therapeutic doses are modified according to these factors. It also notifies if a particular treatment protocol is not applicable for a particular patient. The list of recommendations and the selection is documented within the Cato system. Data from Cato is not fully exported into the hospital medical system, only the received therapy is registered in eMedSol [IP07_1].

OnkoNetwork management did not aim to replace or standardize these IT systems, but intended to develop a new, tailored IT application (OncoLogistic), with the below three interlinked objectives [1,2,8]:

- Patient path management support on OnkoNetwork patients
    - recording of events
    - monitoring of timelines and states
    - documentation of medical decisions
    - organization of Tumour Board meetings

- Medical documentation support on OnkoNetwork patients
    - Patient anamnesis – data entry, data import, and summary
    - Priority status setting
    - Selection of the required investigations along diagnostic protocols
    - Exact diagnosis
    - Treatment protocol

- Evaluation tool of OnkoNetwork
    - Analyses on performance indicators and clinical outcomes
    - Custom subgroup analyses
    - Machine learning options

Authorized users of OncoLogistic include the OnkoNetwork Office staff and management, the Strategic Director, the General Director, the head of the Oncology department, and the Medical director of the Kaposvár University Health Centre. All relevant departments have appointed responsible persons (OnkoNetwork administrators) who have access to the system [5].

The software can handle customized levels of access to data and functionalities. OnkoNetwork administrators were set to have the same level of access as department physicians. Every user has personal ID to log in, and also a dedicated computer in many cases. All data entries can be tracked back to user IDs. Remote access outside the Centre is not permitted, although theoretically the application could manage that, and it could be helpful e.g. for patients to check their records real-time; for primary care physicians to check their patients and also to contribute to the organization of diagnostics; and for the national healthcare payer to check patient data remotely to decide on individual treatment financing requests [IP01_1, IP02_1, IP06_1, IP10_1, IP12_1].

The development of OncoLogistic started in July 2014, and its first version for implementation was released on the 1st of November 2015 [7]. From the 1st October 2015, a test version was available [7]. Hardware requirements at the office and on the server side were also regulated [5]. In practice, OncoLogistic is primarily used for computer-assisted patient path monitoring and management along the OnkoNetwork care process [IP01_1, IP08_1] as described in Section 3.2, supporting the continuity,

comprehensiveness and coordination of care for OnkoNetwork patients, including multi-morbid persons.

The development of OncoLogistic received financial support from EU funds through "Társadalmi Infrastruktúra Operatív Program (TIOP) 2.3.3-13/1 Nemzeti Egészségügyi Informatikai (e-egészségügy) Rendszer - Térségi, funkcionálisan integrált intézményközi információs rendszerek kiépítéséhez szükséges helyi infrastruktúra fejlesztések" (Social Infrastructure Operational Programme - National Health Information Technology (e-health) system – For developing local infrastructure to functionally integrate system at regional and inter-institutional level (personal communication, waiting for supporting documents).

The biggest challenge in the IT development was to achieve the connectivity of OncoLogistic to other IT systems, i.e. to decrease the necessary amount of parallel data entries in multiple systems [IP12_1]. The implemented version still has some limitations in this respect, OnkoNetwork administrators need to manually look for data in various systems and copy-paste it into OncoLogistic [IP01_1, IP04_1, IP05_1, IP06_1, IP07_1, IP09_1, IP14_1]. As an example, MR and CT results from the University are not imported into OncoLogistic, these are copied in picture format therefore search is not possible [IP09_1].

The key issue with data transfer across IT systems is the lack of standards. Many national diagnosis related group and intervention codes had been created for financial purposes and are not sufficiently detailed from medical perspective. Several independent IT software developments across the country resulted in a multitude of applications used by healthcare providers, and the data structure of these medical systems is not compatible with each other. Only regulations or business-driven needs could change this practice. Until that, harmonization of healthcare IT systems can be achieved only in selected cases when it is paid for by someone, and the harmonization process is always a pain [IP02_1, IP12_1].

- *"Data import from the reports of various healthcare service providers is compromised by the lack of standards in laboratory reports (e.g. various labels, units, and normal ranges for hemoglobin results). Changes in the structure of the reports require adaptations on the data search and import functionalities of OncoLogistic. We have learnt a lot from the observed issues so far, and built a significant knowledge base which is unique in Hungary." [IP12_1, initiator]*
- *"The development of OncoLogistic was facilitated by the established experience of the developers in healthcare and software developments. An important barrier was that the software needed to be parametrized for any potential future change in the system. It is not easy to explain to colleagues from Western Europe why do we apply adjustable parameters instead of constants for some variables. The rationale is that according to my experience, all things which can change will change in the Hungarian healthcare system; and those things which can't change will change also." [IP12_1, initiator].*
- *"All pieces of the received data must be evaluated and interpreted by OncoLogistic in an automated way. For a laboratory parameter it is relatively simple: the exact value and the reference range are important. In a radiology report, separate sections discuss the results of*

investigation, the diagnosis based on these results, and other diagnoses. A histology report consists of 12 sections, with macroscopic and microscopic descriptions, etc. When the sample was collected via colonoscopy, two separate reports are received, one on the colonoscopy findings and another one on the histology findings. Sometimes the first report describes that no sample was taken, so there is no need to wait for the second report. And it also happens that the colonoscopy report comes together with the histology report. The system must understand and monitor all these processes – this is the hard thing in IT development." [IP12_1, initiator]

In the planning phase, it was also a big challenge to translate the approved diagnostic protocols into process descriptions / algorithms. This step required the collaboration of IT engineers and physicians, with different way of thinking and language [IP12_1]. Programme writing was preceded by a 1-year planning process reaching consensus across professionals [IP18_1].

A great achievement of OnkoNetwork is that diagnostic protocols are integrated into OncoLogistic therefore the organization of diagnostics could be passed to nurses / assistants in hospital departments [IP04_1, IP10_1].

Facilitators for the implementation of OncoLogistic included presentations, a distributed written description, and also the learning by doing approach for the administrators – the latter was the most effective way for them to learn to use this application [IP01_1, IP02_1, IP08_1, IP09_1]. From the users' perspective, there were no significant changes in OncoLogistic from its implementation [IP08_1].

In addition to OncoLogistic, OnkoNetwork administrators use a wide array of additional IT solutions:

- Since patient subgroup analyses in OncoLogistic are not fully functional at present, patients with comorbidities are listed in a MS Excel file with family history, patient anamnesis, comorbidities, and medications, to allow further research on multi-morbidity. [IP01_1, IP04_1, IP09_1];
- Enrolled OnkoNetwork patients without their signed informed consent forms arrived to OnkoNetwork Office are listed in a MS Word document in a shared folder [IP09_1];
- Discharged patients are listed in MS Excel, recording whether the patient is treated by the administrator's department, or not [IP10_1];
- and even paper-based listings are in use, to support the patient path management process [IP14_1].

However, working in a couple of applications is not a problem in practice [IP10_1].

OncoLogistic is a living being, subject to continuous fine-tuning. As some patients do not follow the typical sequence of investigations -> diagnosis -> Tumour Board -> therapy -> follow-up, these states can be permutated in any custom order in the updated version of OncoLogistic [IP04_1, IP09_1, IP12_1]. Current developments focus on smoother data export / import across MedSol and OncoLogistic, and reverse data transfer functions [IP08_1, IP18_1]. The integration of therapeutic protocols into

OncoLogistic reflecting on tumour size and staging is under development, the main barrier for that was the lack of approved, algorithmic treatment protocols which would be the prerequisite for process description and IT programming [IP09_1, IP12_1].

Future development opportunities for OncoLogistic are its adjustment to all healthcare IT systems in Hungary, scale-up to Hungary and international markets, to extend the scope of the programme to other therapeutic fields, and to allow remote review and evaluation of individual financial support request applications by the national healthcare payer [8]. In addition, integration of primary care and screening programmes into the system is also considered [IP05_1]. The IT system was developed in a way that allows its rapid adaptation to any other region / healthcare system. It is multilingual, theoretically capable to import data from any system. The IT system ownership is at the developer with a permitted use licence bought by the hospital [IP12_1].

OnkoNetwork did not change the use of ICT tools by patients [IP02_1], although OncoLogistic could be utilized also for this purpose [IP12_1].

3.6. Information & research/monitoring

3.6.1. Data collection, monitoring and quality assurance

Cancer mortality is especially high in Hungary, and delayed diagnosis of cancer results in less effective and less cost-effective therapies. The medical documentation of patients is mostly paper-based and is not systematically collected in Hungary. These documents are partly lost by the patients in many cases, hence, physicians see only a part of their medical history. Comparison of data across various hospitals or regions requires special efforts, since there are no established standards for data content and format [IP_03_1, IP05_1, IP07_1, IP12_1]. For comparisons across hospitals, the cooperation of another hospital and granted data access conforming the data protection regulations and laws would be prerequisites [IP12_1].

Beyond routine clinical data collection in the hosting institutions, OnkoNetwork specifically collects data on all enrolled patients in a dedicated IT application (OncoLogistic) [1,2,8,9]. Data collection in OncoLogistic covers healthcare events throughout all departments of the Centre with their timelines, medical decisions with their rationale, and the full related medical documentation including the results of diagnostics, and inpatient and outpatient service delivery reports [8].

Completeness, timeliness, and face validity of the entered data in OncoLogistic is monitored by a dedicated body, the OnkoNetwork Office [5,9]. OnkoNetwork patients with delayed diagnostics or therapy initiation are listed by OncoLogistic, the tailored IT support system for OnkoNetwork. OnkoNetwork Office administrators first check the available documentation in the medical IT system of

the Hospital and clarify whether a data transfer issue explains the identified anomaly. If not, they contact with OnkoNetwork administrators of the relevant department for further clarification [IP01_1, IP08_1, IP09_1, IP10_1]. They do not question the justification stated by the department for any delay or protocol deviation, but ensure that explanations are recorded in the system [IP01_1, IP08_1]. If no solution is found, they notify the supervisor physicians, who negotiate with department physicians on issues that could not be solved by OnkoNetwork administrators, referring the remaining unsolved situations to the Strategic Director of the Hospital [9]. The Strategic Director is also provided with weekly reports on all delayed cases [IP04_1, IP09_1]. He has a unique leadership position and strong commitment to OnkoNetwork, and can solve any situation in the Centre very effectively if needed [IP09_1, IP18_1]. The Hospital General Director may also intervene in the rare escalated cases [IP05_1]. OnkoNetwork Office administrators and supervisor physicians do their best to achieve that Tumour Board documentation is completed and available in OncoLogistic online within 30 days of OnkoNetwork enrolment [IP09_1].

Hence, the operation of OnkoNetwork Office is a robust quality assurance tool in OnkoNetwork, contributing to good physician compliance with the diagnostic protocols, improved patient equity, and timely access to and continuity of care [IP03_1, IP04_1, IP05_1, IP08_1, IP09_1]. All data entries in OncoLogistic can be traced back to user IDs [IP01_1, IP06_1]. Importantly, OnkoNetwork could also achieve that Tumour Board meetings do not face with incomplete diagnostics or missing documentation when deciding on a particular patient's treatment recommendation [9].

No written reports could be gathered on the performance of OnkoNetwork so far, due to its recent implementation on 1st November 2015 [7,9; IP04_1]. It is thought that at least a few years will be necessary to evaluate the clinical and economic outcomes [IP01_2, IP05_1, IP09_1, IP18_1]. Benefits of the programme will be boosted once the cancer screening system and primary care will be connected to it: the earlier the diagnosis, the better assumed clinical and economic outcomes are expected [IP18_1].

Any burden on professionals related to the introduced monitoring and quality assurance system are described in Section 3.4.

3.6.2. Clinical outcomes

The evaluation of clinical outcomes is supported by the collection of patient-level data on the full OnkoNetwork patient population, including a subgroup of OnkoNetwork patients with multi-morbidity [IP07, IP18_1]. Dietetic status is also systematically evaluated and recorded in new head and neck tumour patients from 15th June 2016 onwards [IP09_1]. Comorbidities are listed for all patients in MS Excel, to allow future analyses in this subgroup [IP09_1].

It is expected that OnkoNetwork will result in faster diagnosis [IP01_1, IP03_1, IP04_1, IP05_1, IP06_1, IP08_1, IP10_1], less patient withdrawal in the diagnostic phase [IP06_1, IP08_1, IP17_1], less patients turning to private healthcare providers to speed up the diagnostic process [IP03_1], faster investigation

and control of comorbidities [IP05_1, IP07_1], less inconclusive Tumour Board sessions [IP05_1, IP07_1], earlier start of therapy [IP14_1, IP17_1], less patients with cancer metastases [IP17_1], longer patient survival [IP02_1, IP07_1, IP08_1, IP17_1], and better nutritional status of patients with head-neck tumours during therapy [IP02_1, IP09_1]. Some interview partners suggested that more patients will receive surgical care due to early diagnosis, while the opposite expectation was also mentioned due to decreasing dominance of surgeons in treatment decisions.

Initial analyses suggest that the coordination of healthcare improved, with shortened timelines for diagnosis and therapy initiation [IP03_1, IP04_1]. The mean time from initial indicative diagnosis in Hospital to Tumour Board decision is now 21-22 days in OnkoNetwork with a standard deviation of 14 days [9; IP05_1]. The target upper threshold is 30 days [9], including also the additional diagnostics in multi-morbid patients [IP05_1]. Before OnkoNetwork, the standard deviation of this time period was 40 days [IP12_1] and the mean duration was 64 days [IP18_1] in the Centre. For comparison, the mean duration of cancer diagnosis in other Hungarian hospitals can be as high as about 110 days [IP04_1]. The most important achievements of OnkoNetwork are the standard quality of care and patient equity [IP12_1].

3.6.3. Experience outcomes

Data collection on OnkoNetwork patient experience has a strong focus on the timeliness and equity of access to care, i.e. to early diagnosis and initiation of therapy in the enrolled patients. The routinely collected patient satisfaction surveys are not specific to OnkoNetwork patients, are based on a limited sample size, and are anonymous therefore can't be linked to patient documentation to control for patient characteristics as potential confounders (e.g. patient age, gender, disease severity, existence of comorbidities, etc). Informed consent forms, signed consent forms for sharing radiology findings are also collected [IP09_1] in OnkoNetwork as a quality assurance tool on adequate patient information [IP03_1].

It is expected that patient experience improves, since OnkoNetwork allows more time for physicians to communicate with their patients [IP03_1, IP17_1, IP18_1], the waitlists are getting shorter [IP02_1, IP04_1, IP17_1, IP10_1], patients experience less travel and waiting time on the day of diagnostics [IP09_1], and the number of patients intending to arrive outside from the catchment area of the Centre has recently increased [IP05_1]. However, the remaining time of physicians is not necessarily utilized for patient communication [IP01_1], and patients probably can't link their improved experience to OnkoNetwork [IP03_1]. It is not expected that the waitlists of not enrolled patients will increase, at least in the first years of the model [IP05_1, IP17_1, IP18_1].

Experience of physicians previously fighting for scheduled diagnostic investigations was expected to improve [IP07_1, IP10_1, IP11_1, IP12_1, IP18_1], while the experience of patient path management administrators may worsen due to their increased administrative burden [IP07_1].

3.6.4. Economic aspects

The primary aim of OnkoNetwork was to improve the clinical outcomes [IP05_1]. Economic analyses of OnkoNetwork have not been conducted or designed so far. From the perspective of the Centre, no significant economic impact is expected, since the economic costs are limited to the human resources cost of about 4 full-time employees and the office leader in the OnkoNetwork Office [IP13_1, IP18_1]. In general, no change is expected in the number of diagnostic investigations. The number of outpatient visits is expected to decrease per patient, but probably more patients can be investigated in parallel. In contrast, significant economic benefits are expected to occur at the national healthcare payer [IP02_1, IP05_1, IP07_1, IP12_1].

Economic outcomes can be evaluated from various perspectives. For analysis from the perspective of the public payer, patient-level data on utilization of reimbursed technologies and services is readily available both retrospectively and prospectively, allowing any patient-level analysis. To include healthcare payer costs beyond the services of the hospital, data need to be requested from the healthcare payer itself. Note that the National Health Insurance Fund provides only aggregate data from its database to external researchers even in anonymized form.

For analyses from the hospital perspective, only limited patient-level resource utilization data is collected at OnkoNetwork, and case-based cost measurement is not feasible. Department-level data collection from the hospital perspective has been started in January 2016. For analyses from the patient perspective, either patient-level or department-level data is missing. Informal payments of patients are significant but can't be estimated.

3.6.5. Plans for future analyses

An emphasized additional objective of OnkoNetwork is to build a reliable and large clinical database with prospectively collected patient-level data, to allow the identification of currently unknown risk factors for cancer development as a future research activity of the programme [4, 9; IP02_1, IP18_1].

3.7. Financing

3.7.1. Financing and payment scheme

OnkoNetwork is a bottom-up project without a specific payment scheme / incentive system around it [IP05_1, IP13_1]. The project is funded from regular inpatient and outpatient financing sources provided by the healthcare payer, based on the decision of the hospital's management [IP13_1], with the anticipation that its economic costs for the Centre will be marginal [IP05_1, IP13_1, IP18_1], while a significant improvement can be achieved both in clinical outcomes and in healthcare costs at the national healthcare payer level [IP05_1, IP07_1, IP12_1, IP13_1].

The National Healthcare Services Center (ÁEEK), which is a governmental institute responsible for financing and sustaining the hospitals in Hungary, is aware of the programme and has stated that this operational model is welcomed [6]. However, no additional funds were provided for maintenance or development of OnkoNetwork. Whether an extra financing request for patient path management could be realised in the Hungarian healthcare financing system, it remains unanswered at present [IP13_1].

The model is under intellectual property rights belonging to the General Director of the Hospital [IP05_1]. However, it is considered as a public property to improve the Hungarian healthcare system, and OnkoNetwork is ready to provide it for scale-up in other regions. A fair financial remuneration of the Centre would be welcome in such a case [IP18_1].

OnkoNetwork has received financial support from EU funds for the development of the IT system, through "Társadalmi Infrastruktúra Operatív Program (TIOP) 2.3.3-13/1 Nemzeti Egészségügyi Informatikai (e-egészségügy) Rendszer - Térségi, funkcionálisan integrált intézményközi információs rendszerek kiépítéséhez szükséges helyi infrastruktúra fejlesztések" (Social Infrastructure Operational Programme - National Health Information Technology (e-health) system – For developing local infrastructure to functionally integrate system at regional and inter-institutional level [13].

Payments to providers and to individuals are overviewed in Tables 3 and 4, respectively.

Table 3: Overview of payments to providers in OnkoNetwork
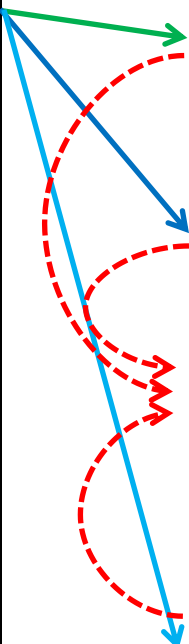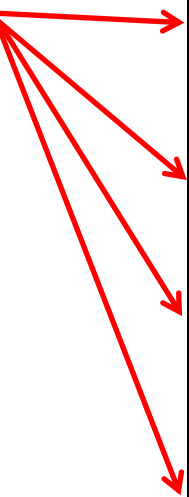
Payer(s)	Mechanism	Provider(s)	Details of payment mechanisms (classified according to Quinn 2015)
National Health Insurance Fund		Acute inpatient care	The standard practice in Hungary is payment per episode retrospectively, based on the fixed value of DRGs. Inpatient care providers in OnkoNetwork do not receive additional funding.
		Outpatient care	The standard practice in Hungary is a fee-for-service retrospectively, based on the fixed value of specific interventions. Outpatient care providers in OnkoNetwork do not receive additional funding
		Patient path management office	There is no established financing scheme for patient path management in Hungary. Patient path management budget and salary is indirectly financed from inpatient and outpatient financing sources.
		Chronic inpatient care	The standard practice in Hungary is a per diem payment retrospectively. Chronic care providers in OnkoNetwork do not receive additional funding.

Table 4: Overview of payments of individuals in OnkoNetwork

Payer(s)	Mechanism	Personnel	Details of payment mechanisms (classified according to Quinn 2015)
Budget of the Kaposvár Complex Oncology Centre		Physicians	Monthly salary retrospectively, not changed by OnkoNetwork. Informal payments from patients may be significant but is not assessable.
		Supervisor physicians	Monthly salary retrospectively, not changed by OnkoNetwork.
		OnkoNetwork administrators of Departments	Monthly salary retrospectively.
		OnkoNetwork Office administrators	Monthly salary retrospectively, not changed by OnkoNetwork.

3.7.2. Incentives for multi-morbid target patients to join OnkoNetwork

OnkoNetwork offers priority status, personal patient path management, and timely access to quality assured healthcare services for the target patients invited. The same benefits are offered to target patients with multi-morbidity, regardless the complexity of their case. The key features of the OnkoNetwork model are explained to the patients before their enrolment [12]. Enrolment has been accepted by all invited patients but only a few exceptions so far [IP10_1].

3.7.3. Incentives for professionals to contribute to OnkoNetwork

OnkoNetwork administrators of the various departments, and supervisor physicians were selected and appointed from the existing staff of the Centre, without providing financial compensation for their additional role [IP07_1, IP09_1, IP10_1, IP13_1, IP14_1]. However, the management of OnkoNetwork acknowledges that administrators in the healthcare have a particularly low salary in Hungary by the law, and more compensation would be needed for them [IP05_1]. In general, salaries in the Hungarian healthcare system are disappointingly low [IP01_1, IP02_1, IP06_1, IP08_1, IP09_1].

The selected OnkoNetwork administrators of the departments typically took the new role on top of their existing responsibilities and tasks [IP02_1, IP06_1, IP10_1]. Nonetheless, in departments with high OnkoNetwork administration workload the OnkoNetwork administrator function can be a full-time position [IP02_1]. Alternatively, some of their other tasks may be taken over by others to deliberate the necessary working hours for their new role [IP03_1].

As the financial compensation is missing, staff members are motivated by other factors, e.g. by the opportunity to work in an innovative and patient-oriented model [IP02_1]. Patient path managers may feel the patients as family members, and they are satisfied when the patients are properly cared [IP06_1]. OnkoNetwork administrators are also motivated by the availability of the necessary infrastructure (e.g. a dedicated workstation with a personal computer), by the open communication at meetings, by the personality of the supervisor physicians, by informal social events e.g. birthday parties, and by the observed successes in individual patient paths [IP01_1, IP06_1, IP08_1, IP09_1]. Supervisor physicians are motivated by the importance of this pioneering initiative in the Hungarian healthcare setting, and by the immaterial appreciation from the colleagues and programme management [IP04_1]. The new and well-designed buildings with their modern facilities are also relevant motivators.

Financial compensation for the IT system development from an EU fund was of symbolic magnitude. The IT engineer was motivated by the importance and complexity of the problem; by the constructive approach and expertise of the team; and by a future opportunity that the IT system can be sold to other hospitals when ready [IP12_1].

- *"Non-physician healthcare workers' salary is ignominiously low in Hungary, by law - it cannot be changed by the Hospital. A financial compensation of +10% would be a fair minimum to those*

department assistants / administrators taking extra roles in OnkoNetwork." [IP09_1, non-physician]

- *"We do not receive financial compensation for our extra tasks related to OnkoNetwork. However, our contribution is appreciated, we receive positive feedback from the Office and receive "thank you" frequently. The pioneering, patient-oriented approach of OnkoNetwork is really motivating." [IP10_1, non-physician]*

3.8. Implementation process

3.8.1. Historical information

The initial concept of OnkoNetwork was raised by Prof. Imre Repa (Professor of Kaposvár University Health Centre, Strategic Director of the Móritz Kaposi General Hospital). He wondered why cancer mortality is so high in Hungary when compared to other European countries, in spite of significant investments [I; IP18_1]. After visiting several Tumour Board meetings in the Hospital he perceived that Tumour Board meetings were not sufficiently effective, due to insufficient coordination (missing diagnostic investigations, or missing investigation results in many cases) [9; IP05_1].

A small team was set up to understand the root causes of high cancer mortality in Hungary, even in a complex oncology care centre with good infrastructure [9; IP05_1, IP12_1]. This core brainstorming team initially consisted of the Strategic Director, two young physicians with daily clinical practice and with good understanding of the care process, an academic professor of neurosurgery, a retired professor of pulmonology, and an IT engineer who was the manager of an IT developer company called Hospitaly Ltd [IP12_1]. Looking for potential explanatory variables they identified two quantitative parameters that could be controlled by the Centre and showed high variability: the time from initial indicative diagnosis of cancer to Tumour Board meetings was as long as 6 months in many patients (see Figure 5), and the time from Tumour Board meeting to the first day of therapy also showed a couple of month delay in some patients (see Figure 6) [1,2]. Time from first signal/symptom noticed by the patient to initial indicative diagnosis in hospital is obviously also a critical parameter, but it is out of the control of the Centre and could not be measured [IP12_1].

To solve the issue of delayed diagnosis and therapy initiation, a patient path management system was decided to be developed as a local initiative. It was clear that higher management decisions are necessary to solve any conflicts of interests across hospital departments (e.g. urgent diagnostics for oncology vs. suboptimal capacity of histopathology) [IP05_1].

- *"Hospital department heads were the most important stakeholders to convince in the planning phase. The concept was first consulted with them. Thereafter it was presented in a plenary hospital meeting with ~200 attendants, followed by small-group discussions. Surgeons had to*

accept that their patients are monitored by supervisor doctors, and that patients are treated by oncologists in the postoperative phase. There were some conflicts but at the end a consensus decision could be built, guided by the patients' interest." [IP05_1, manager]

The planning phase was based on the intensive teamwork of the Strategic Director, the Medical Director, and the Nursing Director of the Hospital, the head of the Kaposvár University Health Centre, heads of all hospital departments contributing to cancer diagnosis or treatment, Tumour Board members, invited external experts, IT staff from the Hospital, and the management and the staff of a contracted IT developer company (Hospitaly Ltd), for several months [1,2,9]. Significant effort was made by Dr. Moizs Mariann (Móritz Kaposi General Hospital, Director General); Király Gyula (Hospitaly Ltd, co-founder of OnkoNetwork); Dr. Ágnes Ruzsa (Clinical Oncologic Centre, Móritz Kaposi General Hospital, Head of Department, Chief Physician); Dr. Zsolt Cselik (Health Centre, University of Kaposvar Radiation Oncologist, Clinical Specialist in Oncology); Dr. Zoltán Völgyi (Clinical Oncologic Centre, Móritz Kaposi General Hospital, Specialist in Oncology); Prof. Dr. Dóczi Tamás (University of Pécs, Professor at the Department of Neurosurgery); Dr. Hadjiev Janaki (Health Centre, University of Kaposvar, Vice-president, radiation oncology); Prof. Dr. Strausz János (Móritz Kaposi General Hospital, Pulmonologist, Director-General consultant); Vilhelm Erika (Móritz Kaposi General Hospital, Controlling team); and by Szaszkóné Böjtös Gyöngyi (Hospital IT manager) [1,2].

Several concurrent objectives were outlined in the planning phase, which were repeatedly modified during the regular meetings and conferences. An example for the modification of objectives was that initially the full patient paths were to be managed by oncologists. But it became clear that it was not realistic due to insufficient oncologist capacity and deeper understanding of the diagnostics by physicians at organ-specific departments [IP12_1].

As a result of the teamwork, the following objectives were set out [1,2]:

I. The oncology patient should not be lost and wasted in the gaps between various healthcare specialties.
II. Tumour Board decision should be made within 30 days of enrolment into OnkoNetwork, and thereafter the treatment should be started within 14 days.
III. The oncology patient should belong to a responsible physician all the time. Cancer treatment should not be initiated before the Tumour Board decision. OnkoNetwork patients have priority status throughout the centre.
IV. Organ-specific oncology care protocols should be developed and implemented.
V. A tailored IT system should be developed to support oncology care. Oncology patient documentation should be stored separately on a parallel server.

The overall aim of OnkoNetwork was to provide timely and equal access to comprehensive and integrated oncology care in a quality-assured manner along clinical protocols, without limiting the physicians in their personalized decisions [9; IP04_1, IP18_1]. In the planning stage, economic impacts were not in the primary focus [IP13_1]. Future perspectives included the integration of the screening

system and primary care into OnkoNetwork, and the development of a valid, prospective clinical database on oncology patients [9].

Development milestones are briefly summarized in Table 5. The work was started with the development of algorithm-like organ-specific diagnostic protocols [IP07_1, IP08_1, IP12_1, IP18_1], harmonized process descriptions [IP12_1], and the definition of new roles in OnkoNetwork [IP12_1], and when the consensus was achieved they turned to the development of a custom IT application [IP18_1] to support patient path monitoring and organization (OncoLogistic) in parallel with the thorough reorganization and harmonization of oncology care in the relevant departments of the Centre [9]. The process descriptions were created by the IT engineer, the clinical protocols were updated by the medical team members, and the hospital management dealt with the reorganization of hospital regulations and work descriptions [IP12_1].

Since no relevant prior experience could be identified in Hungary, the workflow description and the definition of new professional roles were started from scratch [IP04_1, IP09_1]. Thorough discussions with all stakeholders, especially with the heads of departments, organized throughout the model concept development were important facilitators in this phase [IP04_1, IP12_1].

Table 5: Milestones of OnkoNetwork development and implementation. Source: [7,9]

Time period	Milestones
June 2014	Raising the idea of OnkoNetwork, start of preparation
July - Dec 2014	Patient paths and care process description throughout the Centre, start of IT development
Jan – June 2015	Development of OncoLogistic; continuous consultations with the heads of departments
July – Oct 2015	Establishment of the OnkoNetwork Office; harmonized regulations for the relevant departments; OncoLogistic fine tuning and interface development to MedSol and Softic
Sept 2015	Modified Operational Rules in the Centre and in all relevant departments, definition of harmonized oncology care. The implementation was decided by the Board of Directors, and issued by the Instruction of the General Director of the Hospital.
Oct 2015	Test period, fine tuning of OncoLogistic, with continuous feedback from staff members involved in OnkoNetwork.
1st Nov 2015	Start of OnkoNetwork activities.

3.8.1.1. Barriers

In the planning phase, the interdisciplinary collaboration of IT engineers with healthcare professionals occasionally led to situations where differences in their way of thinking and professional languages formed a barrier. Such situations could have been solved by a mediator familiar with both disciplines

[IP12_1]. Development of diagnostic protocols and reconsidering the operation of departments was also a challenge [IP05_1].

Regarding the IT development, a strong barrier was the lack of medical IT system standards in Hungary. It was a not easy to achieve that the application can automatically find the relevant pieces of information in one system and export it into the other system [IP12_1].

Upon implementation, there were some conflicts between OnkoNetwork administrators and department physicians on the proper documentation of work. Implementation was successful due to the strong commitment of the strategic director, the Board of Directors, and of OnkoNetwork administrators, and also due to the activity of supervisor physicians [IP07_1, IP08_1, IP09_1, IP18_1].

The extra administrative workload on administrators is also worth mentioning as a barrier [IP05_1], especially because they have to work in two IT systems in parallel due to imperfect communication of the IT systems [IP12_1]. The lack of capacity development related to the additional tasks in hospital departments could be also a barrier [IP02_1], but it occurred that the selected staff members were highly motivated to take the additional roles. For more details, please see Section 3.7.3.

Fear from the change, and the protection of status quo (individual and departmental interests) were also observable at implementation, as many departments and physicians tend to focus on building their own reputation [IP18_1]. To change this practice, a process-based, managed system was designed [IP18_1]. At initiation, many physicians faced that they cannot make decisions alone but must work with other physicians as a team, to provide integrated multidisciplinary care [IP03_1, IP07_1, IP08_1]. The initial resistance was successfully overcome by the below detailed facilitators.

3.8.1.2. Facilitators

Upper management commitment is a key success factor in OncoNetwork [IP05_1]. Furthermore, a great local facilitator is the excellent cooperation of the Hospital and the University Health Centre, forming together a complex oncology centre providing comprehensive cancer care [IP18_1].

In the planning phase, several interactive meetings were organized where the changes in the scope or in the workflows were instantly communicated, and the received feedback was seriously considered, facilitating the breakthrough of initial resistance [IP01_1, IP02_1, IP03_1, IP04_1, IP07_1, IP09_1].

The good communication of the hospital management with an IT engineer was also a facilitator. Engineers are hardly accepted by physicians as team players in Hungary [IP12_1]. OncoLogistic itself became a facilitator in the implementation phase. Moreover, it was designed in a way that allows its rapid adaptation to any change in or across healthcare systems. The software is multilingual, suitable for scale-up beyond the borders of Hungary [IP12_1].

Implementation of OnkoNetwork was achieved by a change management process, fulfilling all corresponding documentation requirements. The Hospital's and the departments' regulations were adapted to new roles, responsibilities and hierarchy, and the new roles have been integrated into work descriptions in the hospital [IP05_1, IP12_1]. There was no need for macro-level approval / legal support outside the hospital, due to hospital autonomy [IP18_1]. The OnkoNetwork questionnaire and the informed consent form were developed, well-received and are in use throughout the hospital [IP05_1, IP18_1].

Trainings, written instructions to all users, and learning by doing opportunity in the test period were useful facilitators [IP02_1, IP03_1, IP04_1, IP06_1, IP07_1, IP10_1, IP14_1]. The selection of OnkoNetwork administrators from the existing staff of the departments was guided by their recognized experience, and preferably those non-physician colleagues with strong computer skills and/or complex oversight of the care process were selected [IP01_1, IP06_1, IP10_1]. The fluent operation is also facilitated by the personality, good communication and supportive attitude of OnkoNetwork Office administrators and supervisor physicians [IP01_1].

Interestingly, political support to OnkoNetwork was not detectable for a long time. The programme was first recognized by the Hungarian Health Economics Association, followed by the general media and hence patients in other regions. Other oncology centres were initially negative, but later they understood that OnkoNetwork does not compete for their patients. It was the last step when policymakers came into the picture [IP05_1]. Recent news indicate that the State Secretariat for Healthcare and the National Healthcare Services Center decided to scale up OnkoNetwork to >10 regional complex oncology centres (selected county hospitals with complex oncology care) in Hungary [personal information from the General Director of the Hospital].

3.8.2. Present information

As a recent change in OnkoNetwork, nutritional status assessment before treatment initiation has been introduced from 15th June 2016 in new OnkoNetwork patients with head or neck cancer, [IP09_1].

The first enrolled OnkoNetwork patients entered the follow-up phase in May 2016, leading to increasing OnkoNetwork experience regarding patient follow-up [IP01_1, IP14_1]. OncoLogistic had to be adapted accordingly, to properly handle patients with a second Tumour Board session where an apparent delay was observed as an artefact [IP09_1, IP12_1].

The improvement of the connectivity of OncoLogistic to MedSol and Softic requires continuous IT development efforts [IP09_1, IP12_1]. As an example, one of the investigation service providers used to send the results as unstructured text documents, which was not supportive for automated OncoLogistic data import. OnkoNetwork management could recently achieve a change in this respect, by paying for the necessary adaptation and also by some pressure expressed by the strategic director [IP12_1].

3.8.3.   Future implementation/development

From September-October 2016, the integration of primary care physicians into OnkoNetwork is planned, allowing their participation so that they can refer their patients to the necessary diagnostics.

Further future plans include the continuous fine tuning of IT system connectivity [8; IP08_1, IP14_1], and the adjustment of the system to the increasing number of patients [IP14_1]; the coverage of treatment monitoring and patient follow-up management in OncoLogistic [IP09_1, IP12_1]; to allow remote data access for the national healthcare payer to facilitate its decision on individual treatment financing requests [8]; the integration of the programme with cancer screening [IP18_1]; to scale-up the programme to other regions [8; IP05_1, IP13_1, IP18_1]; and/or to expand the project's scope to other diseases e.g. haematology [8; IP05_1, IP18_1].

The highest barrier to scale up OnkoNetwork to the national level is not economic but is apparently the lack of sufficient macro-level commitment [IP05_1].

3.9.   Discussion

3.9.1.   General discussion

OnkoNetwork is a local initiative in Somogy county, aiming to improve clinical outcomes in the target population by the introduction of individual patient path monitoring and management, which is a pioneering exercise in Hungary [1, 2]. The expected clinical benefits are intended to be achieved through improvements in timely and equal access to quality assured and integrated healthcare within the healthcare centre [1,2,5,9].

Multi-morbidity is not enrolment criteria in OnkoNetwork, although about half of the enrolled patients have at least one chronic comorbidity. Integrated care of cancer and e.g. cardiovascular comorbidities is an implicit but important feature of OnkoNetwork, as detailed in Section 3.1.

The programme is discussed in details in the context of the conceptual framework in Section 3.9.2.

3.9.2.   Discussion of the programme in the context of the conceptual framework

3.9.2.1. Holistic assessment and self-management

Neither the holistic assessment of physical, mental and social needs of patients with their individual preferences and capabilities, nor self-management are in the forefront of OnkoNetwork. Note that in Hungary, there are serious coordination deficits even within the healthcare services, healthcare is fragmented and the patients with more complex needs have to wait for weeks or months for their definitive care even within a single institution [9]. Initiators and managers of OnkoNetwork believe that

their model need to be extended to cover the holistic needs of the enrolled patients, since it is always better to recognize and manage these patient needs in a preventive way than to face exaggerated situations later, blocking the continuation of medical treatment [IP18_1]. However, all problems can't be solved at the same time, first the programme put its focus on the integration of medical care itself [IP03_1].

3.9.2.2. Service delivery

OnkoNetwork targets the same ambitious goals in all OnkoNetwork patients: very rapid diagnosis and initiation of therapy in a quality assured environment of un-fragmented care. The necessary diagnostics are personalized, strongly relying not only on the organs affected by cancer, but also on the relevant chronic comorbidities. The developed algorithmic clinical protocols are valuable tools for healthcare service monitoring and quality assurance, but do not limit the responsible therapists in their personalized decisions. However, any deviation from the protocols is logged and justified in the system in a transparent manner, which seems to be a straightforward balance of protocol-driven and personalized care. Treatment decisions made by the Tumour Board are individualized considering tumour origin, grade and stage, as well as the relevant comorbidities and the general physical status / fitness of the patient. The patient plays a central role in the decision on acceptance or refusal of the proposed therapy.

Proactivity and recognition of early symptoms are emphasized in OnkoNetwork, e.g. through the planned integration of the cancer screening system.

At the meso level, a continuous quality assurance system is approached by OnkoNetwork Office and is supported by the OncoLogistic software, to monitor patient paths across all participating institutions which use different medical IT systems.

3.9.2.3. Financing

In the development phase, a symbolic financial support from EU funds was received for the development of the underlying IT system. There is no specific coverage or reimbursement for OnkoNetwork services from any external source. The operational costs of the model are low and are financed from the hospital's budget based on the management's decision. Supervisor physicians and OnkoNetwork administrators working in the departments of the Centre were selected and appointed from the existing staff and have no financial compensation for their additional roles. OnkoNetwork Office administrators have a fixed monthly salary without performance or throughput based financial incentives. Interestingly, immaterial values of OnkoNetwork play an important role in the motivation of the contributing personnel.

There is no patient co-payment for OnkoNetwork services. Any change in informal co-payment of patients for healthcare services is not assessable.

3.9.2.4. Workforce

The establishment of new professional roles, the permanent allocation of responsible therapists to all enrolled patients, and multidisciplinary, quality assured collaboration of physicians across medical fields and institutions within the Hospital have been successfully achieved by OnkoNetwork. Continuous professional training and empowerment of informal caregivers are apparently out of the scope of the model.

3.9.2.5. Technologies and medical products

The two institutions belonging to the Centre use different medical IT systems, and the heterogeneous IT applications of the various service providers with unstandardized data structure further complicate the picture. A tailored IT software, OncoLogistic has been developed to support patient path monitoring and management as well as medical documentation in OnkoNetwork. Now all relevant pieces of medical documentation are collected and organized in a single web-based platform, easily accessible by the authorized users anywhere within the Centre. The rate of inconclusive Tumour Board sessions due to incomplete diagnostics or lost investigation results was perceived to be decreased upon the initiation of OnkoNetwork. Interoperability of the relevant IT systems is still incomplete and requires further development efforts. In the meantime, missing IT functionalities are replaced by human resources (manual searches and data transfers across IT systems).

OnkoNetwork did not change the use of ICT tools by patients, although from a technical point of view, OncoLogistic could be developed into that direction upon request.

3.9.2.6. Information and research

Patient-level clinical data is collected in OnkoNetwork in full details, allowing the necessary risk stratifications in future analyses. Beyond the standardized entry questionnaire on anamnesis, comorbidities, and medications, the whole data content of the medical systems for the relevant patients is accessible for OnkoNetwork administrators. Patients with individual risk factors e.g. cardiovascular comorbidities are identified and their diagnostics and treatments are personalized accordingly.

Regarding patient experience, indicators on timely and equal access to care are routinely monitored. Patient-level data is available for the evaluation of clinical outcomes, but the relatively short lifetime of the programme has not encouraged the management to conduct detailed clinical outcome analyses so far. Economic outcomes are not collected on the patient level.

3.9.2.7. Leadership and governance

The strong and respectful leadership fully committed to clearly defined goals are key facilitators of OnkoNetwork implementation and smooth operation. Responsibilities are clearly defined, and accountability is ensured through escalating levels of quality assurance referrals, from technical

clarifications to top management interventions. Timely access to quality-assured care is continuously monitored and deviations are regularly reported to the top management, together with their justifications.

Shared decision making of professionals has been enforced by OnkoNetwork, stating that the treatment can't be initiated before a multidisciplinary Tumour Board decision. The previous practice allowed a significantly larger room for surgeons. Participation of the patient in shared decision making is formalized in the diagnostic phase, requesting the signature of patient informed consent forms for all diagnostics. Tumour Board meetings are theoretically open for the patients but they attend it only in exceptional cases. Patients have the ultimate right to decide on accepting the treatment recommended by the Tumour Board, as long as they are not under psychiatric care or guardianship. The communication between healthcare professionals and informal caregivers is marginal.

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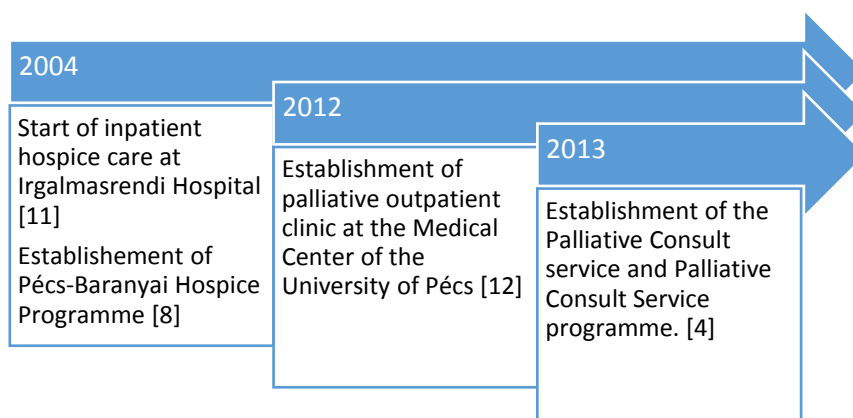
4. Programme 2: Palliative Care Consult Service

4.1. Basic information

4.1.1. General information on the programme

The second Hungarian integrated care programme selected for evaluation in SELFIE is the Palliative Care Consult Service (PCCS) programme at the Medical Centre of the University of Pécs. The programme integrates the palliative care and palliative philosophy in a tertiary care hospital and cancer centre. The palliative care around the Medical Centre in Pécs is organized in four main structures, including a home-based hospice-palliative care service, an inpatient hospice institution, an outpatient palliative care clinic and the consult service. The inpatient hospice care is organized by the Catholic Church (Irgalmasrendi Hospital), the home-based hospice-palliative service is provided by the Pécs-Baranyai Hospice Programme while the consult service and the outpatient palliative clinic are operating within the Medical Centre. The most recently established provider of palliative care in Pécs is the consult service, which started its operation in June 2013 (see Figure 7). The reason for creating this specialized team in an acute care hospital was to provide palliative care for in-patients and to assure the subsequent patient pathway after being discharged from the Medical Centre. Via the consult service the palliative care was integrated in the acute care. The collaboration and cooperation of the Medical Centre, the Hospice Programme and the inpatient hospice care aims to achieve a higher level of coordination and continuity in the process of palliative care.

Figure 7: The timeline of the establishment of the palliative care services in Pécs

2004
Start of inpatient hospice care at Irgalmasrendi Hospital [11]
Establishement of Pécs-Baranyai Hospice Programme [8]

2012
Establishment of palliative outpatient clinic at the Medical Center of the University of Pécs [12]

2013
Establishment of the Palliative Consult service and Palliative Consult Service programme. [4]

The geographical scope of the programme is twofold: 1) as a tertiary centre the Medical Centre attracts patients from the whole South Transdanubian Region (~ 950 thousand inhabitants) for inpatient care in a wide field of professions; 2) the home-based palliative and hospice care is focusing on county Baranya (~400 thousand inhabitants).

The programme is owned by the Medical Centre of the University of Pécs. In 2013 the initiative received EU grant from Social Renewal Operational Programme (TÁMOP 6.2.4 A-11/1-2012-0065) for setting up the palliative consult service [1]. Upon completion of the project (end of 2016) the EU requires the institution to employ the staff of the consult service for a minimum period of time equal with the length of the project implementation (approximately three-and-a-half years) [1].

Departments requesting consultation from PCCS are listed in Figure 8

Figure 8: Number of palliative consultations requested by departments, 2015
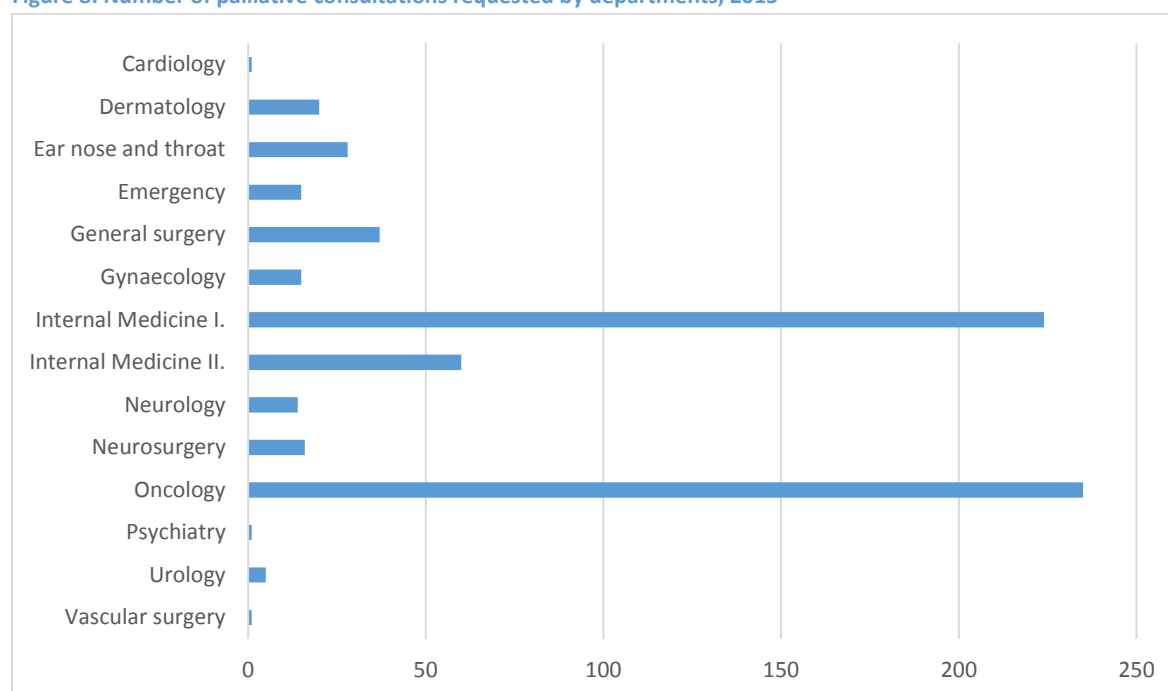
Palliative care services for seriously-ill patients in the programme are provided at the site of the hospital (ward or outpatient clinic) or at patients' home. The target group of the programme comprises patients in the advanced stage of incurable chronic diseases. Based on a regulation of the National Health Insurance Fund on improving complex homecare and institutional hospice services, 80% of the patients involved in care should be oncological patient (with the ICD code "C"). Regarding the other 20% seriously-ill patients with other chronic diseases (AIDS, autoimmune diseases, chronic neurological diseases except stroke, dementia or Alzheimer-disease) can be involved based on the decision of the institution [2]. At the Medical Centre the activity of the consult service focused mainly on patients with locally advanced or metastatic cancer. Currently the ratio of oncological patients is above 90%. It is expected that the proportion of patients with other chronic diseases (COPD, progressive neurodegenerative diseases) will increase, however this is not yet supported by the financial regulations [3] [IP04_2].

These patients mostly have multi-morbidity, although this is not an inclusion criteria to the programme. The descriptive documents of PCCS state that that several co-morbidities are present among seriously-ill

patients, although explicit definition for "multi-morbidity" is not given. As an example, it was highlighted that among oncology patients the cardiovascular, metabolic, respiratory and/or neurological diseases are frequent co-morbidities [4].

Following the basic principles of palliative care the PCCS programme intends to relieve pain and other physical and psychological sufferings to improve the quality of life of patients and their families facing the problem associated with life-threatening illness. To achieve this a multidisciplinary, team work approach is followed, as in an integral part of the philosophy of palliative care. Between 2013.06.01 and 2015.12.31, 462 patients received palliative care services from the team [4; 5] (see Table 6)

Table 6: Number of patients and consultations between 2013 and 2015 in the PCCS programme

Year	2013	2014	2015
Number of patients	84	431	406
Number of consultations	142	594	680

The aim of the programme is 1) providing professional service for seriously-ill (mainly cancer) patients and their families with the support of a specially qualified, interdisciplinary team, 2) providing professional, consultative support for health professionals within the hospital, 3) education and dissemination of the palliative approach across disciplines of the hospital, 4) develop protocols of palliative care within the hospital and create an adequate documentation system. A further goal of the initiative was to introduce the consult service approach as a new form of care in the Hungarian hospice-palliative care [6].

There are no formal definitions for "multi-morbidity", "integrated care", "person centeredness", or "self-management" in the documentation of PCCS. However, all these aspect evolve in the process of service delivery and are integral part of the philosophy of the PCCS programme.

4.1.2.   Sources

The current report is written based on documents provided by the programme and based on the interviews conducted with interviewees assigned by the programme manager. The palliative programme was selected for detailed evaluation by SELFIE consortium in the middle of April 2016. Since then there have been frequent discussions on phone and in person between Syreon SELFIE team and the contacts of the programme. The description of the project was not documented sufficiently to gain detailed information on the concepts and themes derived from the SELFIE framework. Therefore the report was primarily built on the information retrieved from the interviews. The numbers and figures were formed based on the data obtained from the hospital information system and handed over by the managers of the programme.

Documents

The documents used for the document analysis can be found in the references section.

Interviews

To get a comprehensive and detailed insight on the Palliative Care Consult Service programme, 15 interviews were conducted, including managers and initiators of the programme, hospital finance manager, physicians, nurses, coordinators, psychologist, informal caregivers and patients. For the listing of interview partner IDs, stakeholder groups and interview dates, please see Appendix 1. All the interviews were transcribed. The transcriptions were reviewed by one-one researcher of the SELFIE team at Syreon and then sections were chosen for further analysis. For each selected unit a paraphrasing was carried out and then translated into English in a shorter form. Every such entity was put into one or more categories predefined by the SELFIE consortium (T2 to T8 and TS). The report was built through the interpretation and narrative description of these short forms.

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4.2. Service delivery

4.2.1. Design of delivery of care

The coverage of specialist palliative care services such as hospital consult services are very poor in Central and Eastern European countries. The European Association for Palliative Care White Paper recommends to have one home care team per 100,000 inhabitants, one hospital support team per 200,000 inhabitants and one inpatient palliative care service per 200,000 inhabitants. Based on a report

of the European Association for Palliative Care Task Force [7] the coverage for hospital support team is the lowest compared to special palliative care services in Hungary (see Table 7).

Table 7: Coverage of specialist palliative care services in Western Europe, Central and Eastern Europe and Hungary in 2012 [7]

Service	Western Europe	Central and Eastern Europe	Hungary	Recommended ratio	*Coverage of Hungary*
	services per 100,000 inhabitants			service/100,000 inhabitants	*detected/needed services %*
Home care team	0,4	0,21	0,69	1	*69%*
Inpatient palliative care unit	0,35	0,14	0,13	0,5	*26%*
Consult services*	0,3	0,08	0,03	0,5	*6%*

named in the study as hospital support team

The number of the hospital palliative care support teams in 2015 was 4 [8]. Three of these services are run by Pécs-Baranyai Hospice Programme independently form hospitals. The only team working integrated in an acute inpatient hospital is the Palliative Care Consulting Service at the Medical Centre of the University of Pécs. With its 28 clinical departments, 1545 beds and 88,000 inpatients treated annually the Medical Centre of the University of Pécs is one of the largest healthcare providers in the country.

4.2.1.1. Care process, working of the programme in practice

Patient care is provided by a dedicated, trained and interdisciplinary team which is in close collaboration with other professionals from the hospital. The consult service has 2 physicians, 1 psychologist and 1 palliative nurse coordinator [IP02_2]. The function of the team is to react quickly on patients' needs, therefore palliative nurse coordinator specialist is available for face-to-face consultations at any of the 28 clinical departments between 8:00– 16:00, five days each week and answers the hotline during the weekends [9].

The process of palliative care consultation services is presented in Figure 9.

Figure 9: The process of palliative care within the acute care hospital

Requesting consultation → Introductory assessment → Treatment plan → Organization of further care → Follow-up

4.2.1.2. Requesting consultation

The team is available upon request for consultations. The request can only be submitted by physicians of the relevant department. Health professionals working at the bedside have a more direct contact with the patients and the family members therefore the need for palliative care is often detected by a nurse and indicated for the physician on the ward [IP02_2]. An electronic request has to be recorded in the hospital information system (eMedSolution system). The reason for requesting consultation has to be selected in the system which can be 1) managing home-based hospice-palliative care for the patient, 2) transferring the patient to another hospice institute 3) start the palliative care at the ward: psychosocial support, mental care, pain relief or other symptom management [10] (Figure 10).

Figure 10: Reasons for referral, 2013 and 2014, N=515
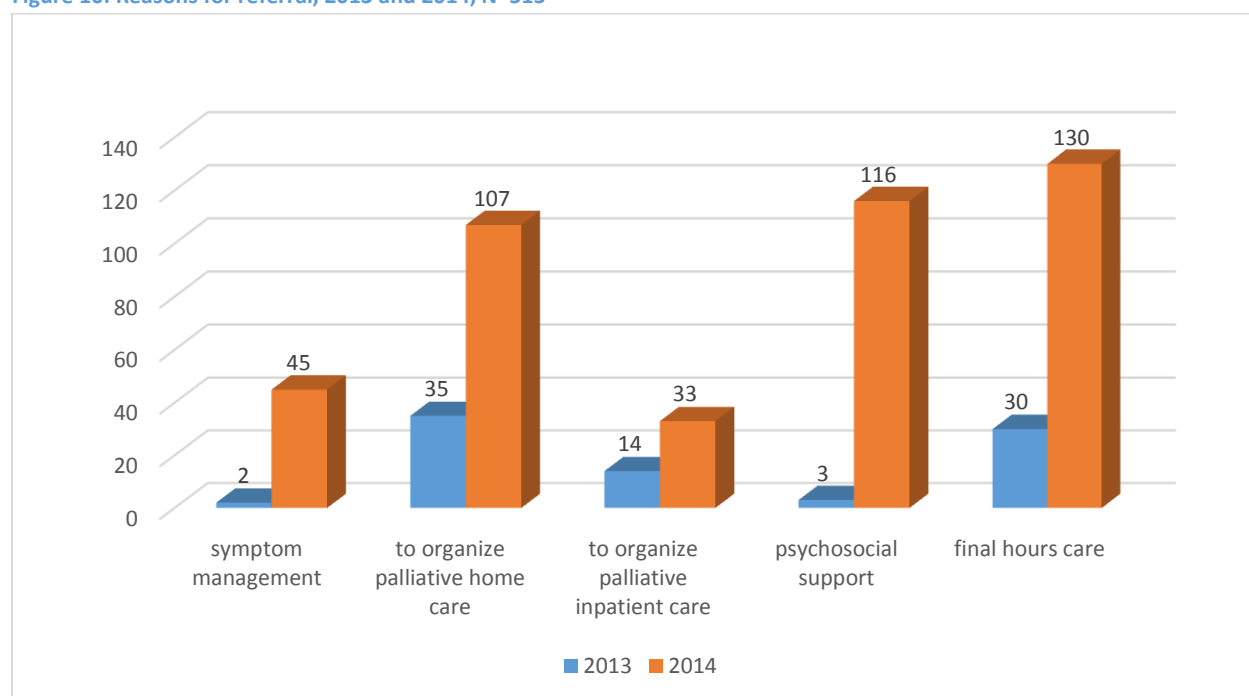
Based on the statistics a significant proportion of the requests relate to managing the transfer of the patients to home care or institutional hospice care [10]. Most of the requests within the hospital come from internal medicine, oncology, dermatology, neurology and ear-nose-and-throat department. However there is an increasing number of referrals from the emergency department. Many patients who were discharged from active treatment to get best supportive care re-enter the Medical Centre through the emergency department and require symptomatic treatment [IP10_2].

4.2.1.3. Introductory assessment

After receiving the request the coordinator of the consult service visits the related hospital department within 24 hours, but mainly on the same day. The coordinator assesses the patient's status and needs.

The medical and social assessment is carried out on the basis of interviews with the patient and family members, reviewing available medical records, consultation with other specialist physician and diagnostic tests [IP04_2]. The assessment includes documentation regarding the state of the disease (including the diagnosis and prognosis), physical and mental status of the patient, pain, other symptoms, as well as the performance status and social, spiritual and cultural aspects, including the preferences regarding the treatment plan [IP04_2]. Information on the patient's status is continually shared with the patient, and involvement of the patient in the treatment and nursing process occurs according to the patient's wishes [IP04_2].

4.2.1.4. Creating a treatment plan

The coordinator of the consult service organizes the involvement of further professionals in the decision making or in providing care according to the patients' demands. Pain management is generally performed by physicians of the relevant departments, although sometimes it is ineffective [IP06_2]. In other cases specialist concentrate on active treatment and management of physical and psychosomatic symptoms are not in their focus [IP05_2]. In the event of a need for pain relief or management of other obsessive symptoms (e.g. nausea), the coordinator involves the palliative physician in the process. The physician considers the expectations of the patient and their family members as regards the aims of the care, the extent to which they managed to understand the disease and its prognosis, the type of care and the place where it is to be provided. The physician also consults with other specialists (e.g. oncologist) if needed to create a comprehensive, personalized treatment plan considering the needs of the patient and the family members [IP02_2].

In case of a need for psychosocial support, the psychologist member of the team is involved in the care process, who assesses the mental status of the patient and take a shared decision with the patients (or with the family member if needed) on the course of the psychosocial support [IP05_2]. The psychologist supports the patient to manage anxiety and clinical depression if it arises in end-of-life matters, as well as other mental health problems associated with serious illness. Psychosocial support is requested dominantly for patients at the oncology department [IP05_2]. The coordinator can also request support from the hospital's dietetics, physiotherapists or social workers if required [IP04_2].

The focus of the services is mainly defined according to the need of patients and family members, therefore, decisions are made by directly involving them. In these terms the patient's goals dominate over aggressive treatment aims and patients may refuse demanding therapies in advanced stage. The services provided by the team concentrate on the individual's preferences, emphasizing a holistic and long term concept of care. The focus is on the quality of life in the remaining time period. [4]

4.2.1.5. Organization of further care

The coordinator keeps contact with the patients and the family members. He frequently (3-5 days a week) follows-up on the patient needs during their stay at the Medical Centre [IP11_2]. He facilitates

the shared decision-making with patients and family members on the further care at home or at a hospice inpatient institution. The decision is supported by further assessment of the patient's environment at home, social and financial capabilities, the availability of family members, informal caregivers to participate in the care etc. [IP04_2]. It is the task of the coordinator to communicate with the host service providers on the treatment plan (e.g. pain relief) to ensure continuity in in care. The coordinator registers the palliative activities and procedures performed in the interest of the patient [IP04_2] and he also plays an important role in education within the institution and raising awareness towards palliative care [IP04_2].

4.2.1.6. Follow-up on patients

The patients discharged from the Medical Centre are mainly followed-up by the general practitioners [IP06_2]. Nevertheless, PCCS programme created several channels for maintaining the continuity of care for patients with palliative service needs. Patients with relatively good conditions are followed by the outpatient palliative clinic, where the pain and other symptoms are assessed and general status of the patients are measured, and the treatment plan of the patient is adjusted if needed [IP06_2]. The psychosocial support of the patients could be started in the hospital and continued in their home. The psychologist of the palliative consult service is employed by the Medical Centre and also has an assignment from the Pécs-Baranya Hospice Programme, this way she can manage the patient both at the hospital and in the home-base hospice care as well [IP05_2]. The physicians of the palliative consult service have a strong cooperation with the home-based hospice care. They visit patients upon the request of the home care coordinator (e.g. to update on the pain management) [IP06_2]. An important benefit of the programme is that the patients and the family members have the opportunity to contact someone after the inpatient care, so continuity of care is ensured also from their perspective [IP05_2].

4.2.1.7. Continuity of care

Continuity of care is ensured through referring the patient directly from the acute hospital to the home-based hospice-palliative care. The strong cooperation between the palliative team and home hospice care is primarily ensured through the overlap in the personnel of the two providers. All four members of the palliative consult service and the physician of the outpatient clinic work in the home hospice-palliative care as well [IP05_2, IP06_2, IP04_2]

To provide a harmonized care process for the patients, the palliative consult service plays a coordinative role in managing the patients' pathway from acute care towards home-care or institutional hospice care. In this role the members of the team communicate with the following providers [4; IP04_2]:

- clinical departments
- dietetics, physiotherapist, social worker of the hospital
- outpatient palliative clinic
- home hospice-palliative care

- inpatient hospice
- general practitioners
- social care institute
- social home care

A weakness of the current system is that the documentation cannot be followed electronically across providers. There is no connection between the electronic health records of the providers (e.g. between medical centre, inpatient hospice, GPs) or data is only available on paper (e.g. in homecare), therefore currently no IT support can be used to facilitate a continuity of care [IP04_2].

4.2.1.8. Coordination of care

There is a daily interaction among the members of the consult service, mainly on the phone. More complex cases are always discussed personally. The leader of the team is a palliative physician who coordinates the cooperation within the group and is charge of consulting with the physicians on the clinical departments and with the management of the Medical Centre [IP02_2].

The needs specified by the different clinical departments regarding palliative care was taken into account when the service mix of the consult service was developed. Therefore there is a congruent cooperation among the team and the clinical departments. However, the collaboration with and the referral to the services is highly dependent on the person of the physician [IP02_2]. At the Medical Centre of Pécs, the younger physicians show more interest and have higher demand on the activities of palliative physicians regarding the management of pain or nausea. This may be due to the educational activity of the Palliative Department [IP06_2, IP02_2]. In many cases, the contact of the team is the head nurse who officially initiates the request through a physician at the department [IP02_2]. The treatment plan determined for the patient is recorded in the hospital information system, further feedback to the physicians is provided upon request [IP06_2].

4.2.1.9. Involvement of informal caregivers

Families of patients receiving palliative care are deeply affected by the challenges of the illness. They witness the care that the patient receives and also provide care for the patient themselves. Therefore it is an important approach of the palliative care to involve family members in the decision making and consider their needs as well [IP02_2]. The palliative consult service has an impact on the view of how family members perceive the tasks regarding the treatment or safety monitoring of patients [IP11_2].

In supporting the decision of the patient and family members, close communication is key. The initial reluctance regarding home care, or the inadequate recognition of the situation is often resolved through the effective communication of the team. Subsequently this is confirmed by the informal caregivers as well [IP11_2]. Family members receive support from the palliative consult service in the form of

information, counselling, or practical assistance (e.g. adequate use of percutaneous endoscopic gastrostomy) [IP11_2].

4.2.2. Self-management interventions

There were no direct references regarding self-management interventions in the documents we received regarding the PCCS programme. However, during the interviews we revealed that support and education of patients and family members on how to manage medical aspects of illness, how to manage life roles and how to adapt to the changing conditions brought on by the progression of the illness are core elements of the PCCS model care.

The PCCS programme encourages the patients to take care of themselves to the extent of their capabilities and strength and to require additional help only when it is needed. Besides the health professionals of the hospital the psychosocial support of the team assists the patient in maintaining this approach [IP14_2].

The self-management interventions concerning the medical aspects of care involve the followings:

- The patient receives appropriate information and has the **ultimate right to decide on his/her care, the patient's autonomy is respected**. In the Hungarian context this model can be regarded as patient oriented.
- The palliative consult service gives education to the patients and the informal caregivers **on nursing activities** such as
  - cleaning the feeding tube [IP10_2],
  - drainage of secretions from the bronchi [IP10_2, see quotation Q1],
  - putting on bandage [IP08_2],
  - Anticoagulant injection [IP14_2, see quotation Q2],
  - adequate use of percutaneous endoscopic gastrostomy - PEG [IP11_2],
  - ostomy replacement [IP07_2]
  - bed-sore prevention and positioning [IP14_2]
- Patient education related to **proper diet** (e.g. to avoid constipation), consultation in matters of food intake are also an important element in supporting self-management. This may lead to improved outcomes such as reducing cost of medication, alleviating or preventing pain and other symptoms.
- In order patients do not let themselves go, they have to feel that they can **manage the daily activities**. During their recurrent visits the palliative team members assure patient to keep up doing everyday activities such as taking a walk or doing the shopping (once discharged to his home). The ongoing encouragement supports maintaining the self-management of the patient. [IP14_2, IP11_2]
- The psychologist of the team provides the patient resources and tools to be able to better **cope with the concerns** of the disease progression. [IP11_2, see quotation Q3]

Education related to self-management interventions is provided by the hospital department, which are complemented by the activities of the palliative consult service and home hospice care [IP09_2]. In case of more complex self-management tasks, longer educational period is required. Example: ostomy provision or wound care where both the active healthcare staff and homecare specialists are involved. Example: procurement of tools or appliances related to ostomy provision, or procurement of bandage. The homecare also needs to monitor self-management activities. Example: if the wound is properly managed [IP14_2].

The acceptance of self-management interventions by the patients and family members are heavily influenced by the supportive communication of the consult service [IP02_2]. The self-management interventions can have a significant influence on health outcomes and costs.

1) For example, appropriate usage of percutaneous endoscopic gastrostomy (PEG) can prevent using antibiotics, requirement for other PEG, low nutrition, or even hospitalization [IP11_2].
2) The patient-education regarding the adequate diet (e.g. to avoid constipation) leads to improved outcomes such as reducing cost of medication, alleviating or preventing pain and other symptoms [IP02_2].
3) The daily activities of the patient may result in improved quality of life, or even avoided complications such as pressure sore or pneumonia, which can save cost for the patient and the healthcare system [IP14_2, interview quotation Q4]

We found that self-management interventions are essential elements of palliative care at the Medical Centre. To support this finding we selected some interview parts to give an insight on how stakeholders of the programme relate to self-management methods. Although the approach is applied in providing care, these activities are not formalized in the PCCS programme.

Quotations:

Q1: „Personally I only see their work from outside, but I do think that they are active in supporting patients through education and teaching them activities which can be done by the patients themselves. For example if patients have a feeding tube they have to learn how to maintain and clean it in order to prevent congestion or blocking. Obviously patients are informed about these during the feeding tube placement, but it is important to repeat these information and discuss the experience of patients about the usage. For example I have seen patients with muscle weakness who were not able to withdraw their own secretions, but they were able to drain it with this device. In these cases the patient education is very important. "[IP10_2, physician]

Q2: „There are patients who are not capable of handling or do not want to do their injection at home by themselves. In these cases the team members and another homecare providers have to do this task every time as well. However, majority of the people and their family members can be educated for the appropriate use of injections and can be informed about how to pay attention for this process. For

example if a specialized nurse needs to visit the patient for this purpose twice a day, he/she can show, practice and then supervise the family member on how to do the injection. If he/she sees that the process is appropriate and safe without support, the nurse can be relieved from this task." [IP14_2, non-physician]

Q3: „Personally I only see the patients when they return for visit, I do not visit them in their home. However, when patients return here we do see that they can accept their conditions and they can manage some activities of their own disease. For example laryngeal cannula, it is not enough to teach patients how to do the cleaning of the laryngeal cannula because they also need constant encouragement and permanent support. To be honest this activity is hard to be accepted even by nurses. This is even more difficult with a person who is not used to these kind of activities. If they are supported in these, they can accept their own condition better because with an appropriately cleaned cannula they can breathe normally, there are no retained secretions, pneumonia can be prevented. Without appropriate cleaning of the cannula there can be some serious consequences such as complications, pneumonia and progression of the disease. These things are easily comparable among those who receives such support and those who do not." [IP11_2, non-physician]

Q4: „I think the Palliative Mobil Team is capable of providing psychological support to the patients during their visit. They will not say to the patients in very bad conditions that they should stay in bed, but rather they can facilitate conversations and encourage them to try to be as active as possible. For example they can convince them to go down to the grocery store and buy some bread even if they feel very week. These are small tricks which are useful to motivate patients to maintain their self-management activities and to not feel left alone. These may result in better quality of life for their remaining period by preventing bedsores (pressure sores), pneumonia etc." [IP14_2, non-physician]

4.3. Leadership & governance

The PCCS programme serves a bridge between the clinical departments, home-based hospice-palliative care, institutional hospice care and home-based social care. One of the main goals of the PCCS is to organize the pathway of the patient across the different providers by considering patients' needs and personal goals. Therefore the communication with the different providers is one of the main activities of the coordinator of the team. Based on the received documents we could not identify any formalized agreements regarding the cooperation with other service providers, however in the interviews we gained an insight on the existing relationships and how they work in practice.

The relationships of the PCCS programme with other departments and partners are presented in Figure 11.

Figure 11: Relationship of PCCS regarding palliative care
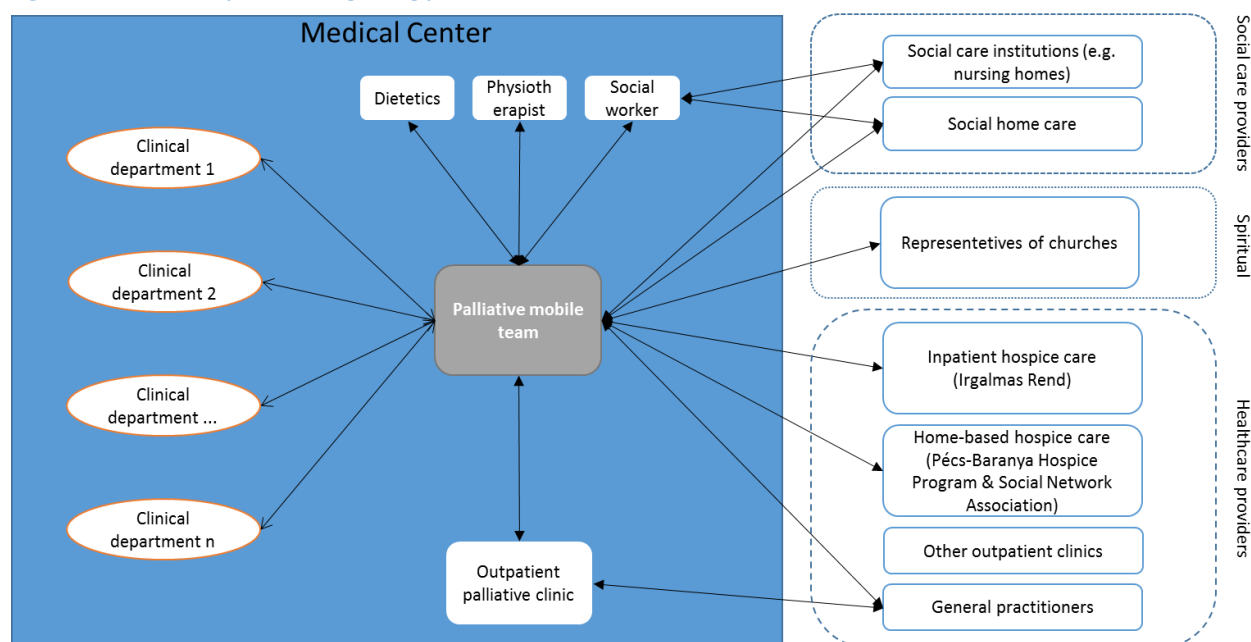
4.3.1. Relationship within the institution

The palliative consult service has a regular contact with clinical departments, dieticians, physiotherapists during the palliative care process within the institution [IP02_2]. Based on the opinion of a palliative physician at the Medical Centre it took some time to develop trust towards the activities of the palliative consult service and to harmonize the principles of the care process, but the confidence in the services provided by the team could be established through regular consultations and the feedback from patients and family members. [IP13_2] The cooperation within the institution is detailed in chapter 4.2.1. Design of delivery of care.

4.3.2. Relationship outside the institution

The holistic assessment of the patient discloses if any social support is needed. In these cases the palliative consult service involves social workers in the process to organize further social care for the patient, either in a social care institution or at home, depending on the patients' needs [IP14_2]. The services of the social care providers relate to the everyday activities of the patient such as support in shopping, cleaning, catering, filling in prescriptions etc. [IP04_2]

There is also a strong collaboration with the churches. According to the belief of the individual patient, the palliative team facilitates the spiritual guidance of patients by involving representatives of the relevant churches (e.g. confession or administering the last sacrament by the catholic church) [IP13_2].

The palliative consult service's most improved collaboration outside the Medical Centre is with the home-based hospice-palliative care. The cooperation is primarily ensured by the personal overlap between the providers. The human resources of the Pécs-Baranya Hospice Programme rely on the healthcare workers within the hospital (as described in chapter 4.2.1. Design of delivery of care) [IP06_2]. Continuity of care is ensured as patients are referred to homecare directly by the consult service [IP08_2]. When patient are transferred from the inpatient institution to homecare or to another facility, the palliative care team will hand over all information to the team who will be providing subsequent care. The communication is however two-way, implicating that professionals of the home-based care indicate the consult service if a patient with the need of palliative care is re-admitted to the hospital [IP02_2]. In specific cases palliative patients are sometimes referred to other outpatient clinics operating outside the Medical Centre as well [IP02_2].

The cooperation with the general practitioners is key in the effective pathway management of palliative patients [IP06_2, IP02_2]. To facilitate this the palliative team members provide a certified training for GPs on the eligibility for palliative care, communication, documentation etc. The education contributes to the adequate distinction of the competencies between the GPs and palliative care specialists, resulting the patients with specifically palliative needs will be referred by GPs to the tertiary hospital [IP06_2].

4.4. Workforce

Regarding the palliative care Consult Service three new professional roles have been created to support the delivery of palliative care in the programme. The palliative coordinator is an established new profession dedicated to the operation of the consult service. The palliative physician and the psychologist also play a new role in their old professions, tailored to the needs of the palliative care Consult Service [IP02_2]. The core task, rights and duties of the new professional roles were defined by adapting international experiences adjusted to the local conditions [IP02_2]. The activities of the palliative physician and the psychologist can be considered innovative in Hungary because they provide palliative care within an in-patient care setting, which was not performed previously in the Hungarian healthcare system [IP06_2]

4.4.1. Palliative physician

The aim of the palliative physician's activity is to relieve pain and treat other specific symptoms of the patient. The palliative physician sets up a comprehensive, personalized treatment plan considering the needs and goals of the patient and the family members [IP02_2]. If necessary, the physician initiates further consultations with other specialists (e.g. oncologist). It is also the role of the leading physician to give an orientation to the team in the organizational structure of the healthcare provider regarding palliative care and to perform proactive cooperation on developing it.

Special license is required to provide the activities of a palliative physician. Currently such licence does not give permission to prescribe specific palliation-related medication or dietary supplement with discounts [IP06_2]. The licence can be obtained by accomplishing a 1-year training in the area of palliative medicine and pain treatment.

4.4.2. Psychologist

In the Hungarian healthcare system the activities of psychologist are usually performed outside of inpatient care providers. The psychological support within Palliative Care Consult Service is therefore an innovative approach of the programme [IP05_2]. The psychologist member of the team is involved in the care process in case there is a need for psychosocial support at the ward. The psychologist assesses the psychological and emotional status of the patient and decides together with patients (or with the family member if needed) on the course of the psychosocial support [IP05_2]. The psychologist supports the patients to overcome anxiety and clinical depression if it arises in end-of-life matters, as well as other mental health problems associated with serious illness.

The psychologists who operate as part of the palliative consult service have to have degree in psychology, otherwise no other specific requirements are needed regarding qualification. However experience in the field of psychosocial support for people with serious disease is expected [IP05_2].

4.4.3. Coordinator

The coordinator of the consult service manages the interdisciplinary cooperation and organizes the involvement of further professionals in the decision making or in providing care. The coordinator has a pivotal role in the programme because he keeps contact with the patients and the family members and exchanges information with other members of the team and with team management. He facilitates the shared decision-making with patients and family members on the further care at home or at a hospice inpatient institution. It is also the task of the coordinator to communicate share with host provider all the relevant information on the treatment plan [IP04_2].

The coordinator's duty is to properly keep the medical records on the palliative activities to gather data and compile comprehensive statistics on the procedures of care [IP04_2], [5]. The coordinator also plays an important role in education within the institution and raising awareness towards palliative care [IP04_2].

A professional training with a special focus on palliative-hospice care and managing patient pathway is required to being involved in the palliative consult service as a palliative nurse or coordinator. [IP04_2] The training also covers the aspects of managing multi-morbidity in case of cancer patients. [IP04_2]

Based on the interviews we explored some challenges and difficulties related to the situation of the professionals working in the team.

- Over a longer term there is a risk of burnout among team members due to the limited human resources available set against an increasing number of patients. Improving the number of professionals is therefore important, however the financial support has to be established [IP12_2]
- In the field of palliative care, the salary of physicians is very low. The activity of the palliative physicians is motivated mainly by personal beliefs and attitudes [IP13_2].
- There is a general shortage of physicians in Hungary. The focus of health politicians is not primarily on improving the situation of palliative physicians, therefore no essential changes can be expected in the near future. [IP13_2]
- In general, the Hungarian patient population still has a reluctant attitude towards the psychological support, which makes the acceptance of the psychologists difficult. [IP05_2]

4.5. Technologies & medical products

The improvement and enhanced use of information and communication technology (ICT) systems were not in the focus of the PCCS programme [IP01_2]. There was a development performed in the hospital information system (eMedSolution) used at the Medical Centre to support the palliative care process within the institution [IP04_2]. This special platform is used by the physicians to request consultation and to keep record of the electronic documentation [IP10_2].

The system contains information on the reason of requested consultations, recommendations and information related to further care process of the patient (e.g. information for the GP) [IP04_2].

Electronic documentation also includes specific information on 1) the patients' ability to self-care and 2) the level and type of pain on a specific symptoms scale [IP04_2].

The IT system within the hospital is capable of recording and keeping track of the patient's medical records [IP14_2], while the home-based hospice care has only paper-based documentation. This is not efficient because patients sometimes loose the papers or do not take them to the GPs or to the hospital in case of readmission [IP06_2]. A deficiency of the current system is that the documentation cannot be followed electronically across the providers, therefore currently no IT support can be used to facilitate a continuity of care [IP04_2]. After transferring patients to another care provider (e.g. homecare, hospice) the follow-up of patients is delivered through phone and personal visits (as described in chapter 4.2.1. Design of delivery of care) [IP04_2].

Based on the interviews we found that there are future plans on better utilizing the ICT tools in the care process.

- For example a new nursing information system will be introduced in the hospital, which will contain information on the psychological condition, on the status of wounds, ability for self-care and other aspects that could be important for homecare [IP14_2].

- The manager of the programme suggested several innovations related to palliative care, which could be introduced in the future: interventions indicated based on remote monitoring of the patient, assessment of the patients based on measurements and tests performed in patients at home, e-Health or mobile-health applications [IP12_2].
- From the perspective of informal caregivers such as family members, there could be some special needs in communication, for example video-based consultation or sharing pictures (e.g. on the condition of the ostomy). In these cases the physicians could have a better follow-up of the patient [IP07_2].

The need for supportive ICT applications was defined by informal caregivers, suggesting that these could be used by the younger generation of family members [IP07_2]. However there are many patients who do not have computers or smart phones therefore the implementation of IT applications have serious limitations [IP09_2].

In conclusion, it remains a challenge for ICT interventions to be fully understood and supported by the public as well as by the key decision makers. The document analysis and the interviews show that the possibilities of ICT applications are not exploited sufficiently. This needs to be addressed by the programme accordingly. Further research is needed to investigate the role of ICT in palliative care in Hungary and how ICT intervention could improve quality of care for patients.

4.6.   Information & research/monitoring

The PCCS programme regularly performs retrospective, anonymous analyses on the palliative consult service's activity. These analyses include the following dataset:

- **Number of consultations** requested by clinical departments
- **Reasons for referral**: symptom management, organization of palliative home care, organization of palliative inpatient care, psychosocial support, exitus care
- **Time-data on entering and leaving the palliative care process**: average time between admission and consultation referral, average time between consultation and transfer to home-care, average time between consultation and transfer on inpatient hospice-care, average time of patient's death within the Medical Centre after consultation
- **Leading symptoms at enrolment**: pain, cachexia, dyspnoea, confusion, exsiccation, bleeding, constipation/diarrhoea, nausea/vomiting [10]

Although there has been no quality assurance system established within the programme, the members of the team (lead physician and coordinator) take effort to publicize the indicators of their activity. The data of the analyses are compared to previous year's results and the information are presented at the

internal meetings of clinical directors and head nurses, where the challenges and opportunities for further improvements are discussed.

An important conclusions derived base on the evaluation of the PCCS programme's operation between 2013 and 2015 was that on one side the increasing number of referrals prove the success of the programme [IP02_2], however the activity of the palliative consult service is not known entirely within the institution therefore the need for palliative care is not covered completely within the Medical Centre [IP14_2].

A formalized evaluation taking into account the three dimensions of the Triple Aim model (health outcomes, cost and utilization of services, experience of care) is not carried out. There are informal ways of giving feedback on the satisfaction with care, for example in newspaper articles or in other natural ways of acknowledgements given by the patients or the family members. However these are difficult to be used for the promotion of the project [IP13_2]. The PCCS programme in Pécs can be considered as a pilot for the country. Based on the experiences here, a formalized functional model could be developed which gives the appropriate legal framework for the activities. Therefore, a formalized evaluation is demanded where the relevant outcomes are measured objectively.

4.6.1. *Influence of service delivery on health outcomes and satisfaction*

Based on the interviews conducted with the stakeholders of the programme, several aspects have been identified on how the service delivery of Palliative Care Consult Service influence the health outcomes, satisfaction and costs, as summarized in Table 8.

Table 8: Assumed influence of Palliative Care Consult Service programme on health outcomes, satisfaction and costs.

	Health
Patient	Improved the quality of life of patients, due to receiving more attention and care
	Improved spiritual and physical status, due to psychosocial support
	Improved capability of coping with fears, due to psychosocial support
	Improved quality of life in the daily activities, due to psychosocial support
	Improved quality of life due to effective management of the symptoms
	Maintaining dignity, due to effective symptoms management
	Feeling more safe despite being discharged from the hospital, overcome insecurity and feel less stressful, due to providing continuous care
Family member	Decreased anxiety of the family members, due to continuity of care
	Improved quality of life, decreased burden for the family members, due to referral of patient to home-based hospice care
	Experience
Patient	Improved confidence in knowledge and skills of professionals, due to psychosocial support
	Satisfaction with care, due to shared decision-making on treatment plan
	Satisfaction with care, due to named coordinator and continuity of care
	Satisfaction with care, due to timely access to publicly financed psychosocial support or dietetics consultation
Family member	Improved trust in knowledge and skills of professionals due to effective communication
Employees	Decreased workload due to the shorter length of stay and lower number of re-hospitalizations and visits at the emergency department
	Cost
Healthcare Payer	Decreased number of re-hospitalizations and visits at the emergency department, due to the managed pathway of the palliative patients
Healthcare Payer, Inpatient care Provider	Shorter length of stay, due to the managed pathway of the patient
Healthcare Payer	Decreased cost of treating complications (re-hospitalization), due to the education of the patient and informal caregiver (e.g. adequate use of percutaneous endoscopic gastrostomy or lifestyle counselling)

Some measurements are already performed in the care process. Pain is assessed by the palliative consult service during the introductory assessment of the patient and during the follow-up visits. The outpatient palliative clinic measures the pain at every visit and follows-up on the changes. Some of the

clinical department (e.g. General Surgery) assess the pain level regularly, for example at the General Surgery pain level is recorded in every 12 hours within the hospital during the stay including patients with palliative care need [IP14_2]. Every clinical department has an internally approved satisfaction survey filled out by the patients at the time of discharge. However this is a generic survey not focusing on the aspects of palliative care.

It was recognized by the management of the programme and the members of the team that an appropriate evaluation of the effects and outcomes have to be carried out and the experiences have to be summarized in a more scientific approach [IP02_2]. Therefore several recommendations were made on aspects and content of measurements.

Recommendations made by the manager of the programme on potential outcome indicators [IP12_2]:

- Health outcomes: Quality of life (generic and specific questionnaires) in an observational study;
- Economic outcomes: length of hospital stay, bed occupancy, treatment costs, drug utilization;
- Satisfaction: patient's satisfaction with care; satisfaction of healthcare workers.

Recommendations made by the initiator of the programme on the evaluation of care provided by PCCS [IP02_2]:

- Heath outcomes: measuring better general condition of the patients, decreased pain level, effects of better sleeping and better eating (Potential instruments: Edmonton Symptom Assessment System – ESAS, Palliative Care Outcome Scale – POS);
- Patients' satisfaction measurement;
- Satisfaction of the clinical departments (it can ease the burden of hospital departments by reducing their workload and reducing length of stay);
- Cost-effectiveness

Recommendations made by the psychologist on measuring changes in the psychosocial condition of the patient [IP05_2]:

- Anxiety or depression test quiz before and after the psychosocial treatment course
- Conducting qualitative interviews with the patients on the effect of the treatment

In conclusion, the current assessments of the PCCS programme relate to the operation of the programme and less to the effects on health, costs or experience. The management of the programme is aware of the importance of enhancing the evaluation methods in order to promote the results towards decision-makers and other potential providers. Therefore a joint thinking has begun with the PCCS a programme and Hungarian SELFIE team to explore and discuss various options for outcome measurements in three major areas: health outcomes, patient experience, and economic aspects of the palliative consult service.

4.7.   Financing

Palliative care within acute hospital settings is a relatively new form of care in Hungary. The regulations regarding the formal authorization of the operation of palliative consult service are already established and the necessary permissions are issued by the Office of the Chief Medical Officer. The authorization is a prerequisite for reimbursement agreements, however no contract could be signed between National Healthcare Fund and the hospital regarding financing palliative consult service, because current financial regulations do not acknowledge this dedicated form of care. Therefore legislation is currently ambiguous [IP03_2].

4.7.1.   Financing mechanism

Despite the lack of reimbursement from the National Healthcare Fund, the PCCS programme could be funded from different sources. The focus of the current report is on the PCCS programme coordinating care between clinical departments, outpatient clinics and homecare, therefore we included these providers in presenting the financial mechanism of funding palliative care.

Inpatients in Hungary are reimbursed through DRGs, therefore a specific amount of reimbursement can be assigned to every patient visited by the palliative consult service in the hospital. The value of the DRG has to cover all cost of treatment and operation, therefore it includes not only the cost of medicines, labour cost, hotel services but also have to cover diagnostics, internal consultations and overheads as well.

All palliative care services provided by the consult service are regarded by the management as internal consultations for inpatients. Therefore, a cross-financing method the so called "endo-financing" system was established to transfer DRG revenue from clinical departments to the palliative consult service. The basis for the monthly settlement is the number of services provided by the team multiplied by the fee of the services. Dietetics and physiotherapist's inpatient services are financed with an identical method.

The names and values of codes used by the palliative consult service are shown in Table Table 9.

Table 9: Codes used to record palliative activity by PCCS programme

Code	Name of service
11041	Consultation
11301	Control visit
81924	Wound care, bandage exchange
81926	Changing wound dressing
81929	Infected wound care, bandaging
89442	Pulse oximetry
91311	Dietetic education of chronic patient
93602	Psychological test filling
96004	Supportive sociotherapy

The code list is managed on a national level by the Department of Health. Revision of the list and the assigned fees are performed infrequently, therefore the number of codes is limited and their values are outdated. Unfortunately the available codes only cover about 60-70 % of all activities performed by the team [IP03_2]. Based on a comparison made with UK financial procedure code list, the financial management of the Medical Centre found that about 20 procedures are missing from the Hungarian system in total (e.g. recording symptom questionnaire) [IP03_2 and IP06_2].

The financial mechanism for funding the operation of PCCS programme is presented in Table 10.

Table 10: Financial mechanism

Payer(s)	Mechanism*	Provider(s)	Details of payment mechanisms (classified according to Quinn 2015)
National Healthcare Fund		Clinical department	Per episode – DRG system for hospital inpatient reimbursement (retrospectively)
Clinical department		Palliative consult service	1) Per service – fee-for-service based on International Classification of Health Interventions, internal cross-financing between clinical departments and palliative consult service (retrospectively) 2) Per time period – the monthly wages of two members of PCCS are financed by EU grant (prospectively) 3) Per time period – monthly lump sum for operational costs of the team (prospectively)
EU grant		Outpatient palliative clinic (oncology clinic)	Per service – fee-for-service based on International Classification of Health Interventions (retrospectively)
University of Pécs (other budget)		Home-based hospice palliative care	Per service – fee-for-service based on number of visits (retrospectively)

*Green line: payment per episode; blue line: payment per service; red line: payment per period

Based on the interview with a representative of a clinical department, we learned that even though the hospital department finances the request for palliative consultation, this has no influence on the frequency or the number of requests. The appropriate care and the future placement of the patient is more important than the financial considerations [IP14_2]

The other source of financing the operation of the consult service is the EU grant [TÁMOP 6.2.4 A-11/1-2012-0065], which pays for the wages of the coordinator and the psychologist in the team. Since the cost of the operation is not covered entirely through "endo-financing" and EU grants, the Medical Centre subsidizes the operation from other sources of the annual budget [IP02_2].

The Medical Centre has a financial agreement for the reimbursement of the outpatient palliative clinic, which this way is in a more sustainable situation, although the lack of the necessary codes and the insufficient value of fees does not allow the complete coverage of all operational costs. Therefore, additional funds are provided by the Medical Centre. It has to be noted that the outpatient palliative clinic is financed as an oncology clinic, therefore only those activities related to the care of cancer patients can be reimbursed.

From the financial perspective, the home-based hospice-palliative care is organized independently from the Medical Centre. The Pécs-Baranya Hospice Programme has a separate financial agreement with the National Healthcare Fund. The reimbursement is paid by visits capped by the payer. A physician's visit is reimbursed by 6.8 euros (1 EUR = 310 HUF) which is a very low amount even in Hungary, therefore physicians have their main job elsewhere (e.g. GPs). The Pécs-Baranya Hospice Programme also receives donations from different organization and private persons to maintain its operation [IP06_2].

External sources were needed to commence the operation of the PCCS programme. The financial support from the EU grant will expire by the end of 2016, therefore the future operation of team has to be reconsidered from a financial perspective [IP03_2].

4.7.2. Considerations for the future

Adequate public reimbursement is needed in order to enhance the operation of the programme. It is a goal of the programme management to achieve the establishment of a dedicated financial mechanism, similarly to homecare or institutional hospice care [IP02_2].

A basic expectation towards the financing scheme is that it should provide sufficient sources for the institution to offer decent wages for the specialized palliative care professionals to work full-time in the programme only. This is currently not fulfilled [IP13_2]. In order to achieve this, the current list of codes for medical interventions should be supplemented with procedures of palliative care. Then patient-level cost collection is required that will be the basis for determining the corresponding fees. With this method, a reasonable reimbursement level could be set [IP03_2]. Furthermore, the palliative consult service should be acknowledged within the current healthcare system as a new form of care associated with an adequate a financing technic [IP03_2].

A further improvement of the financial aspect of palliative care would be if certain medical tools or equipment were able to be assured for homecare. For examples special bandages for the treatment of pressure sore, nutrients and nutritional supplements could be offered and prescribed for patients by palliative physicians [IP10_2].

Regarding the economic sustainability of the programme, it is important to analyse the effect of the PCCS programme on the cost of care within the hospital. The services provided by the palliative consult

service are expected to save costs (salary of involved professionals vs. decreasing cost of care) which can serve as an argument for maintaining the operation [IP02_2].

4.8. Implementation process

4.8.1. Historical information

4.8.1.1. Main goals of the programme

The goal of the Palliative Care Consult Service programme was to establish a skilled, multidisciplinary team to provide inpatient palliative care to the different clinical departments in an acute hospital. It mainly provides specialized consulting for seriously-ill patients and their family members. The provided services focus on improving the quality of life through relieving the patient's symptoms, management of psychiatric patients and their families, coordination of offering additional treatment options for patients and creating a comprehensive treatment plan considering patients' needs and goals [6].

Services are provided by a dedicated, trained, interdisciplinary team in close collaboration with other professionals at the hospital. The objective of the team was to fit their services into the care processes of the clinical departments and to operate as a bridge between acute hospital and other palliative care providers to ensure continuity in care [6].

There were also economic aspects considered in the implementation of the Palliative Care Consult Service programme. It was expected that as a result of the team's activity, the length of stay would decrease among patients involved in the programme, the cost of treatment could be reduced, unnecessary readmissions of patients would be avoided and patient pathways would be managed in a more efficient way [6].

4.8.1.2. Motivations for starting the programme

The ineffective management of palliative patient pathway across the healthcare in Hungary generated the need for setting up consult services, which can provide complex and integrated approach in coordinating palliative patients [IP12_2]. The healthcare decision-makers recognized this need, which manifested in a call for application [TÁMOP 6.2.4 A-11/1-2012-0065] on formulating consult services. Based on the experiences of palliative physicians working at the Medical Centre the need for palliative care within an acute care has emerged due to over- or undertreating patients as there was no proper management of physical and psychical symptoms at this segment of care. PCCS can provide appropriate treatment based on the patients' symptoms and needs. Treatment objectives are defined jointly with the patient and family members [IP02_2].

In Hungary there is a negative association regarding institutional hospice care. It is regarded as a place for "hopeless" patients, therefore patients prefer to receive care at home. This option is offered by palliative consult service based on the holistic assessment and goals of the patient [IP11_2].

In general, the Hungarian patient population still has a reluctant attitude towards psychological support. Without any motivation, patients do not turn to psychologists. Therefore, there is an unmet need among seriously ill patients at acute hospitals, which could be fulfilled by the palliative team's psychologist [IP05_2].

Based on the opinion of a head nurse at the Medical Centre previously, before the start of PCCS programme it was difficult to find the proper institution which can take over patient from acute care and can provide specialized care (e.g. narcotic pain relief). The patients spent therefore longer time in the acute hospital before getting transferred elsewhere. This issue is now effectively managed by the PCCS team [IP11_2].

From an economic perspective, it can be concluded that compared to foreign countries, the use of healthcare resources in Hungary are unreasonably high among patients with potential palliative need [IP02_2]. This problem is also addressed by the establishment of the palliative consult service.

The inspiration for establishing the PCCS at the Medical Centre of the University of Pécs came from a palliative physician who gained experiences abroad (USA and UK) in this field [IP02_2]. The forerunners of the team were the home-based hospice-palliative care operating since 2004 and the outpatient palliative clinic started in 2012 [IP02_2].

4.8.2. Present information

4.8.2.1. Implementation process

At the initial phase of the programme, departments with the highest mortality rates were identified within the Medical Centre. Professional leaders (both clinicians and nurses) of the relevant clinical departments were involved in the discussions. Brainstorming was carried out and other meetings were held about the potential aim of the programme, principles and process of palliative care. The management of the Medical Centre was also involved throughout the development of the programme. The main challenge in the implementation was the acceptance of the palliative care principles at the clinical departments and to fit services to the acute care processes. Programme initiators were able to overcome these challenges by efficient communication and the support from the management. Moreover in the initial phase the EU grant gave a strong support regarding the implementation [4].

The first step of implementation was to visit every clinical department and to give information on the goals of the programme, the principles of palliative care and the criteria for enrolling patients in the programme [IP02_2]. The specific needs of the different clinical departments were assessed and discussed personally during referrals and directors meeting [IP04_2]. In the introductory phase it was

not enough to give information verbally on this new form of care, but written documents had to be created containing information on evidences, data and results of previous palliative care programmes [IP02_2]. A palliative consult service sought to fit its service portfolio to the needs specified by the clinical departments. The success of the cooperation depended in many cases on the attitude of the individual physician towards the philosophy of palliative care. There are still some physicians in clinical departments who do not initiate any palliative referrals. In many cases, the head nurse became the contact with the team. In Hungary currently the essence of palliative care is embedded deeper in the nursing training system as compared to medical education [IP04_2, IP02_2]. Another important step of the implementation process was the development of the electronic referral module in the hospital information system [IP02_2].

The political commitment for starting the programme was noteworthy. The legal framework for the operation of consult service has been created and without the EU grant the programme would had not yet started [IP12_2]. On the other hand, the lack of proper financial scheme for ensuring the sustainability of the programme is still a deficiency to be alleviated. The local management is very committed not only to sustain the operation of the programme but to expand the resources of the team [IP02_2].

One of the difficulties during the implementation process was to obtain permission for operation. In Hungary it was the first time when a permission had to be issued to authorize the operation of a palliative consult service [IP02_2]. However, the procedure of formal authorization was efficiently facilitated by the initiator of the programme, who is a well-known, acknowledged professional in the field of palliative care in Hungary [IP12_2]. The other difficulty was that palliative physicians did not receive a licence to prescribe specific palliation-related medication or dietary supplement with discounts [IP06_2].

The implementation of the palliative consult service in an academic environment was important in terms of educational aspects. The lack of knowledge regarding palliative care can be managed by involving palliative care in the curriculum of the medical education. At the University of Pécs this is a straightforward approach, because there is an overlap in the human resources of the palliative team and the Palliative Department at Medical Faculty. This way it is ensured that the practical experiences and the best practices adopted form abroad become implanted in the graduate and postgraduate education of medical doctors.

The acknowledgement of the programme is increasing within the institution. This is proved by increasing number of requesting referrals [IP05_2].

4.8.3.   Future implementation/development

Based on the opinion of the stakeholders expressed during the interviews, several considerations can be made concerning the future improvement of the PCCS programme.

The PCCS programme in Pécs can be regarded as a pilot programme for the country. Based on the experiences here, a formalized functional model could be developed which gives the appropriate legal framework for the activities. In addition, this model can serve as an example for other institutions across the country [IP02_2].

Based on opinion of the programme manager, a challenge over the next 10 years will be to create a palliative care unit within the Medical Centre. In order to achieve this, acute hospital beds have to be dedicated to active palliative care [IP12_2]. Homecare patients could be admitted to the palliative care unit in case of complex needs. The medical centre in Pécs is pioneering in creating the appropriate conditions for such a department in Hungary. [IP13_2]

The future activities of the PCCS may relate to the preparation of a summary for family members about informal caregiving and basic supportive activities (e.g. what should be done in case of lack of appetite or increase in pain level). Satisfaction of family members and patients should also be assessed in the future. [IP04_2]

Most important things to consider for improving the programme: higher recognition within the hospital; more professionals in palliative care; sufficient financing [IP06_2]

Improving human capacities is important because of the increasing number of consultations and future developments (5 hospital beds for in-patient palliative care). Such improvement could be the establishment of another team. [IP12_2]

4.9. Discussion

4.9.1. General discussion

Although most patients in the Palliative Care Consult Service programme have chronic comorbidities, the focus of the programme was not primarily on treating patients with multi-morbidity but rather to relieve symptoms of patients with incurable diseases. Based on the results of the European Association for Palliative Care Task Force survey [7] the coverage of palliative care services has improved significantly in the past years and are widespread in Western European countries. In Central and Eastern European countries, including Hungary the available services are still insufficient to meet the palliative care needs of the population [7]. The PCCS programme can be regarded as an innovative approach in Hungarian context, therefore it is beneficial to draw conclusion on the experiences after a three-year-operation period. It is particularly interesting how the integrated, multidisciplinary and patient-centred approach was accepted in the Hungarian healthcare setting and what challenges the programme had to face. In this qualitative report the features of the programme were explored in a structured way.

Impressions gained through the interviews helped understanding the operation of the programme in a wider context.

4.9.2. Discussion of the programme in the context of the conceptual framework

Below, the Palliative Care Consult Service programme is described in the context of the SELFIE conceptual framework for Integrated Care for Multi-Morbidity. First the holistic approach is described in the programme, where after each component, starting at the top and moving clockwise, is described at the micro, meso, and macro level.

4.9.2.1. Segment 'Holistic understanding of the individual'

Holistic assessment of the patient's need is a core element of the PCCS programme. It is carried out on the basis of interviews with the patient and family members, reviewing available medical records, consultation with other specialist physician and diagnostic tests [IP04_2]. The assessment covers not only clinical information (e.g. state of the disease) but physical and mental status, pain, other symptoms as well as the performance status and social, spiritual and cultural aspects. The assessment aims to offer a treatment plan in line with the preferences of the patient and the family members [IP04_2]. The wishes expressed by the patient along with the opinions of the family and the multidisciplinary team are the basis for the palliative care treatment plan.

4.9.2.2. Segment 'Service delivery'

Macro: The PCCS programme was originally a bottom-up initiation that met with the top-down requirement of the health policy to increase the efficiency of patient pathway management. Therefore, the regulatory framework for the operation of palliative consult services were established, however policies to integrate care across organizations and sectors are missing.

Meso: The collaboration evolved naturally across the providers (Medical Center, Homecare, Hospice Institution, GPs). It has not yet been formalized through any contracts, or organizational or structural integration. The strong cooperation among providers is facilitated by the overlap in human resources (members of the team work for more providers in parallel).

Micro: Based on the principles of palliative care, service delivery is person-centered, because the needs and goals are assessed and the wishes of the patients and family members are considered. A tailored care is provided by offering alternative treatment options. Informal caregivers are involved in the decision making and in the education of self-management interventions. In addition to the palliative care concept the PCCS programme supports the continuity through coordination of care across providers and managing patient pathway (e.g. the transfer of patient form acute care to homecare).

4.9.2.3. Segment 'Leadership and governance'

Macro: The political commitment of healthcare decision makers to establish consult services was proved by the provision of EU funds to start the programme. Almost certainly it would have not started without this incentive. On the other hand, no financial support was provided enhance the programme or to sustain the operation after the implementation period.

Meso: The management of the Medical Centre was very supportive in the implementation of the programme and in providing the sufficient fund for the operation. The management on the meso level compensated for the deficiencies present on the health policy level.

Micro: In the PCCS programme the concept of shared decision making is very important in the process of care. As mentioned earlier, patients and family members are involved in the decision on further treatment. Individualized care planning (personalized treatment plan is established) and coordination among healthcare providers are the major tasks of PCCS team members.

4.9.2.4. Segment 'Workforce'

Macro: Members of the palliative team are involved in under- and postgraduate medical education at the Medical Centre of the University of Pécs in order to support knowledge transfer for future physicians. On the other hand, there is a general shortage of physicians in Hungary and the focus of health politicians is not primarily on improving the situation of palliative physicians, therefore no essential changes can be expected in the near future [IP13_2].

Meso: New professional roles with specific qualification requirements had to be established (coordinator, physician) to start the programme, with the intent to ensure quality of care. This was regarded by the initiator [IP02_2] and manager [IP12_2] of the programme as important quality requirement. Involvement of informal caregiver support is also in focus of the programme because on one side they overtake considerable workload from acute care providers, on the other hand it is beneficial for the patients and family members as well.

Micro: The PCCS works with a multidisciplinary team (physician, nurse, psychologist, dietetics, physiotherapist available) and a named coordinator (coordinator of the team), who is continuously available for consultation. A high risk was identified regarding staff retention (burnout, low income, no priority in health politics), which may have a strong influence on the future operation of the team.

4.9.2.5. Segment 'Financing'

Macro: Regarding the financial aspects of the programme, there are big deficiencies on the macro level. No direct reimbursement is provided for the operation of palliative consult services and so far no concept has been publicized on how to incentivize the cooperation between health and social care in order to increase efficiency in care.

Meso: A secured budget was provided by the government to start this programme, which was a great incentive in the initial phase (EU grant for a specific time period).

Micro: Instead of a proper coverage and reimbursement system, an internal financing methodology is used to provide funding for the programme. The enhancement of the programme will require a dedicated financing method for the reimbursement of palliative consult services.

4.9.2.6. Segment 'Technologies and medical products'

None of the macro or meso level elements of the conceptual framework were applicable for the evaluation of the PCCS programme.

Micro: The only ICT development regarding the PCCS programme was the improvement of the EMR (electronic referral system). The interviews revealed that the possibilities of ICT applications are not exploited sufficiently and that further research is needed to investigate the role of ICT in palliative care in Hungary and how ICT intervention could improve quality of care for patients

4.9.2.7. Segment 'Information and research'

None of the macro or meso level elements of the conceptual framework were applicable for the evaluation of the PCCS programme.

Micro: Besides the data regarding the utilization of hospital resources (length of stay, readmissions, ER visits etc.) there are only limited individual level data (electronic documentation) available to perform an evaluation regarding the Triple Aim (health, cost, experience). A prospective data collection has to be performed in order to gain information that can be used for scientific and research purposes.

4.10.   References

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Appendix: List of interview partners

Interview partner number	Stakeholder	Interview date
Programme 1 (OnkoNetwork)		
IP01_1	Non-physician staff #1	08/06/2016
IP02_1	Non-physician staff #2	08/06/2016
IP03_1	Physician #1	09/06/2016
IP04_1	Physician #2	08/06/2016
IP05_1	Manager	09/06/2016
IP06_1	Non-physician staff #3	08/06/2016
IP07_1	Physician #3	09/06/2016
IP08_1	Non-physician staff #4	08/06/2016
IP09_1	Non-physician staff #5	09/06/2016
IP10_1	Non-physician staff #6	09/06/2016
IP11_1	Non-physician staff #8	22/06/2016
IP12_1	Initiator #1	21/06/2016
IP13_1	Sponsor/Payer	22/06/2016
IP14_1	Non-physician staff #7	22/06/2016
IP15_1	Patient #1	19/07/2016
IP16_1	Patient #2	19/07/2016
IP17_1	Physician #5	19/07/2016
IP18_1	Initiator #2	22/06/2016
IP19_1	Informal caregiver #1	28/07/2016
IP20_1	Informal caregiver #2	28/07/2016
Programme 2 (Palliative Consulting Service)		
IP01_2	Manager #1	14/06/2016
IP02_2	Initiator	27/05/2016
IP03_2	Sponsor/payer	14/06/2016
IP04_2	Non-physician staff #1	14/06/2016
IP05_2	Non-physician staff #2	14/06/2016
IP06_2	Physician #1	14/06/2016
IP07_2	Informal caregiver #1	21/07/2016
IP08_2	Patient #1	21/07/2016
IP09_2	Patient #2	21/07/2016
IP10_2	Physician #2	02/08/2016
IP11_2	Non-physician staff #3	02/08/2016
IP12_2	Manager #2	03/08/2016
IP13_2	Physician #3	03/08/2016
IP14_2	Non-physician staff #4	17/08/2016
IP15_2	Informal caregiver #2	17/08/2016