

Work Package 2 Report

# Croatia



## Work Package 2: Thick descriptions of

- GeroS
- Palliative Care System

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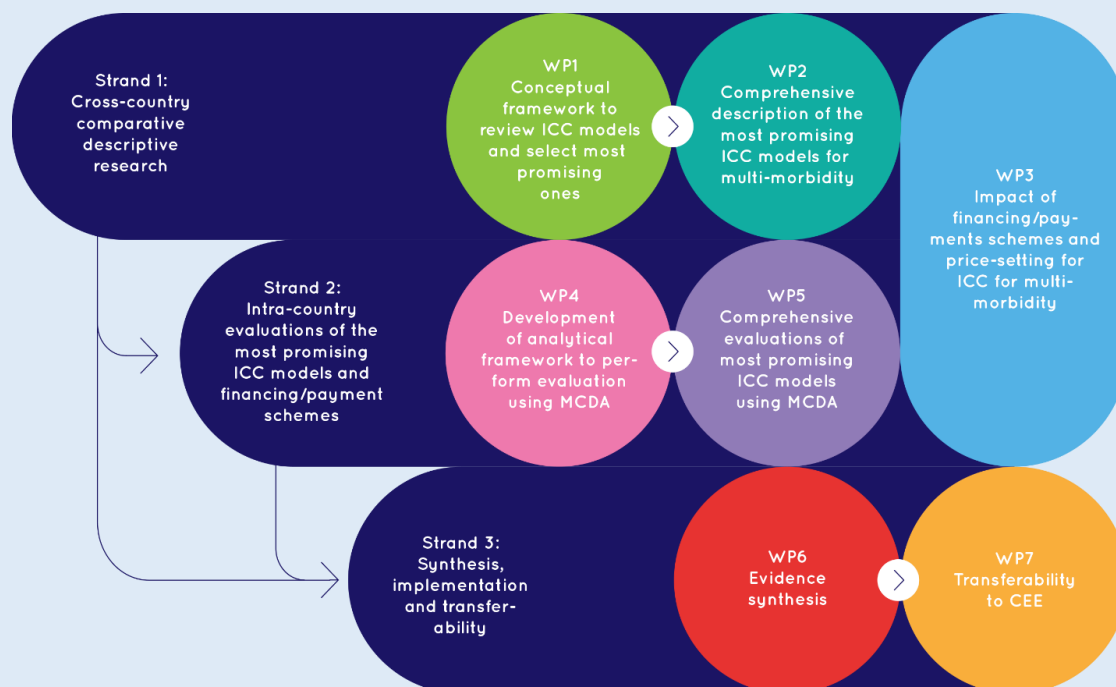
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## The SELFIE project

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

### GeroS

The GeroS programme represents an integrated care model for geriatric patients with multi-morbidity. The programme is currently still in its pilot phase and has therefore not yet been fully implemented at the national level.

#### **Service delivery**

GeroS is designed as a 15-module system for monitoring and evaluating the health needs and functional ability of insured persons over the age of 65 and, in particular, geriatric patients receiving corresponding care. One purpose of the programme is the digitalisation of all health and social care records for this age group. GeroS involves primary healthcare providers, specialists, hospitals, long-term care providers, homes for the elderly and centres for social care. Individual care plans, a person-centred attitude, proactive care and risk stratification form part of the programme. Management of polypharmacy and clinical guideline interaction will also be provided once the programme has been fully implemented. The programme is based on a holistic assessment of the multi-morbid person and informal caregivers. GeroS aims to rationalize geriatric healthcare through the categorization of elderly persons in institutional and non-institutional care. Self-management interventions are supported by indirect empowerment from the Reference Centre for Health Gerontology through educational material and guidelines.

#### **Leadership & governance**

The GeroS system is a subsystem of the Central Health Information System of the Republic of Croatia (CEZIH) and, as such, is inseparably linked to the latter. All health data which already exist in CEZIH are relocated to the GeroS system once an insured person turns 65. The 15 modules are being integrated into CEZIH on a step-by-step basis. In addition to health and social care providers, several patient associations, healthcare associations and one city foundation are also involved in the programme.

#### **Workforce**

New professional roles will be developed from already established professions. New professions will be characterised by the prefix "geronto" in order to indicate that they provide specific care to geriatric persons. Currently, the programme is confronted with a lack of educators.

### **Technologies & medical products**

The digitalisation of health and social care records via a central database lies at the heart of the GeroS programme. Most of the ICT applications intended to be used in GeroS already exist in CEZIH. However, not all modules that are intended to be part of the GeroS system have as yet been fully integrated. There are however plans to extend the integration of modules to all levels of healthcare, as well as to strengthen the connection with the social care system. Furthermore, some homes for the elderly involved with the programme use a computer system named DOGMA, which integrates all individual documents and supports cooperation between all involved professionals.

### **Information & research**

The primary focus of the GeroS programme is to systematically collect data on various determinants from health as well as social domains. A monitoring system for the programme has already been introduced, while a quality assurance system is still to be established.

### **Financing**

The financing and payment scheme is based on national mandatory health insurance through the Croatian Health Insurance Fund for healthcare and services in homes for elderly persons for social care. Sustainability, however, is not guaranteed, and remains a barrier to the full implementation of the GeroS system.

## **Palliative Care System**

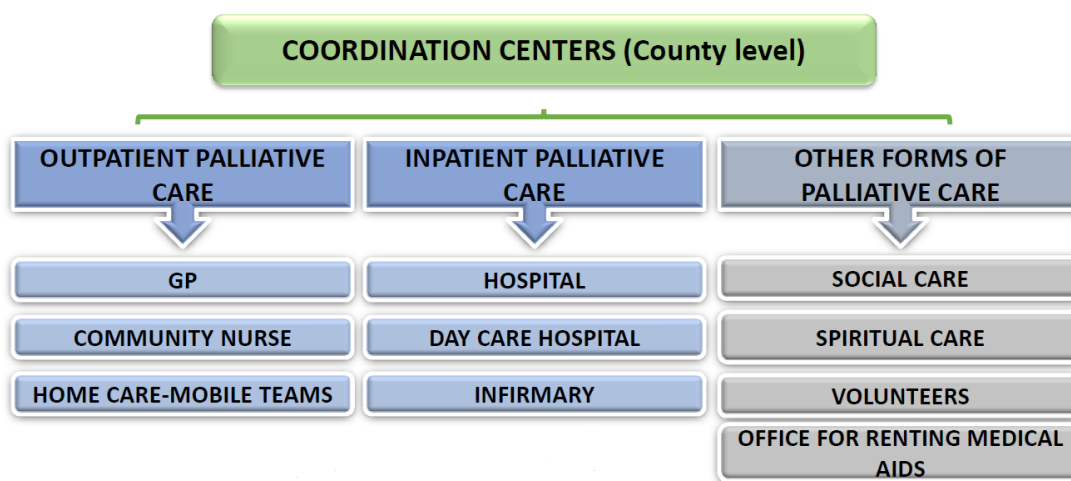
It is estimated that a minimum of 20% of cancer patients and 5% of non-oncological patients need palliative care in the last year of their life. The Palliative Care System is an integrated care programme specifically designed for palliative care patients; it is based on the Croatian National Healthcare Strategy and the Strategic Plan for Palliative Care 2014–2016. The system is planned to be introduced on a nationwide level, but is currently still in its pilot phase.

### **Service delivery**

Stakeholders and resources exist in four key domains: the healthcare system, social welfare system, school/higher education system, and civil society. The Palliative Care System involves outpatient palliative care, inpatient palliative care, as well as extended forms of palliative care, as can be seen in the figure below. Coordination Centres for palliative care coordinate care between hospitals, ambulatory palliative care, (mobile) specialised palliative care teams and social care, providing vertical,

horizontal and inter-sectoral cooperation and collaboration at the county level. Informal care givers and volunteers are included, as well as institutions for the renting of medical aids and devices. The care process is based on patient-centred care, organised around a palliative care patient. It is based on a holistic assessment of the palliative care patient: in addition to health care, it includes social care, spiritual care, and the individual's family.

### Organisation of care in the Palliative Care System



### Leadership & governance

Currently, the Palliative Care System is not fully integrated into the national healthcare system; it is a pilot-level project in different parts (counties) of Croatia. Changes in the legal framework are required for full implementation at the national level. The Committee for Palliative Care, appointed by the Ministry of Health, is responsible for further activities regarding the implementation of palliative care and the development of a new Strategic Plan for Development of Palliative Care in Croatia for the period after 2017. The strategic development of the palliative care system at national level is planned to be achieved through three key steps: 1) removing barriers to the provision of existing/potential forms of palliative care; 2) empowerment of all stakeholders in order to provide better palliative care in existing conditions; 3) improving the existing situation through the construction of new organizational structures.

### Workforce

The Palliative Care System involves various professions, including physicians, nurses at different health institutions, community care nurses, psychologists, social workers, volunteers and informal caregivers,



mobile teams, university staff and priests. Mobile multidisciplinary specialist palliative care teams, an example of a new innovative role in the Croatian palliative care model, are established at the county level. In Istria County, for example, the team is made up of a specialist in radiotherapy-oncology and two nurses as full-time permanent members, as well as various specialists from other medical fields as part-time members. Furthermore, the CEPAMET centre at the University of Zagreb's School of Medicine provides workshops on palliative care for different stakeholders.

### **Technologies & medical products**

ICT applications such as electronic health records, internet applications, mobile phones and telemedicine are planned to be used in the future to enable sustainable links between the palliative care network. Currently, the Palliative Care System does not use a common IT system at the national level. However, some counties are already using special software to identify and monitor palliative patients.

### **Information & research**

The introduction of continuous systematic data collection within the Palliative Care System as well as a national registry of palliative care patients are planned. A system to monitor target attainment according to the Strategic Plan for Development of Palliative Care is not yet fully established. However, questionnaires have been sent to primary healthcare centres, hospitals and counties to evaluate the extent to which certain elements of the Palliative Care System have already been established. The results are mixed: While some elements (e.g. cooperation with other institutions) have been widely established, others have not yet found their way into practice.

### **Financing**

The financing and payment scheme is based on the national mandatory health insurance through the Croatian Health Insurance Fund for healthcare and services in homes for elderly persons for social care. Beyond regular funding, the Croatian Health Insurance Fund provides additional funds for 10 pilot projects in primary healthcare centres. Supplementary funding is also provided by some counties.

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## 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<sup>1</sup> 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 (Ryle, 1949). In the 1970s, it was established as a qualitative method to investigate implicit social practices in their specific contexts by the anthropologist Clifford Geertz (Geertz, 1973). 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

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<sup>1</sup> Three in the case of the Netherlands.

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 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.” (Geertz, 1973: 22)*

In recent decades, Geertz’ methodological and conceptual work has influenced empirical research in several disciplines (McCloskey, 1988). In sociology, it is widely used in a variety of research fields, including research of care practices (Maloney-Krichmar and Preece, 2005).

As shown in Figure 1.1, 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 1.1: 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 1.1).

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 (Mayring, 2001). This method involves the following steps of abductive interpretation<sup>2</sup>:

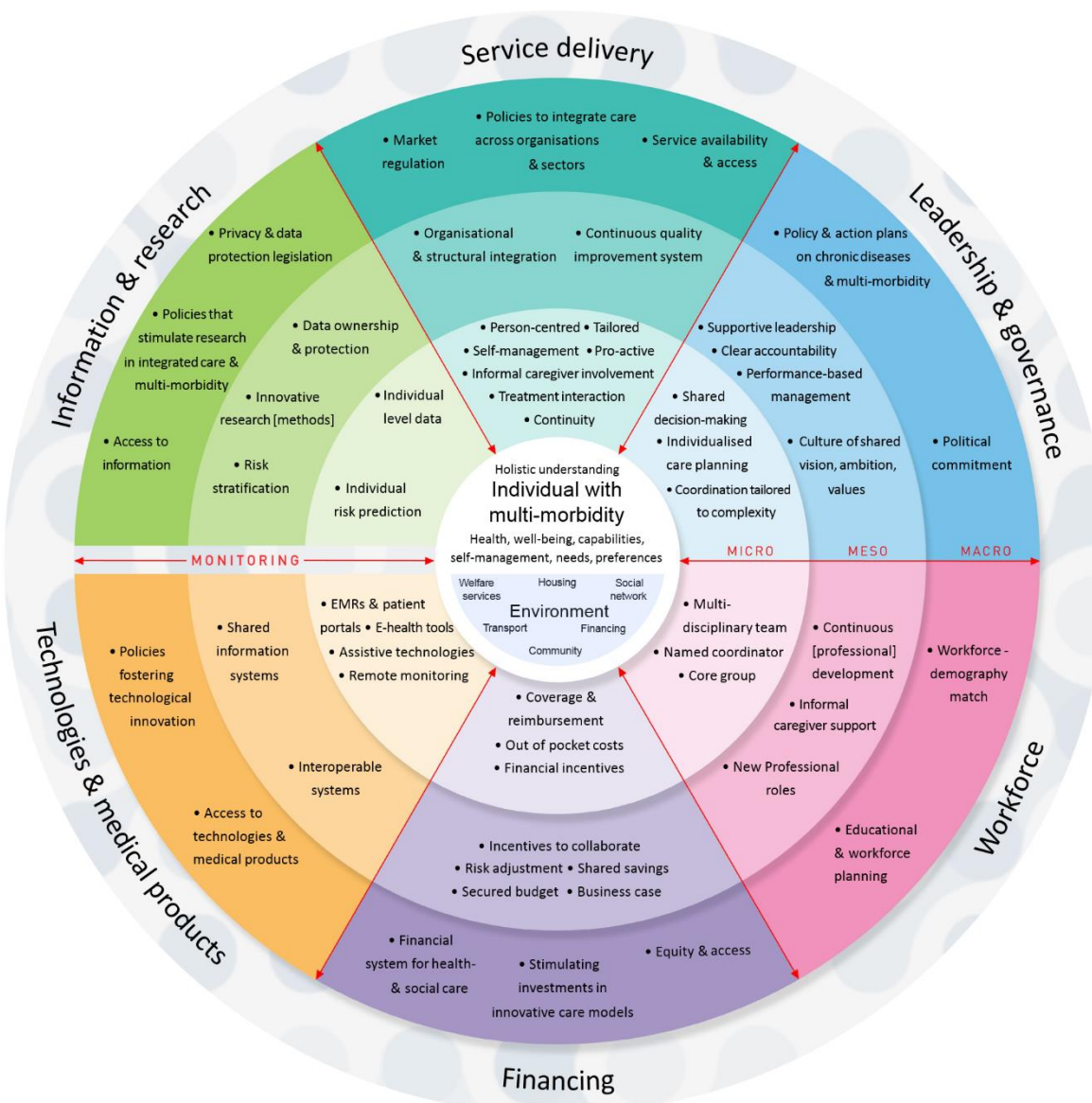
- Selecting units of analysis
- Paraphrasing these units of analysis
- Transforming the paraphrases to short forms
- Constructing categories, where possible

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<sup>2</sup> Timmermans and Tavory (2012) define abduction as a "creative inferential process aimed at producing new hypotheses and theories based on surprising research evidence."

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 1.2.

Figure 1.2: Conceptual framework for the delivery of care for persons with multiple chronic conditions



Source: Leijten et al. (submitted manuscript, 2016)

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 2<sup>nd</sup> steering committee meeting in Vienna on January 25<sup>th</sup> and 26<sup>th</sup> 2016. Second, a special training course was held at IHS Vienna for researchers directly involved in the thick description on April 14<sup>th</sup> 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.

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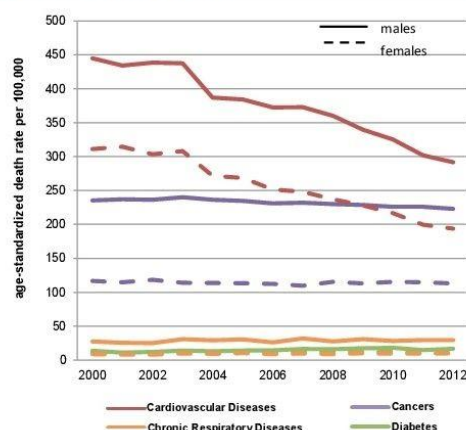
## 2. Macro level

### Croatia

Total population: 4 307 000

Income Group: High

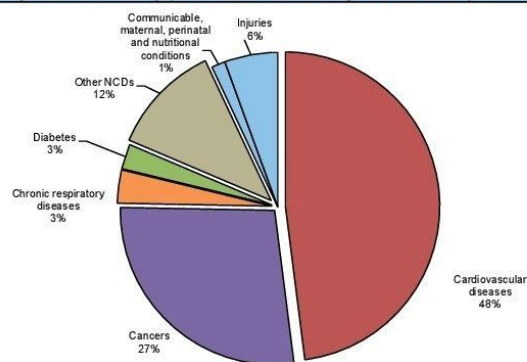
#### Age-standardized death rates



Percentage of population living in urban areas: 57.8%

Population proportion between ages 30 and 70 years: 53.7%

#### Proportional mortality (% of total deaths, all ages, both sexes)



Total deaths: 50,000  
NCDs are estimated to account for 93% of total deaths.

#### Adult risk factors

	males	females	total
Current tobacco smoking (2011)	36%	30%	33%
Total alcohol per capita consumption, in litres of pure alcohol (2010)	17.7	7.1	12.2
Raised blood pressure (2008)	46.4%	43.2%	44.7%
Obesity (2008)	24.4%	23.9%	24.2%

#### National systems response to NCDs

Has an operational NCD unit/branch or department within the Ministry of Health, or equivalent	Yes
Has an operational multisectoral national policy, strategy or action plan that integrates several NCDs and shared risk factors	No
Has an operational policy, strategy or action plan to reduce the harmful use of alcohol	Yes
Has an operational policy, strategy or action plan to reduce physical inactivity and/or promote physical activity	No
Has an operational policy, strategy or action plan to reduce the burden of tobacco use	Yes
Has an operational policy, strategy or action plan to reduce unhealthy diet and/or promote healthy diets	Yes
Has evidence-based national guidelines/protocols/standards for the management of major NCDs through a primary care approach	No
Has an NCD surveillance and monitoring system in place to enable reporting against the nine global NCD targets	No
Has a national, population-based cancer registry	Yes

Source: World Health Organization - Noncommunicable Diseases (NCD) Country Profiles, 2014

[http://apps.who.int/iris/bitstream/10665/128038/1/9789241507509\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/128038/1/9789241507509_eng.pdf?ua=1)

Table 2.1: Key facts and figures about Croatia

	Croatia
Population	4.3 million (2015)
Population ≥ 65 yrs (%)	17.7 (2011)
Model of care	Bismarck (national social health insurance system)
Life expectancy (yrs)	75 M & 81 W (2015)
Birth rate	9.3/1000 (2014)
Gross mortality rate	12.0/1000 (2014)
Infant mortality	5.0/1000 live births (2014)
Healthcare expenditure % GDP	7.8% (2014)
Healthcare expenditure per capita €/year	1 652 US\$ (2014)
Coverage (% population)	99.7%
Public funding	Croatian Health Insurance Fund (HZZO)
Supplementary health insurance in CHIF (% population)	58% (2015)
Private insurance (% population)	Private health insurance in Croatia is negligible
Number of physicians per 100 000 inhabitants	300 (2013)
Number of hospital beds per 1000 inhabitants	5.5 (2015)

Source: References 1-6

## 2.1. Service delivery

Croatia is a small Central-European country (of approximately 4.3 million inhabitants); it became the 28<sup>th</sup> Member State of the EU on July 1, 2013. In 2012, the National Health Care Strategy 2012-2020 was implemented. Strategic developmental objectives of the healthcare system include strengthening the connections and continuity throughout the healthcare system, standardizing and improving the quality of healthcare (strengthening the HTA as one measure), increasing efficiency and effectiveness of the healthcare system, making healthcare more available, and improving health indicators (7).

The *Croatian Healthcare System* (based on the principles of social health insurance) is primarily determined by three key acts: the Healthcare Act, the Mandatory Health Insurance Act and the Patients' Rights Protection Act. The *Croatian Social Care System* is determined by the Social Care Act.

The basic legal frameworks of the healthcare and social care system in Croatia are summarized in Table 2.2.

Table 2.2: The basic legal frameworks of the healthcare and social care system in Croatia

The basic legal framework of the health and social care system	
<b>Healthcare Act</b>	Determines the principles and measures of healthcare, rights and obligations of persons using healthcare, holders of social welfare concerning the health of the population, contents and organizations performing healthcare activities, and monitoring;  <i>Zakon o zdravstvenoj zaštiti (Official gazette No. 150/08, 71/10, 139/10, 22/11, 84/11, 12/12, 70/12, 82/13, 159/13, 154/14, 70/16)</i>
<b>Mandatory Health Insurance Act</b>	Determines the right and obligations for insured persons and from health insurance; division of the health insurance into basic (mandatory, implemented by the Croatian Health Insurance Fund-HZZO and financed by the contributions paid by the insured, contributions paid by employers, contributions by other contribution payers, special contributions for using healthcare abroad, special contributions in case of a work-related injury, contributions from the state budget and income from interest, dividends and other income), supplementary, additional, and private (which are voluntary); <i>Zakon o obveznom zdravstvenom osiguranju (Official gazette No. 80/13, 137/13); Zakon o dobrovoljnom zdravstvenom osiguranju (Official gazette No. 85/06, 150/08, 71/10)</i>
<b>Patients' Rights Protection Act</b>	Regulates moral ethical and civil behavioural standards of the users and the providers of the healthcare services; based on the principles of humanity and availability;

	<i>Zakon o zaštiti prava pacijenata (Official gazette No. <u>169/04</u>, <u>37/08</u>)</i>
<b>Social Care Act</b>	<p>Regulates methods of performance and financing of the activities of social care, beneficiaries, the rights of beneficiaries of social care, the procedure for the exercise of these rights, and other issues important for the performance of the activities of social care</p> <p><i>Zakon o socijalnoj skrbi (Official gazette No. <u>33/12</u>, <u>157/13</u>, <u>152/14</u>, <u>99/15</u>)</i></p>

One of the priority measures in the Croatian National Health Care Strategy 2012-2020 (7) is strengthening inter-sectoral cooperation (among ministries). The strategy advocates the “health in all policies”, “whole-of-government”, and “whole-of society” approaches and enumerates examples of the existing and possible forms of cooperation that should be strengthened and coordinated. The healthcare system is in many ways connected with the social welfare system, and the support and community care programmes for the most vulnerable groups such as physically and mentally ill chronic patients and dying persons, as well as their family members, should result from the cooperation of those two sectors. Health is taken into account in both the decision-making process and in policy implementation. Health impact assessment is conducted in cases of reform proposals that may have an effect on the health of the population.

Since 2004, the Ministry of Health provides programmes to promote the quality of life of the elderly through the programmes “Living and assistance for the elderly” and “Help for the Elderly” by counties.

Under the Croatian Ministry of Health, the Unit for Health Gerontology of Andrija Stampar Teaching Institute of Public Health, as the Reference Centre for Health Gerontology, acts at the national level. There are also Gerontology Centres as multifunctional centres of immediate and integral multidisciplinary care for elderly people in the local community.

In the Development Strategy of Social Welfare, 2011 to 2016, one of the priorities is to improve inter-agency coordination, especially taking care of the harmonization of development of social welfare services with the availability of health services. The Ministry adopted the Strategy of Social Welfare for the elderly in the Republic of Croatia for the period 2014-2016 (8-10).

People in palliative care mostly have multi-morbid conditions and complex care needs.

The Strategic Plan for the Development of Palliative Care 2014-2016, as one of the operational documents, elaborates development measures and concrete activities connected with the organizational and legal framework of palliative care and priority measures related to the strategic development of palliative care (12).

## 2.2. Leadership & Governance

Governance of the health and social care system and main actors are briefly presented in Table 2.3.

Table 2.3: Main decision makers in Croatia

Main decision makers in Croatia	
<b>Ministry of Health</b>	<p>Determines health policy, planning, and evaluation, including the drafting of legislation, regulation of standards for health services and training; a public health programme, including monitoring and surveillance of health status, health promotion, food and drug safety, and environmental sanitation; regulation of capital investments in healthcare providers in public ownership;</p> <p><a href="https://zdravlje.gov.hr/">https://zdravlje.gov.hr/</a></p>
<b>Ministry of Social Politics and Youth</b>	<p>Performs administrative and professional tasks related to the social welfare institutions, the care and protection of people and families, youth, persons with disabilities, victims of trafficking, refugees, asylum seekers, and professional activities related to foster care and adoption</p> <p><a href="http://www.mspm.hr/ministarstvo-9/9">http://www.mspm.hr/ministarstvo-9/9</a></p>
<b>Croatian Health Insurance Fund (HZZO)</b>	<p>Determines managing the Health Insurance Fund and contracting healthcare services; a key role in the definition of basic health services covered under statutory insurance; the establishment of performance standards and price setting for services covered by the HZZO; pricing and reimbursement decision on drugs and medical devices (after an appraisal process by the Drugs Committee and Medical Devices Committee);</p> <p><a href="http://www.hzzo.hr/">http://www.hzzo.hr/</a>  <a href="http://www.hzzo.hr/en/">http://www.hzzo.hr/en/</a></p>

As already mentioned above, the National Healthcare Strategy 2012-2020 and Strategic Plan for the Development of Palliative Care in Croatia for the period 2014-2016 describe governance and main actors on integrated care related to palliative care patients. Under the Croatian Ministry of Health, the Unit for Health Gerontology of Andrija Stampar Teaching Institute of Public Health, as the Reference Centre for Health Gerontology, acts at the national level.

### 2.3. Workforce

The goal of the Strategic Plan for the Development of Human Resources in Healthcare (11) is to ensure the optimal number of human resources for the implementation of all healthcare measures.

Five types of medical professionals (medical doctors, nurses, dentists, pharmacists, and midwives) fall within the system of coordination of minimum training conditions according to Directive 2005/36/EC on the recognition of professional qualifications. Croatia meets these minimum training conditions for all five categories of medical professionals. However, according to the National Health Care Strategy 2012–2020, the field of nursing education is insufficiently regulated.

In the Development Strategy of Social Welfare 2015 to 2017 (10), a specific objective “Improving the quality of professional work providers” is recognized as being of utmost importance. To develop professional training programmes according to the needs of professional workers and users, general and specific needs for specialist training were obtained through expert worker surveys in centres and other social welfare institutions and through data analysis and targeted professional discussions at the level of relevant professional groups.

There are many different health and social workers included in two Croatian integrated chronic care models, palliative care and care for the elderly.

New professional roles are planned in the Strategic Plan for the Development of Human Resources in Healthcare 2015 to 2020 (11). For example, in the area of primary healthcare and public health, graduated nurses can take part in activities in prevention programmes; in hospitals they can take part in quality systems introduction and assurance, coordination of transplantation and explanation, and control/management functions. There is a need for the creation of task shifting and skill mix catalogues, defining a network of centres of excellence, training centres, and cabinets. Task shift and skill mix programmes should be introduced gradually in the healthcare system by redistributing tasks among professions horizontally or vertically, from the level of primary healthcare to the clinical institutions.

The palliative care specialized mobile team is an example of a new innovative role in the Croatian palliative care model and will be discussed in details later in this document.



## 2.4. Financing

The Croatian Health Insurance Fund (HZZO) is the sole insurer in the mandatory health insurance system, which provides universal health insurance coverage to the whole population.

The payment system of primary and hospital healthcare includes several mechanisms. The payment of healthcare in primary healthcare is performed via capitation, with an additional mechanism of paying the price for service, i.e. a mechanism of paying per therapy. Hospital healthcare facilities contracted the budget with HZZO for a period of one year (advance payment of services) until 2015, when the new model was introduced, through contracting individual diagnostic therapy groups and diagnostic-therapy procedures (payment after the performance of agreed-upon procedures).

The central government finances clinical hospitals and clinical hospital centres, whereas counties finance general and special hospitals and primary healthcare centres in their ownership. Monitoring of the indicators of success (KPI - number of insured persons per acute bed within a particular period of time, and the total number of cases in specialist-consultant healthcare per health professional) and the indicators of quality (QI - general morbidity rate, the percentage of treatment in a day hospital and the percentage of treatment with reserve antibiotics in the total number of cases) has begun.

The funds for financing social welfare activities are provided mostly by the state budget, at about 96%, while the remaining 4% of revenue is provided for special purposes according to the Social Welfare Act.

Integrated care will be financed through the same mechanisms described above.

At the moment, integrated care is only partially implemented in the health and social care system in Croatia. According to HZZO, palliative care now receives about 20 percent of citizens in the last year of life, in contrast to only one per thousand before three years ago. The turning point was the implementation of the Strategic Plan for Development of Palliative Care from 2014 to 2016.

The Strategic Plan for Development of Palliative Care predicts the increase of the number of palliative care beds from 142 to 300, education of 1500 health professionals, increasing of the number of hospital palliative care teams, organization of coordination centres in counties, and other “interventions” in the health system to ensure incurable patients and their families the best possible quality of life. The goal of the strategic plan is that palliative care is available 24 hours seven days a week and for it to become equally available in all parts of the Croatia. Financial policies are aligned with this strategic plan.

Sustainability of funding of integrated care will be ensured through same mechanism applied for the whole healthcare and social system in Croatia (13).

For example, the Ministry of Health has invested 2.2 million HRK over the last two years in the Department for prolonged treatment with palliative care in the Knin Hospital “Croatian Pride”. In Rijeka, the Hospice Marija Krucifiksa Kozulić was established, funded by Caritas of the Archdiocese of Rijeka, the City of Rijeka, and the County. The Archdiocese of Rijeka provided the available space and 8.5 million HRK were invested in the adaptation, while the County and City of Rijeka helped with the purchase of equipment with one million HRK. In New Marof City, The Department of Palliative Care in the Special Hospital for Chronic Diseases New Marof was opened (the Ministry of Health has allocated 2.5 million HRK and the Special Hospital and the Varazdin County, 2 million HRK). The Croatian Health Insurance Fund is constantly increasing the capacity and expanding the network of hospital palliative beds, ensuring sustainable funds.

## 2.5. Technologies & medical products

From 2014, Croatia has had the Strategic Plan for Development of e-Health in the Republic of Croatia (14). The National Healthcare Strategy 2012-2020 recognized computerization and e-Health as a priority.

The existing information systems in healthcare should be functionally improved through the development of e-waiting lists, e-appointment, e-certificates of entitlement to orthopaedic aids, e-lists of medicines, e-guidelines for prescriptions, e-clinical guidelines, e-prevention, e-managing of chronic diseases, e-patronage nursing, e-transplantation, e-archive of health documentation, national public health information and communication system, information system for sanitary inspectors, information systems as a support to the quality management in healthcare, information systems for county medical emergency centres, systems for managing documents and digital records of diagnostic devices, systems for managing physician and nurse documentation, a system for support to joint procurement and other joint processes of hospitals and entire healthcare, connecting occupational medicine practices, connecting with private health service providers, and mHealth – using mobile devices in medical and public health practice. In September 2016, the e-card was released in the test phase. The Central IT healthcare system already allows prescribing in digital form (e-prescription) and electronic appointment booking (e-ordering). The plan is to carry out the digitalization of the medical treatment of patients

(order letter, findings, discharge letter in e-form), to communicate between all stakeholders in the health system.

Along with the e-card, the Patient Portal (mHealth) was released in a test run in September 2016 (available with a specific web address). The informatics system DOGMA is already implemented in Centres and Homes for the elderly in Zagreb through funds from the Ministry of Social Politics and Youth. A new ICC Model, the so called GeroS System, should be deeply integrated into the Central Informatics' System (CEZIH) and upgraded. Telemedicine will be fully integrated into the service of emergency medical services and other health activities, and will together with mHealth provide treatment at a distance (which compensates for the lack of experts) and the establishment of a more active role of patients in their own treatment. According to the Strategic Plan for Development of e-Health in the Republic of Croatia, funding for eHealth will be increased and other sources of funding in addition to the state budget will be used for fully implementation, for example funds from the EU, the World Bank, and local governments.

## 2.6. Information and research

The Croatian legal framework on data privacy consists of the Act for Protection of Patients' Rights (Official gazette No. 169/04, 37/08) and Rules on the confidentiality of information and the right of access to information of the Croatian Health Insurance Fund (Official gazette No. 18/09, 33/10 and 8/11), which are in accordance with other Acts (Data Secrecy Act, Personal Data Protection Act, and the Act regarding the right to information access). Since 2006, these acts are in compliance with EU legislation (Official gazette No. 118/06). They do not constrain implementation of integrated care.

As will be discussed in detail, Croatia has the GeroS Project /monitoring and evaluation of health needs and functional ability of persons with geriatric insurance and geriatric patients inseparably linked to the national health system CEZIH (Central Health Information System of the Republic of Croatia).

One regional research programme is conducted by the School of Public Health (Medical Faculty Zagreb), "Living with chronic disease: patient experience".

The Ministry of Social Policy and Youth published three invitations to submit projects and programmes in 2014 relating to various forms of care for the elderly, including the financing of three-year programmes of civil society organisations for the provision of the service "Hello for Help" for the elderly,

organising daily activities for the elderly in local communities, and the services of transport for the elderly to medical institutions and other relevant institutions, and the services of advising the elderly about the potential harmful effects of contracts of maintenance for life or contracts of maintenance until death. In 2014, the Ministry financed a total of 78 projects and programmes attempting to increase the quality of life of the elderly. The funds were secured from the state budget and partially from the revenues from games of chance (7,409,435.54 HRK in total).

The Andrija Stampar Teaching Institute of Public Health (holder of the ICC project GeroS), with its Reference Centre for Health Gerontology of the Ministry of Health, is a carrier of the initiative for the City of Zagreb for the competition of the European Innovation Partnership in the field of active and healthy ageing (European Innovation Partnership on Active and Healthy Ageing), awarded with the status of “EIP on AHA Reference Site 1 star”. The main objectives of reference sites for innovation in the field of active and healthy ageing are improvements in health and quality of life with a focus on the ageing population; providing support for long-term sustainability and efficiency of the health and social care system and strengthening the competitiveness of the EU industry through business and expanding to new markets. It is also a collaborative partner in JA-CHRODIS (EU Joint Action on Chronic Diseases and promoting healthy ageing across the life-cycle project) which explore the potential to reduce chronic disease - DM and cardiovascular disease.

The EU project CareWell was conducted in Croatia as well: delivering integrated care to frail patients through ICT, part of which was the Croatian pilot project. Six primary healthcare teams participated in it, comprised of the Primary Healthcare Centre Zagreb family GPs, field nurses, and 110 patients (divided in intervention and control groups), aged over 65 years. The aim of the project was to analyse the effect the improved service on health parameters of elderly patients, who have complex needs and are suffering from chronic diseases, as well as on their quality of life and healthcare system efficiency.

In the field of informatization and e-health development, different European or regional projects are finished or are ongoing in Croatia – specifically with CHIF as a partner. Examples are epSOS (European Patient Smart Open Service); INCA - INclusive INtroduction of INtegrated Care (<http://www.in3ca.eu/?cat=1&lang=en>), with the aim of proposing a model that promotes higher coordination of socio-sanitary services while reducing costs, improving patient experience, and achieving greater efficiency from health delivery systems; EESSI - Electronic Exchange of Social Security Information (with aim of strengthening the protection of the social security rights of citizens who are

mobile by fully computerising application of the EC law on social security); AdriHealthMob, (<http://adrihealthmob.eu/project>), with aim of systematizing a set of procedures (guidelines) that can facilitate the development of a sustainable strategy capable of ensuring citizens easy access to health and care services.

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### 3. Programme 1: “GeroS”

#### 3.1. Basic information

Table 3.1.1: Basic information about the programme

Information category	Description
Programme name	GeroS
Contact details, programme management	Spomenka Tomek-Roksandić, MD, PhD, +385 1 4696273, <a href="mailto:spomenka.tomek-roksandic@stampar.hr">spomenka.tomek-roksandic@stampar.hr</a> Andrija Štampar Teaching Institute of Public Health, Unit for Health Gerontology - Ministry of Health Reference Centre
Starting date of the programme	Initiatives on June 6, 2014 February 27, 2015 final project document
Geographical scope	Republic of Croatia
Target group of the programme	People older than 65 years (insured persons and geriatric patients)
Number of patients treated in the programme	761 100 (17.7% of 4 300 000 inhabitants)
Aim of the programme	<p><b>Monitoring</b> and <b>evaluation</b> of health needs and functional abilities insured persons older than 65 and geriatric patients</p> <p><b>Computerization</b> of all health and social care records from services provided to geriatric patients, regardless of ownership of institutions in which they are located, as well as geriatric patients on long-term treatment in a hospital for chronic diseases, long-term treatment and palliative geriatric care</p> <p><b>Keeping</b> of all geriatric patient/ insured persons older than 65 data in one place in the Central health Information System of the Republic of Croatia, CEZIH, under the trademark GeroS.</p> <p>CEZIH is co-developed and operated by the National Reimbursement Fund.</p> <p><u>On the system level:</u></p> <ul style="list-style-type: none"> <li>- Detection and evaluation of health needs and functional capacity of insured persons older than 65 and geriatric patients</li> <li>- Integration of primary, secondary, and tertiary healthcare and social care (connecting the family doctor team with community health nurse activities, institutions for home care, physical therapy</li> </ul>

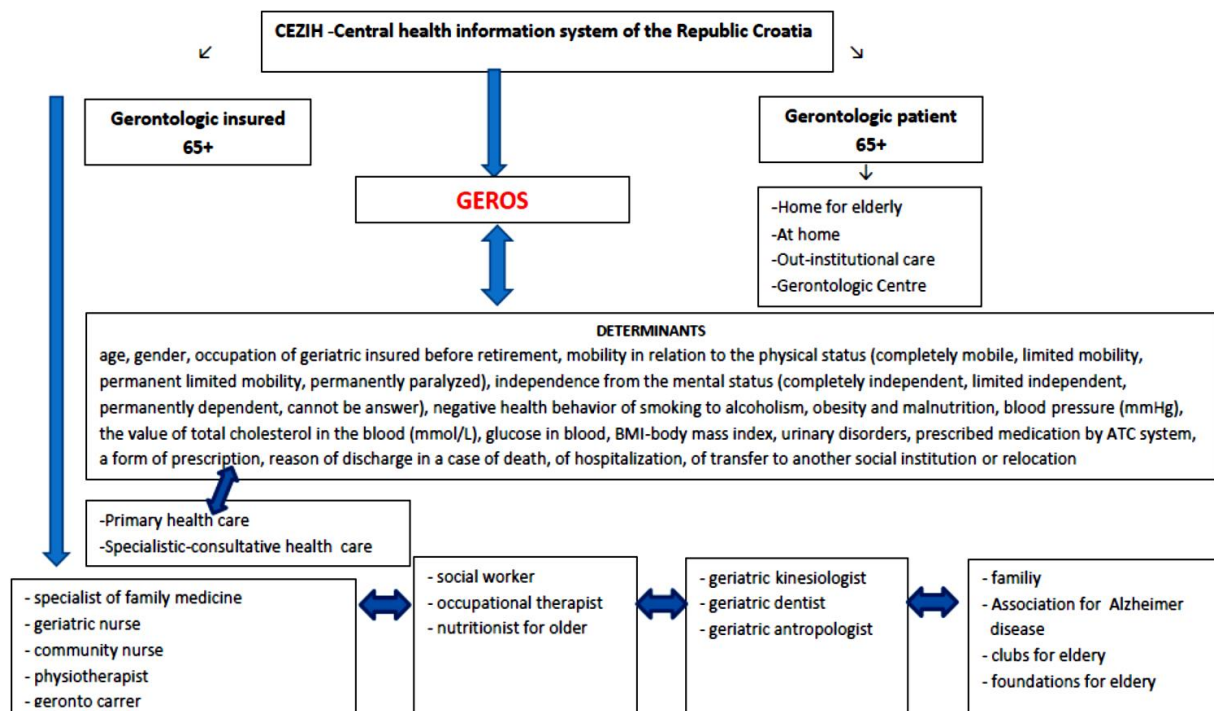
		<p>and rehabilitation at home, and palliative-geriatric care)</p> <ul style="list-style-type: none"> <li>- Rationalization of working hours of various specialists in the interdisciplinary team</li> <li>- Facilitation of mutual communication between employees</li> <li>- Improving quality of health</li> <li>- Rationalization in costs</li> <li>- Continuous medical education of the interdisciplinary gerontology team</li> <li>- Improving of algorithms, gerontology, and geriatric norms of health welfare and geriatric healthcare</li> <li>- Projection and planning of future health needs of the elderly</li> <li>- Correction and enhancement of existing standards and norms in Homes for the elderly</li> </ul> <p>“Four degrees of geriatric healthcare with nursing documentation” monitoring</p> <ul style="list-style-type: none"> <li>- Rationalization in physical rehabilitation</li> <li>- Detection of overlap in renting medical aids (unified list of medical aids)</li> <li>- Rationalization and planning in the area of service provision of health/medical tourism of insured persons older than 65</li> </ul> <p>Palliative - geriatric care objectification of health status and functional disability of geriatric patients in seeking palliative - geriatric care.</p> <p><u>On the patient level:</u></p> <ul style="list-style-type: none"> <li>- Detection of physical status</li> <li>- Detection of leading and concomitant diagnosis</li> <li>- Detection of nutritive status NRS2002 (Nutritional Risk Screening 2002) web service</li> <li>- Detection of risks as prevention of hospitalization</li> <li>- Detection of overlapping in healthcare procedures</li> <li>- Detection of negative behaviours</li> <li>- Signal for preventive or systematic examination of the elderly</li> <li>- Revision of drug lists in a regular time period by primary care physicians</li> <li>- Obtaining correct and timely information when applying for available, adequate capacity of Homes for elderly persons</li> </ul>
Definition/understanding of “integrated care”	of	No definition of integrated care was found.
Definition/understanding of “multi-morbidity”	of	No definition of multi-morbidity was found.
Definition/understanding of	of	No definition of patient-centeredness was found.



“patient centeredness”	
Definition/understanding of “self-management”	No definition of self-management was found.
Organisational form and ownership	<p>The Programme is a fully integrated subsystem of the Central Health Information System (CEZIH) of the Republic of Croatia operated by the Croatian Health Insurance Fund.</p> <p>For a detailed organisational form see Scheme 1 and 2</p>
Involved partner organisations	Under governance of the Ministry of Health Reference Centre for Health Gerontology, the Programme includes all three levels of healthcare and social care for people older than 65 years.
Involved disciplines and professions	Primary healthcare, specialist-consultative healthcare, family medicine specialists, geriatric nurses, community nurses, physiotherapists, “geronto” carer, social workers, occupational therapists, nutritionists for the elderly, geriatric kinesiologists, geriatric dentists, geriatric anthropologists, informal caregivers - volunteers, family, associations, clubs, Foundations.

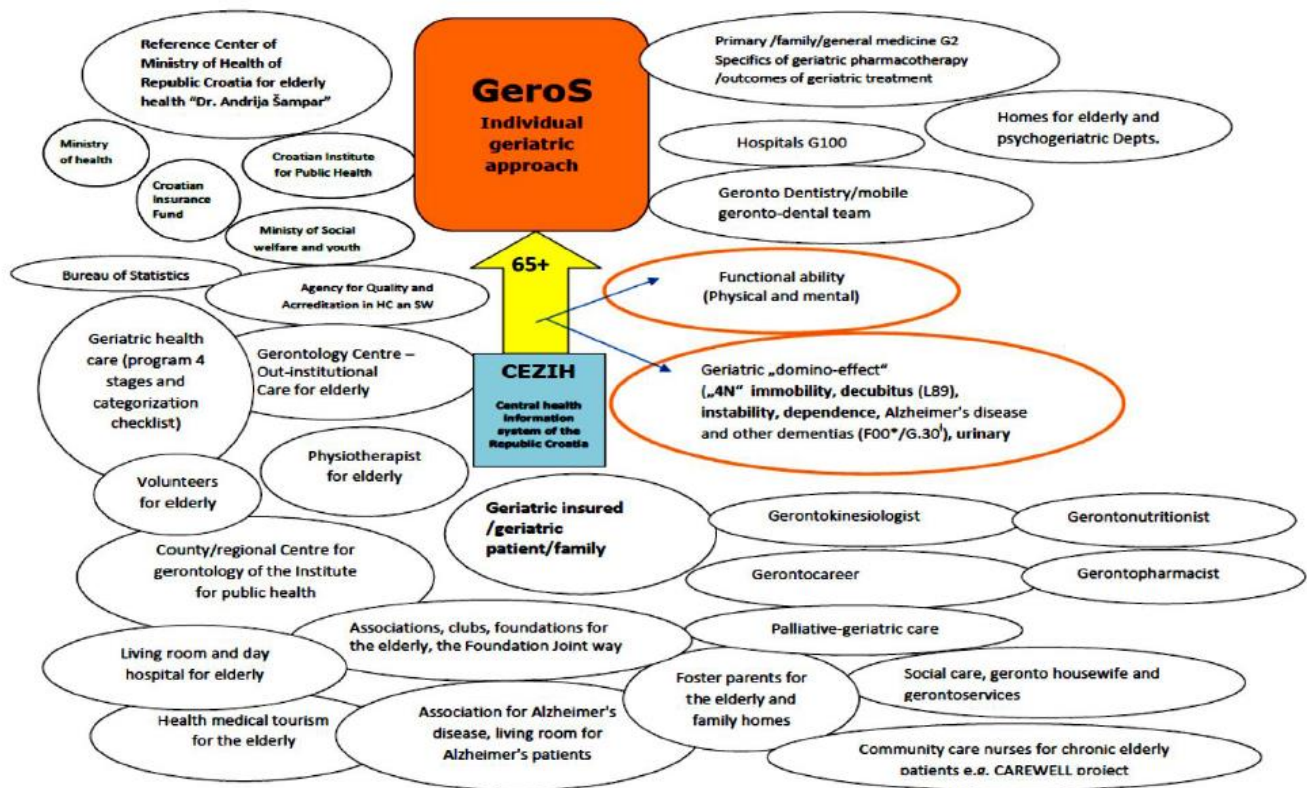
**GeroS** is described in detail in the Project documentation (1,2).

Figure 3.1.1: Organizational form and ownership of the programme (including legal form)



Source: [http://www.zdravljezasve.hr/html/zdravlje06\\_Aktivnostarenje.html](http://www.zdravljezasve.hr/html/zdravlje06_Aktivnostarenje.html)

Figure 3.1.2: Organizational form and ownership of the programme (including legal form)



Source: Reference Centre of Ministry of Health of Republic of Croatia for Health Gerontology

## 3.2. Service delivery

### 3.2.1. Design of delivery of care

GeroS is a pilot programme. It is designed as a subsystem integrated in the Central Health Information System (CEZIH) and is dedicated to monitoring and evaluation of health needs and functional ability of insured persons older than 65 and geriatric patients (1).

CEZIH is operated by the Croatian Health Insurance Fund (HZZO). After their 65<sup>th</sup> birthday, records of all health and social care services for insured persons older than 65 will be pulled from CEZIH and relocated to GeroS. The Programme was designed as a step-by-step implementation of different Modules into CEZIH, currently mainly on the primary level. GeroS includes: primary healthcare specialists - consultant healthcare, hospital healthcare, and long-term care, Homes for elderly persons, and Centres for social care. Through computerization of medical records (from social workers, nurses, physiotherapist, and occupational therapists), palliative careboards and business processes, GeroS digitally expands the data set available for the geriatric patient and insured persons older than 65. It ensures that relevant information and changes are promptly and effectively available to interested parties, in accordance with their responsibilities in the system.

According to Project documentation (1), GeroS consists of 15 Modules (Functional specification): Module for Administration, Module for Homes for the elderly, Module for ordering on the Waiting list, Module for Centres for Social Care, the Panel Module, Module for primary healthcare, Module for specialist-consultative healthcare, Module for Hospitals, Module for nurse documentation for geriatric healthcare, Module for out-institutional care and activities, Module for social workers records, Module for work therapeutic documentation, Module for physiotherapeutic documentation, Insured Module (expanded Patients Portal), and Module for Reports.

The reasons for the establishment of GeroS were (1):

Subject	Process
Geriatric patients (65 +) drug list Medical procedures Homes for elderly persons	Regular GP revisions NON duplication (NO overlapping) Simplification in obtaining information for applying for Homes Planning of future capacity in Homes

<p>Home for elderly persons and non-institutional care - Gerontology centre</p> <p>Family doctor teams, community health nurses, institutions for: home care, physical therapy, and rehabilitation, palliative-geriatric care</p> <p>Preventive or systematic examination</p> <p>Homes for elderly persons</p> <p>Community health nurses</p> <p>Various specialists in the interdisciplinary team</p> <p>Employees in healthcare involved in care for elderly persons</p> <p>Physical rehabilitation of elderly persons</p> <p>Occupational - therapeutic measures and procedures</p> <p>Focused geronto - public health programmes for elderly persons</p> <p>"Four degrees of geriatric healthcare" - nursing documentation (19 patterns) as a standard of the Croatian Nursing Chamber</p> <p>Categorization of geriatric patients and insured persons older than 65 in the institutional and out institutional care</p> <p>Continued education in gerontology, geriatrics, and geriatric healthcare</p> <p>Health and social system</p>	<p>Easier and transparent review of waiting lists</p> <p>coordination between institutions and rationalization of services</p> <p>Connection between them</p> <p>Signal to GP</p> <p>Application of nutritional norms</p> <p>Screening of nutritional risk in the elderly (method of Nutritional Risk Screening 2002 - NRS 2002)</p> <p>Prevention of possible hospitalization of the elderly arising from malnutrition</p> <p>Rationalization of working hours</p> <p>Facilitation of mutual communication between them (e.g. exchange of documentation)</p> <p>Proper redistribution of resources for identified medical needs</p> <p>Reduction of services in the institutions (rationalization of costs)</p> <p>Easier selection of gerontology technology aids</p> <p>Unified list of geriatric technological aids</p> <p>Lending of medical aids</p> <p>Projection and planning for future health needs of the elderly</p> <p>Achievement of higher functional capacity of elderly persons</p> <p>Achievement of higher quality of life for elderly persons</p> <p>Health geriatric care according to functional abilities of insured persons older than 65 /patients</p> <p>Rationalization of geriatric healthcare (type of service, cost of service)</p> <p>Planning of the required interdisciplinary team of geriatric experts</p> <p>Link between them</p> <p>Detection of geriatric problems in care offering solutions for inclusion of experts from various fields in care</p>
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Existing standards and norms, e.g. frequency and length of time for geriatric dentist service	Correction and enhancement
Health/medical tourism of insured persons older than 65	Rationalization and planning services
Geriatric patients in palliative- geriatric care	Objectification of health status and functional disability
	More accessible, more efficient, and better movement through healthcare levels, in homes, Homes from elderly persons, and palliative geriatric hospital care

According to the Initiator and Manager of the Programme (2,3) from the Ministry of Health Reference Centre for Health Gerontology, GeroS now exists within the Central Health Information System of the Republic of Croatia (CEZIH) only at the primary healthcare level (IP01\_1, page 7, line 273-277).

There is a special application in the frame of primary healthcare panel which is filled out electronically. It is important to stress that CEZIH, as a health information system, is not implemented in all Homes for elderly (social care). That is a reason why some of their physicians enters data in CEZIH (those which are obligated by employment contracts) but some do not. Similarly, some of the main nurses in Homes for the elderly fulfil it, and some do not. This also depends on the level of computerization. In the process, data records sheets are filled out as a paper version and electronically. The Ministry of Health Reference Centre for Health Gerontology received records in both manners. Through the application of “Four degrees of geriatric healthcare”, data is currently collected from many Homes for the elderly. All records collected in the Reference Centre are transferred into indicators for future care planning.

From the funding perspective, GEROS is in the development stage. The Croatian Health Insurance Fund and their employees participate in the development of the system in order to connect all data regarding health insurance. It is expected that in the future physicians at any level of healthcare would not have to enter additional data - all data will be generated from their usual clinical work. Evaluation criteria of the Programme have not yet been seen (IP03\_1, page 5, line 162-163).

Even in the developmental phase, the Programme is recognized as useful and valuable from the physicians’ perspective (IP06\_1, page12, line 412-414).

When it is fully integrated, it will connect different sectors-institutions, contribute to better cooperation between their employees, involve rationalization in the health system and, what is most valuable, give

patients “more different approaches” to their physician and the entire health system (IP06\_1, page 9, line 309-312).

In the Reference Centre, they expect a lot of work on the Programme until its full implementation.

*IP: “This is a programme which I consider really valuable but it is still in the implementation phase, so to get what we expect will take more time and energy to enliven in the way how it is designed, considering that it includes a lot of different institutions and technical implementation.” (IP05\_1, page 1, line 17-19)*

The Manager and Initiator of programme confirmed that strong political support for the Programme was obtained (IP01\_1, page 1, line 9-11). The Reference Centre for Health Gerontology is appointed by the Ministry of Health (IP01\_1, page 3, line 106-108). There is agreement at the international level with Alma Mater Europea. In Croatia, there is cooperation with governmental institutions, such the Agency for quality and accreditation of healthcare regarding quality indicators, with different faculties (e.g. Kinesiology, Economy, Medicine, School of Dental Medicine, Pharmacy, Education and Rehabilitation, Tourism) and regarding new professional roles, with the Croatian Institute of Public Health, Croatian Health Insurance Fund, Statistical Bureau, and Pension Fund. Every action from the Programme is extensively covered by media under patronage of the Reference Centre. Care pathways are described in great detail in the nurse documentation for geriatric healthcare in Homes for elderly: “Four degrees of geriatric healthcare with nursing documentation and procedural guide for general/family medicine in the Homes for the elderly person with categorization guidelines”. It serves as the standard of the Croatian Nursing Chamber (4, 5).

In order to achieve the objectives in the development of nursing documentation, authors were governed by the theory, model, and concept of Roper - Juchli geriatric healthcare, the standard process model V. Fiechter - M. Meier, patterns of health and social functioning, V. Henderson’s and D. Orem’s theories, and partly by the ICNP - International Classification for Nursing Practice (4).

Nursing documentation of geriatric healthcare according to the theory of Roper – Juchli model includes 12 activities of daily living. Through holistic access to observation, following and improving physiological, psychological, social and spiritual abilities of insured persons older than 65 is encouraged, as well as developing autonomy and independence of older persons in the activities of daily living, in order to keep their functional ability, health promotion, and quality of life (4). Nursing documentation consists of 19

Forms (some of them exist in electronic form, some in a paper version): Parent form – biography-live events; Nursing anamnesis according to the Roper/Juchli model; Plan of the geriatric healthcare process; Healthcare - first shift; Healthcare – second shift; Healthcare – night shift; Preventive healthcare - first and second shift; Specific procedures of healthcare/observation of health condition; Evaluation/nurse report; Evidence of ordinate and received therapy; Braden scale for assessing the risk of bedsores; Prevention and following of bedsores; Intake and output of liquids during 24 hours; Feeding Protocol; Geriatric form for prevention of falls (S. Huhn); Incident report; Pain Assessment; Nurses discharge letter for insured persons older than 65; Category Checklist - 4 degrees of geriatric healthcare and Description of categorization factors of geriatric home users per categories (4).

The Category Checklist is carried out by a nurse through the assessment of 16 parameters (5):

Personal Hygiene, Dressing/undressing, Feeding, Elimination and aids for incontinence, Walking/Standing, Sitting, Moving/rotating, Risk of falls (Huhn scale), Status of awareness, Risk of bedsores (Braden scale), Vital signs, Communication, Specific procedures in healthcare, Professional follow up/diagnostic procedures, Preparation and application of therapy, Education (1).

Insured persons older than 65 and members of their family, on request, can gain insight in nursing documentation of geriatric healthcare in which store all obtained data (4).

Rationalization of geriatric healthcare, through categorization of geriatric patients and insured persons older than 65, in institutional and non-institutional care will be obtained (3).

DOGMA is an ICT programme used in Homes for the elderly in the capital city of Zagreb. Its owner is the City Department of Social Welfare and Persons with Disabilities. DOGMA collects all data from parent registry, extra parent books, records of users in their rooms, birthday books, records tracking users during weekends and holidays for maids, records of user daily absences, the personal data for medical service, personal lists, adaptive user lists, an individual plan for the user, computer records of users, candidates and former users at home, a monthly report for the cash register on the movement of users and change of user status, notices of death, and location or termination of accommodation to the relevant Centre for social welfare. Nursing documentation (19 Forms) is entered into DOGMA partly in electronic form and partly manually from the paper version.



Care is performed continuously for 24 hours (24/7 care) for each user/patient and performed by nurses and carers in three shifts.

*IP: "Every day I am in contact with the doctor, we talk either via phone, when they are not present, for 24 hours, not only me but also my nurses." (IP01\_7, page2, line 47-48)*

One Head Nurse from a Home for the elderly was involved from the beginning in the development and implementation of the programme "Four degrees of geriatric healthcare" with nursing documentation in her Home (IP01\_7, page 1, line 11-12). She considers GeroS to be an advantage, an upgrade to DOGMA which was already designed to be upgraded. GeroS is a broader project, encompasses more participants, and DOGMA applies only within Homes for elderly persons. Some services in it are disconnected from the accounting system (IP07\_1, page 5, line 156-159). GeroS will prove a better connection between patient data and between services provided to them (IP07\_1, page 2-3, line 67-70).

Nurse care is already provided categorization accordingly, but using GeroS it will be visible and provide a real picture of health services because users are now categorized according to social categories (IP01\_7, page 4-5, line 132-139). DOGMA is designed for upgrading and fits into GeroS, but GeroS is a broader project and encompasses more participants. DOGMA works only inside the Home. GeroS will assure integrity and continuity of the insured during their stay in the Home, in the residential or stationary part, e.g. after return from hospital care.

*IP: "When a user comes to the hospital and says that he is in a institution or a Home for the elderly, they quickly send him back, so we have many of these specific procedures, cannulas, urinary stoma ... there is nothing that is not in the home for elderly ... apparatus for oxygen, everything" (IP01\_7, page 2, line 42-44)*

One social worker from a Home for elderly persons said that the Home cannot provide service for users with different types of dementia because additional specialists and more working space are needed (IP015\_1, page 6, line 189-193). One nurse from a Home for elderly persons noticed a deficit in staff, especially carers (IP014\_1, page 4, line 142-147).

The Ministry of Health Reference Centre for Health Gerontology collects, extracts, and assesses data from Record sheet number 1 (monitoring of health needs in Homes for the elderly) and the Record sheet number 4 (monitoring the health and social needs in the Geriatric Centres and in non-institutional

care for the elderly) (1). The nurse in charge of implementing “Four degrees of geriatric healthcare with nurse documentation” at the Reference Centre gives support to all stakeholders in that process, from nurses to directors of county public health institutes (IP013\_1, page 4, line 139-144). Non-physician medical staff from the Reference Centre stress that in addition to nurse documentation all data from Records sheets are valuable in order to deeply understand the work of all stakeholders (e.g. social worker, occupational therapist). Record sheet number 4 differs slightly from number 1 and it is not filled out by a healthcare practitioner, nurse, or doctor as the record sheet number 1; it is filled out by a social worker (IP010\_1, page 3, line 83-95). Studying these lists, the Reference Centre tries to deeply understand all kinds of services, not only health services (IP010\_1, page 2, line 43-51).

Nurse documentation (19 Forms - Tracking lists, Questionnaires, Assessment Scales) and Record Sheets 1 and 4 produced in GeroS allow production of guidelines for individual geriatric approaches in geriatric care – a person-centred attitude. An individual care plan and risk stratification is provided through the Programme “Four degrees of geriatric healthcare monitoring”. It includes proactive care. For example, risk stratification is performed at admission to the Home for elderly persons. When someone enters a Home in the fourth degree of care (the worst case), it does not mean that they will stay in it forever, on the contrary, their status is constantly monitored according to a personalized care plan; preventive measures are taken in order to prevent further deterioration of function, and after recovering they will be moved to another degree of geriatric healthcare. Nurses and physicians from the Home for the elderly confirm that purpose of nursing documentation is the individual approach to the patient’s needs. Employees do their best to achieve it.

*IP: “Yes, the purpose of the nursing documentation is the individual approach to the needs”  
(IP07\_1, page 3, line 84)*

*IP: “We don’t have a default scheme for everyone and we do our best to make it an individual approach.” (IP07\_1, page 3, line 106-108)*

A physician from a Home for the elderly always has an individual care plan for a patient and stressed the role of the physician in it (IP06\_1, page 3, line 92-97). The physician must permanently educate the patient (IP06\_1, page 7, line 220-226).

A physician from the Reference Centre also confirmed that individual care plans can be found and that the Programme implemented risk stratification (IP05\_1, page 2, line 37; IP05\_1, page 2, line 35).

He said that guidelines for care can be produced in the Programme but the Programme is intended for monitoring and patient personal goals cannot be seen from it (IP05\_1, page 2, line 32-33).

GeroS gives a “signal” to a general/family doctor about terms for preventive or systematic examination of the elderly. In the Programme, the main carrier of protection of health of the elderly is the general/family doctor, supported by instructions and education from the Reference Centre (6). This is the very important role of GeroS. With data sent from physicians, the Centre creates instructions. Elderly persons are encouraged to have co-responsibility; as a concrete example, the Centre made recommendations for protection from heat for the aging population. Thanks to this programme, fewer calls from the elderly population to the emergency service were recorded (IP01\_1, page 6, line 218-226).

GeroS enables a link with the community health nurses. With screening of nutritional risk in the elderly (using the method of Nutritional Risk Screening 2002 - NRS 2002) (7), they prevent possible hospitalizations of the elderly arising from malnutrition and also from unnecessary use of psychiatric drugs, because depression is frequently anticipated as a reason for malnutrition.

The Reference Centre encouraged nutritional status monitoring at all levels of care for elderly people.

*IP: “Monitoring of the nutritional status of geriatric patients that appear in the hospital is for us a fantastic indicator.” (IP01\_1, page 9, line 333-334)*

The Nutritional Risk Screening 2002 programme can be expanded extensively using GeroS (IP011\_1, page 9, line 281-283).

Regarding management of polypharmacy and guideline interaction, GeroS allows primary care practitioners to perform regular “audits” of lists of drugs which geriatric patients (65 +) take (1). An interviewed primary care physician agreed that the programme helps in reducing polypharmacy (IP06\_1, page 5, line 168-173). In the Reference Centre it has been noticed that the Programme significantly reduces the number of drugs per patient.

*IP: “When we started 12 to 13 years ago, maybe 14, with the record sheet, for example, we were getting, say, 8-9 drugs per patient, and after our education, our workshops in the Homes for elderly persons, with experts, we have come to the fact that today, older people, on average, are registered to take 3 drugs.” (IP010\_1, page 4, line 127-130)*

Examples of practices can be followed and, based on that, guidelines for reducing polypharmacy can be developed in the Reference Centre (IP05\_1, page2, line 57-59). The programme is based on a holistic assessment of the multi-morbid person, his/her capabilities and the environment around him/her - in addition to healthcare, it includes social clubs, funds, family, and volunteers (8). The Reference Centre has confirmed that the Programme is based on holistic assessment.

*IP: "GeroS is a holistic assessment and this is the aim of GeroS, because we really wish that everyone at their point of action, the scope of work, give own conclusion and opinion about that person." (IP010\_1, page 9, line 320-322)*

Holistic assessment is especially visualized through many non-institutional activities for elderly persons (IP05\_1, page 1, line 26-30). Social workers advise and encourage elderly persons to express themselves in the Home for the elderly (IP015\_1, page 8, line 275-282). Through GeroS, potential geriatric users can obtain information in a simpler manner and apply for available, adequate capacity in the Homes for elderly persons.

The programme allows planning of the necessary future capacity of Homes for elderly persons, easier and transparent review of waiting lists, and coordination with the possibilities of non-institutional care (3, IP010\_1, page 8, line 275-287). GeroS allows connection between the family doctor team with the community health nurse and institutions for: home care, physical therapy, and rehabilitation in homes and palliative-geriatric care.

*IP: "GeroS allows monitoring of treatment outcomes, it's very innovative, it will be seen where the system failed, where individuals failed, at which level of the system." (IP01\_1, page 6, line 207-208)*

Categorization of users entering a Home for elderly persons will rationalize costs of care (IP07\_1, page 3, line 79-82).

Informal caregivers are involved in the programme as family members or volunteers. The Reference Centre for Health Gerontology at the Teaching Institute for Public Health "Dr. Andrija Štampar" announces guidelines for the elderly on their web page, and extensively releases them through media. Family members can come to the Centre physically or call it via phone. Homes for elderly persons make

contract with volunteers (9). Social workers consider family and volunteers very useful in the patients' lives.

*IP: "They are primarily involved by giving us information about the users, I am talking about family, which is essential for us to know, to understand the structure of one's personality. They are important to us because they are our technical support, in the sense that they accompany users in some treatments, examinations, medical treatments, and so on. One aspect includes talking with users, walking with them outside, I don't know, visiting them instead of family members." (IP015\_1, page 14, line 532-538)*

The Reference Centre gives support to family members of the elderly and promotes such communication through media.

*IP: "Our programmes are media covered enough, and this is some kind of communication with the family. At any time, family, family members can come to us physically or call us on our phone numbers and contact us." (IP010\_1, page 6, line 210-212)*

The Reference Centre has noticed that volunteers do not help geriatric patients; they help their family to live with them after e.g. a stroke (IP010\_1, page 12, line 433-446).

The Manager of the Programme stresses associations and foundations for the elderly as informal caregivers (IP01\_1, page 7, line 251-253). GeroS includes various specialists in the interdisciplinary team. It includes all kind of medical professionals. From non-medical professions it includes social workers, occupational therapists, nutritionists, anthropologists, informal healthcare givers, volunteers, foster caretakers, patient associations, clubs, priests, and family (3, 10, IP010\_1, page 6, line 197-201).

The care process supports and improves continuity, comprehensiveness, and coordination of care for multi-morbid persons through the GeroS alarm system, which is continuous linkage of three levels of healthcare and informal caregivers with the patient in the centre. This attitude is visible at Gerontology workshops performed by the Reference Centre which empower staff that enter geriatric patient/insured person data in GeroS, and educate them to better understand the care process (3, 10, 11, IP010\_1, page 3, line 71-77.; IP010\_1, page 6, 197-201; IP010\_1, page 6, 204-207).

### 3.2.2. Self-management interventions

Patients/insured persons older than 65 are encouraged through written or oral instructions, practical education, and through individual conversations (IP07\_1, page 3, line 91-94; IP07\_1, page 3, line 84-89).

Self-management interventions are mostly well accepted by multi-morbid persons, but it depends on the character of the person alone. From one nurse experience, users often insist on self-management.

IT knowledge can help a lot in self-management interventions. Social workers have been noticing that it gives them a higher level of independence (IP015\_1, page 6, line 401-404). From the physician perspective, self-management interventions depend on the character of the person alone (IP06\_1, page 6, line 205-207).

Self-management interventions are also supported by volunteers (12).

Self-management interventions are supported by indirect empowerment from the Reference Centre for Health Gerontology. Through educational material and guidelines, we will raise the awareness of patients/insured persons about health with more knowledge (IP05\_1, page 3, line 73-77). GeroS follows negative health behaviour and will change the payment schema in the reimbursement process for the elderly; for example, a change of diet habits after myocardial infarction. It will include greater engagement of health professionals in primary care and in prevention actions to help them in their efforts.

*IP: "Within GeroS, in our Centre for Gerontology, we follow negative health behaviour; we are one of the first to monitor medical needs, meaning negative determinants of health behaviour that are specific just in a particular elderly gerontology patient and insured persons older than 65 ..... So there is a shared responsibility of monitoring the elderly, if they are still an alcoholic, if they still irresponsibly take medication, then a different billing of that service will be enacted." (IP01\_1, page 6, line 211-216).*

One physician emphasizes the responsibility of primary care.

*IP: „I think it could work on some kind or at a specific time on TV or in the newspapers, generally to expand it, and then on the other hand, every physician must assume that part themselves." (IP06\_1, page 6-7, line 218-220)*

### 3.3. Leadership & governance

Long term care and social care are part of the project. Long term care is still split between the healthcare system and the social welfare system (13, 14).

Long term medical care is provided in the stationary part of Homes for the elderly. All procedures are recorded in DOGMA, according to “Four degrees of geriatric care” (4, IP07\_1, page 4, 137-139). From the nurse’s perspective, in practice they are managed by the “Four degree of geriatric health care with nursing documentation”.

Social care is performed through the work of social workers with users in Homes for the elderly. They have an advisory role and spend a lot of time solving their basic social needs/rights related to accommodation and insurance (IP015\_1, page 3, line 131-143). The motivation for and purpose of the relationship/partnership, according to the Manager and Initiator of the Programme, is the overall rationalization of geriatric healthcare and costs related to it (3).

*IP: “.....to the goal is to rationalize the growing geriatric consumption, to actually not duplicate provided services, how to actually prevent and apply quaternary prevention for older people, and that means not applying excessive medicalization, non-invasive and unnecessary diagnostic pathways in the elderly, but rather to involve all participants which participate in the healthcare of older persons.” (IP01\_1, page 2, line 50-53)*

Partners in healthcare are now linked through CEZIH and will be linked through GeroS (1).

*IP: “GeroS allows monitoring of treatment outcomes, it’s very innovative, it will be seen where the system failed, where the individual failed, and at which level of the system.” (IP01\_1, page 6, line 207-208)*

Relevant barriers and facilitators can be only hypothetically assessed because GeroS is a pilot project.

The Reference Centre for Health Gerontology is under the jurisdiction of the Ministry of Health and has its support as a facilitating factor (IP01\_1, page 3, line 106-108).

The Project is now indirectly performed during regular work of different institutions: through the Central Health Information System of the Republic of Croatia, CEZIH - in some already existing components for all insured persons in the country, and through DOGMA, the IT system in some Homes for elderly

persons in Zagreb City which performs “Four degrees of geriatric healthcare with nursing documentation”, which are social care institutions. Homes for the elderly can be under different jurisdictions because they can be established by units of local and regional governments, cities and counties, religious groups, companies, associations, and other domestic or foreign legal or physical entities under the conditions prescribed by the Law on social care (15). Clear relationships between the Ministry of Health and Homes for the elderly were not seen in the interviews. As a consequence of the undefined relationship between the health and social sectors, nurses and social workers in social care institution felt a bit neglected (IP07\_1, page 4-5, line 132-139.; IP015\_1, page 9, line 315-324).

*IP: “And when medical staff, most often carer staff, not appointed nurses, but to highlight the carers, who believe that because they perform healthcare on the user, that they are more important than non-medical staff, which I am, I can, at some point, of course, agree that they are extremely important, but I cannot agree that my job is not important, because I do not exclude them, nor exclude myself. I think we both needed, again, together, to work.” (IP015\_1, page 19, line 713-718)*

The same impression regarding social care came from nurses in charge in the Reference Centre (IP013\_1, page 12, line 477-479). It will be a challenge to connect the now separate IT operations performed through CEZIH and DOGMA into one IT programme, organizationally (involving many different institutions), technically, and financially. At this moment this can be considered as barrier.

*IP: “This is a programme which I consider really valuable but it is still in the implementation phase, so to get what we expect, it will take more time and energy to enliven it in the way it is designed considering that it includes a lot of different institutions and technical implementation.” (IP05-1, page 1, line 17-19)*

### 3.4. Workforce

New professional roles must be developed from old professions with the prefix “geronto”, in order to provide specific care to geriatric persons. This must be introduced in the curriculum of their education. There is a lack of educators at the moment (1, IP01\_1, page 5, line 172-192). Through 48 geronto workshops, all already included staff (medical and social domain) gets familiar with new professional roles, and this can be taken as facilitating factor. Financing and less developed non-institutionalization are the most relevant barriers when implementing these “new” professional roles in the programme.



Even if a geronto housewife already has a place in CEZIH, the need for it is far greater (IP015\_1, page 7, line 250-257).

### 3.5. Technologies & medical products

In some Homes for elderly persons in Zagreb, the computer system DOGMA is installed. It is used to indirectly follow patients through an overview of performance of nurse and social worker tasks. Using it, the Manager of the Home has an overview of their work with the users and can perform reorganization (IP07\_1, page 5, line 146-152).

In Homes for the elderly there is an alarm system for urgent help, and nurses have pagers. Some users have tablets for communication with the kitchen (IP07\_1, page 5, line 167-174). Given the complexity of the whole GeroS system and the large number of entities which will be involved in it, the proposal is implemented in three stages (1):

**Phase 1:** Installing a central database, web applications, all web services, and then involvement of family doctors, social welfare centres, the Centre for Gerontology, the Croatian Health Insurance Fund, and the Croatian Institute for Public Health

**Phase 2:** Ministry (health, welfare), County/regional Centre for Gerontology, hospitals, all health institutions, community nurses, a web portal for the insured

**Phase 3:** Development of advanced reports and the inclusion of entities that bring auxiliary descriptive materials (volunteers, priests, foster parents, associations, etc.)

ICT applications are not yet used in whole range. Some of the documentation, which is predicted to be part of GeroS, is still in paper form. E.g. the Ministry of Health Reference Centre for Health Gerontology supplies Record sheets No 1 and 4, which are filled out partly on paper and partly electronically and have a connection with the web service NRS2002 (for nutritional risk screening 2002 – NRS 2002) and data in it. GeroS is designed to be an upgrade of that documentation and connection between documentation (16, 17). In the Homes for the elderly, some of the documentation regarding 4 degrees of geriatric care or from the social worker domain, which entered in the DOGMA system, is still in the paper form which slows down the workflow because data must be entered manually. In relation to DOGMA, GeroS is designed as an upgrade of DOGMA regarding the wide spectrum of data in it and the possibility of connectivity under the Central Health Information System of the Republic of Croatia

(CEZIH), as declared by non-physician medical staff from the Reference Centre (P010\_1, page 2, line 32-51).

One nurse educated at the Reference Centre workshops compared DOGMA and GeroS and stressed the importance of integration of medical and social data (IP01\_1, page 2-3, line 67-70).

As GeroS will be integrated in the Central Health Information System of the Republic of Croatia, all applications used through it (services, waiting lists, status of orthopaedic tools, number of drugs used by each user...) it will be visible, some of them as alerts, and used for the elderly in GeroS (18).

The Croatian Health Insurance Fund (HZZO) operates in the Central Health Information System of the Republic of Croatia, CEZIH. The head of its IT staff explained that their computer system is constantly upgraded with new applications e.g. for home care and physical therapy at home, e-medical aids, e-prescriptions. This will potentially be a part of GeroS (IP019\_1, page 2, line 58-63).

In GeroS, a patient with multiple illnesses will not have to go to their doctor to get confirmation for medical aids, they will just call them, and the doctor will release confirmation in CEZIH. The supplier and deliver of medical aids then will be able to reach it. The same principle already exists with prescriptions, and pharmacists see the benefit of it (IP19\_1, page 2, line 65-69). There is also a Patient Portal as the separate Module 13 in GeroS (1).

The most relevant barrier seems to be how to provide a sustainable financial budget for full integration of all GeroS Modules in CEZIH, on the national level. One possibility could be the usage of Structural EU funds. This is also connected with political, legal, and organizational aspects.

In HZZO, they are of the opinion that in relation to already existing components (the preventive panel and chronic disease panel) in CEZIH, which can be used by GeroS, benefits regarding rationalization of costs will be obtained through connection of services (IP019\_1, page 2, line 79-82). Namely, in primary care there exist preventive panels and chronic panels. The elderly with multi-morbidity are already involved in them. There are also national preventive programmes which are not strictly intended for insured persons older than 65. Anyone who lives and has residence in Croatia is involved according the programme schedule. The structure of GeroS related to primary and secondary healthcare is *de facto* finished. GeroS gets stuck on the mobile teams, e.g. mobile dentist who would then go to a Home for

the elderly (IP019\_1, page 3, line 94-102). It seems that primary healthcare is very well ICT covered and that possible obstacles for involving GeroS are on the hospital level.

*IP: "Always everyone complains that there is little money. Understand? But other obstacles, no one mentions them. Because this group used it, the obstacles are mostly in hospitals. In primary care, they are all now computer literate and it is for them ... nothing new. So, it is made as application-friendly to them so that they don't refuse to work with it." (IP019\_1, page 4, line 160-163)*

It is interesting that HZZO recommend computerization of volunteers (IP019\_1, page 5, line 174-180).

HZZO cannot see a clear relationships in caring for the elderly, because on the one hand, Homes for elderly persons (social welfare) can have different owners and, on the other hand, all persons in Croatia are insured by HZZO and because of that included in CEZIH (IP019\_1, page 7, line 254-263).

The most relevant facilitator is the fact that most of the applications intended to be used in GeroS already exists in CEZIH, integrated in their pathways. For upgrading of existing Modules, public tender will probably be announced (IP019\_1, page 7, line 276-278). Beside that, IT experts from CEZIH have lot of experience with e-mobile health and medical records which already exchange information with some European countries (IP019\_1, page 4, line 128-134). All partners included in the project see that it will be a valuable tool in everyday work and express enthusiasm in building it.

*IP: "Everyone has a common goal and indeed all the partners would like to participate in this project and... they are full of ideas to improve it, to do it better." IP019\_1, page 8, line 300-301.*

### 3.6. Information & research/monitoring

There will be systematic data collection within the programme. All health data which already exist in CEZIH for insured persons older than 65 and geriatric patients will be relocated to its subsystem GeroS, created for those older than 65. GeroS will be used as the main identifier and identification number of the insured. Attributes associated with a person under each ID contain information on the name, last name, gender, date of birth, personal identification number, and address in a structured format.

According current legislation, monitoring is provided by two types of records (Record sheet No 1 sent from Homes for the elderly and Record sheet No 4, sent from Gerontology centres. Record sheets are collected and processed in the Ministry of Health Reference Centre for Health Gerontology):

Record sheet No 1 is for monitoring of the health needs of insured persons older than 65 in Homes for the elderly, and Record sheet No 4 is for the monitoring of health and social needs of the elderly in non-institutional care - Geriatric Centres.

**Record sheet No 1** is filled out partially in a paper version and partially electronically. It is filled out by medical staff (nurses and physicians). It is related to the following functional units of **monitoring individual insured persons older than 65**: age, gender, occupation of insured persons older than 65 before retirement, mobility in relation to the physical status (completely mobile, limited mobility, a permanently limited mobility, permanently paralyzed), independence regarding mental status (completely independent, self-limited, permanently dependent, cannot be determined), negative health behaviour related to smoking and alcoholism, obesity and malnutrition, blood pressure (mmHg), the value of total cholesterol in the blood (mmol/L), glucose in blood, BMI index, body weight, urinary disorders, prescribed medication by the ATC system, the form of prescription, reason for discharge in case of death, reason for hospitalization or transfer to another social institution, or relocation.

**Record sheet No 4** includes **monitoring and evaluation of gerontology determinants, using particular geroprofilactic measures in general/family medicine**. It is filled out by social workers.

Data will be grouped and matched for a registry of medical needs and the functional capacity of older people (with a sub registry for people older than 100 years); it will used for analyses, reports, files of the program's evaluation, and professional-methodological instructions for implementation - in order to prevent gerontology duplication (NO overlapping) and the differentiation of medical procedures of the monitored determinants of insured persons older than 65 and geriatric patients, to give a “signal” to other participants in the whole chain for proactive measures.

Even though it is in a pilot phase, a monitoring system is provided for the programme. According to the Manager and Initiator of the Programme, monitoring is predicted in the form of a quality manual with standardized questionnaires for quality in social care institutions (IP01\_1, page 10, line 382-397).

The quality assurance system has not yet been established within the programme. Until the programme is systematically established, the Ministry of Health Reference Centre for Health Gerontology processes records obtained from Record sheets No 1 and 4, and publishes the results in the Health Service Yearbook of Zagreb City for 2015 (19).

### 3.7. Financing

According to data from the Ministry of Social Policy and Youth, MSPM, the owners of Homes for elderly persons in Croatia can be states or counties, towns, associations, religious communities, and private physical or legal entities. For all of them it is essential that service providers meet the requirements stipulated by the Ordinance on the minimum requirements, and that they are enrolled in the Ministry's (Ministry of Social Policy and Youth, MSPM) register of service providers.

Accommodation is a social service, which may include housing, feeding, caring about health (not health services), social worker services, psychosocial rehabilitation, physical therapy, occupational therapy, and activities in free time, depending on the identified needs and the user's choice. When service providers provide the accommodation service, it is implied that they provide a full "package" of the aforementioned activities. Those providers who have contract with the Ministry are in the network, all others are outside it.

Services outside the network are provided entirely on a free-market basis and the accommodation service fee is paid from the users' own income on a monthly basis. The Ministry pays providers for those users who are accommodated on the basis of a social care centre decision. The user has to participate with all their income and properties in paying for their accommodation.

The unit of account is the number of users to which accommodation services are provided, not the number of service activities. The Ministry pays the service provider according to the number of users and the number of days (how many times each user used accommodation services), on the basis of invoices.

MSMP cannot pay a provider for healthcare because the Croatian Health Insurance Fund does not allocate many funds for it. Depending on the service provider (private entity or state), workers are paid from the funds remitted for accommodation. Doctors' services: Home users are their users in primary healthcare, insured by the Croatian Health Insurance Fund; their visits are considered Home visits. The

doctor is not constantly present, and when they do not work or are not on duty, the Home engages emergency services. Insured persons older than 65 /patients are insured by the Croatian Health Insurance Fund, regardless of the proprietor (owner) of Home. The Manager and Initiator of the Programme states that the money exists, although financing is considered a barrier to put GeroS into function.

*IP: "Today, the programme "Four degrees of geriatric healthcare" is conducted in Homes for elderly persons, with GeroS and with the informatics firm that made this possible. But this is still not unified at the level of Croatia for which the Croatian Health Insurance Fund has responsibility, for which it certainly has funds and has received funds. Croatia has the resources to improve healthcare for the elderly, it just needs to redistribute them ..... experts gets the impression that there is a waste of funds in the health system". (IP01\_1, page 8, line 314-317)*

A representative of the sponsor/funder confirmed that there is no knowledge regarding financing of GeroS.

*IP: "Now ... Since I have no knowledge that the Croatian Health Insurance Institute is directly involved in financing the development of GeroS, the Croatian Institute for Health Insurance for people who are covered by that programme actually pays health safeguards in accordance with the valid Law and Decision." (IP03\_1, page 1-2, line 31-34)*

Incentive systems for multi-morbid persons and professionals are not presented.

### 3.8. Implementation process

As already written, the project is in a pilot phase. For sustainable national implementation, some important decisions should be made in the near future, related to legal, financial, and organizational issues. The implementation process at the national level has not started yet. There is a high level of political commitment to support the implementation of the programme. The most relevant barrier to bridge the gap between the pilot programme and its realization is how to provide a sustainable financial budget for the full integration of all GeroS Modules into CEZIH, on the national level, as a full connection with social care. One possibility could be usage of Structural EU funds. Cultural changes were not mentioned in the programme.

An IT professional from the Croatian Health Insurance Fund (HZZO) stated that the implementation of GeroS must be solved by national consensus.

*IP: "And, it is normally associated with finance, but I think, the decision on the movement of something like that must be a national consensus. As the consensus when we computerized primary care." (IP019\_1, page 8, line 316-318)*

It was added that in HZZO they already have an IT solution for taking over data (transfer) from primary care to Homes for elderly persons. Political will is an important factor. It has also been noticed that it will be necessary to make adaptations for different categories of insured persons older than 65 , e.g. for farmers (IP019\_1, page 8, line 297-300). The most relevant facilitators are the enthusiasm of project holders and recognition of the importance of the project in society (Ministries, professionals, patients associations).

*IP: "Everyone has a common goal and indeed, all the partners would like to participate in this project and... they are full of ideas to improve it, to do it better." (IP019\_1, page 8, line 308-309)*

### 3.8.1. Historical information

Improvement of healthcare for the elderly and cost rationalization was the main goal in starting the programme. An initiative was launched (June 6, 2014) from the Ministry of Health Reference Centre for Health Gerontology - - Andrija Stampar Teaching Institute of Public Health in coordination with the Croatian Health Insurance Fund and Alma mater Europea, for introducing determinants of monitoring health needs of insured persons older than 65 in institutional and non-institutional care for elderly persons in the Central Health Information System of the Republic of Croatia (CEZIH). Policy makers, funders, and professionals were all involved in the process (1).

### 3.8.2. Present information

This is still a pilot project, but some results are visible on a restricted sample of geriatric participants.

### 3.8.3. Future implementation/development

Political support has generally been obtained for further sustainable development at the national level, through different development phases envisaged in 2017, 2018, and 2019. Detailed financial and some legal structures should be completed in the near future.

## 3.9. Discussion

### 3.9.1. General discussion

The Programme under the brand name GeroS represents an integrated care model for geriatric patients with multi-morbidity. It is in a pilot phase and is designed as a fifteen-Module system for monitoring and evaluation of health needs and functional ability of insured persons older than 65 and geriatric patients older than 65. The system is inseparably linked to the national health system CEZIH (Central Health Information System of the Republic of Croatia) as its subsystem in which all records already provided from health and social care services will be “pulled” or relocated on the insured person’s 65<sup>th</sup> birthday. The Programme will be fully integrated through step-by-step implementation of different Modules into CEZIH. It is currently mainly on the primary healthcare level. The current situation is that the Ministry of Health Reference Centre for Health Gerontology collects, extracts, and assesses data from Record sheet number 1 (monitoring of health needs in Homes for elderly persons) and Record sheet number 4 (monitoring the health and social needs in the Geriatric Centres and in the non-institutional care for elderly persons).

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

#### Service delivery

According to Project documentation, GeroS includes: primary healthcare specialists - consulting healthcare, hospital healthcare and long-term care, Homes for elderly persons, and Centres for social care. From the Initiator and Manager of the Programme (the Ministry of Health Reference Centre for Health Gerontology) we found out that GeroS exists within the Central Health Information System of the Republic of Croatia (CEZIH) only at the primary healthcare level. There is a special application in the frame of the primary healthcare panel which is filled out electronically. Evaluation criteria of the Programme have not yet been seen. Even in the developmental phase, from the perspective of the included workers, the Programme is recognized as useful and valuable. When it is fully integrated, it will



connect different sectors-institutions, contribute to better cooperation between employees, involve rationalization in the health system and, what is most valuable, give patients “more different approaches” to their physician and the entire health system. It is important to stress that CEZIH, as a health information system, is not implemented in all Homes for elderly persons (social care), but in primary care there exist preventive panels and chronic panels for all persons with health insurance. This means that elderly persons with multi-morbidity are already involved. There are also national preventive programmes which are not strictly targeted at insured persons older than 65. Anyone who lives and has residence in Croatia is involved according to the programme schedule. Care pathways, including 24/7 care and proactive care, are described in detail in the nurse documentation for geriatric healthcare in Homes for elderly persons: “Four degrees of geriatric healthcare with nursing documentation and procedural guide for general/family medicine in the Homes for elderly persons with categorization guidelines”. It serves as the standard of the Croatian Nursing Chamber. Nursing documentation consists of 19 Forms - some of them exist in an electronic form, some in a paper version.

DOGMA is an ICT programme used in Homes for elderly persons in the capital city of Zagreb. Its owner is the City Department of Social Welfare and Persons with Disabilities. Nurses from the Homes for elderly persons consider GeroS an advantage, as an upgrade to DOGMA which will provide better connection between patient data and between services provided to them. GeroS will assure integrity and continuity of insured persons older than 65 during accommodation in a Home, in the residential or stationary part, e.g. after return from hospital care.

The Ministry of Health Reference Centre for Health Gerontology receives paper and electronic versions of Record sheets. Through application of the “Four degrees of geriatric healthcare”, data are currently collected from many Homes for elderly persons. All records collected in the Reference Centre are transferred into indicators for future care planning. Non-physician medical staff from the Reference Centre stress that, in addition to nurse documentation, all data from Records sheets are valuable in order to deeply understand the work of all stakeholders (e.g. social worker, occupational therapist). Record sheet number 4 differs slightly from 1 and it is not filled out by healthcare practitioners, nurses, or doctors, as is record sheet number 1; it is filled out by a social worker. Nurse documentation and Record Sheets 1 and 4 produced in GeroS allow production of guidelines for an individual geriatric approach in geriatric care – a person-centred attitude. An individual care plan and risk stratification is provided through the Programme “Four degrees of geriatric healthcare monitoring”. It includes proactive care. Nurses and physicians from Homes for the elderly confirm that the purpose of nursing

documentation is the individual approach to the patient's needs. Employees give their best to achieve it. A physician from a Home for the elderly always has an individual care plan for a patient. A physician from the Reference Centre also confirmed that individual care plans can be seen and that the Programme implemented risk stratification. He said that guidelines for care can be produced in the Programme, but the Programme is intended for monitoring and the patient's personal goals cannot be seen from it. GeroS gives a "signal" to a general/family doctor about the terms for preventive or systematic examination of the elderly. In the Programme, the main carrier of protection of the health of the elderly is the general/family doctor supported by instructions from the Reference Centre. GeroS enables a link with the community health nurse. By screening for nutritional risk in the elderly (using the method of Nutritional Risk Screening 2002 - NRS 2002), the nurse prevents possible hospitalizations of the elderly arising from malnutrition and from the use of psychiatric drugs, because depression is frequently anticipated as a reason for malnutrition. Regarding management of polypharmacy and guideline interaction, GeroS allows primary care practitioners to regularly "audit" lists of drugs which geriatric patients (65 +) take. An interviewed primary care physician agreed that the Programme helps in reducing polypharmacy. In the Reference Centre, they have noticed that the Programme significantly reduces the number of drugs per patient and is useful for development of guidelines for preventing polypharmacy. The Programme is based on a holistic assessment of the multi-morbid person, his/her capabilities, and the environment around him/her - in addition to healthcare, it includes social clubs, funds, family, and volunteers. Through GeroS, potential geriatric users can obtain information in a simpler manner and apply for available, adequate capacity Homes for the elderly. The Programme allows planning of the necessary future capacity of Homes for the elderly, easier and transparent review of waiting lists, and coordination with the possibilities of non-institutional care.

GeroS allows a connection between the family doctor team with the community health nurse and institutions: for home care, physical therapy, and rehabilitation at home and palliative-geriatric care. Informal caregivers are involved in the programme as family members or volunteers. The Reference Centre gives support to family members of the elderly and promotes such communication through the media. The Manager of the Programme stresses associations and foundations for the elderly as informal caregivers. The rationalization of geriatric healthcare, through categorization of geriatric patients and insured persons older than 65, in institutional and non- institutional care will be obtained.

## Self-management interventions

Self- management interventions are encouraged in patient/insured persons older than 65 through written or oral instructions, practical education, and through individual conversations. They are mostly well accepted by multi-morbid persons. One nurse has described how she encourages users in her Home for elderly persons on self-management interventions. Through this, users help her and other staff to achieve staffing norms. From her patient experience, users often insist on self-management. IT knowledge can help a lot in self-management interventions. Social workers have noticed that it gives users a higher level of independence. From a physician perspective, self-management interventions depend on the character of the person alone. Self-management interventions are also supported by volunteers. The Reference Centre for Health Gerontology supported self-management interventions by indirect empowerment, through educational material and guidelines which raise awareness in patients/insured persons to care about their health with more knowledge. GeroS monitors negative health behaviour and will change the payment schema in the reimbursement process for the elderly. For example, changes in diet habits after myocardial infarction will be monitored. This will include greater engagement of health professionals in primary care and in prevention actions to help the elderly in their efforts. One physician emphasizes the responsibility of primary care.

## Leadership & governance

Political support for the Programme has been obtained. The Reference Centre for Health Gerontology is appointed by the Ministry of Health. There is agreement at the international level with Alma Mater Europea. The Reference Centre for Health Gerontology is under jurisdiction of the Ministry of Health and has its support as a facilitating factor. The motivation for and the purpose of the relationship/partnership, according to the Manager and Initiator of the Programme, is the overall rationalization of geriatric healthcare and costs related to it. Partners in healthcare are now linked through CEZIH, and in the future they will be linked through GeroS. Relevant barriers and facilitators can be only hypothetically assessed because GeroS is a pilot project.

The project is now indirectly performed during regular work of different institutions:

1. Through the Central Health Information System of the Republic of Croatia, CEZIH - in some of already existing components for all insured persons in the country, and,
2. Through DOGMA, an IT system in some Homes for the elderly in Zagreb City which performs “Four degrees of geriatric healthcare”, which are social care institutions.

Homes for elderly persons can be under different jurisdictions because they can be established by the state, units of local and regional governments, cities and counties, religious groups, companies, associations, and other domestic or foreign legal or physical entities under the conditions prescribed by the Law on social care. Clear relationships between the Ministry of Health and Homes for the elderly were not seen in the interviews. As a consequence of undefined relationship between the health and social sectors, nurses and social workers in social care institutions felt a bit neglected. The same impression regarding social care nurses was found in nurses in charge of the Reference Centre. Social care is performed through the work of a social worker with users in Homes for the elderly. They have an advisory role and spend a lot of time solving the basic social needs/rights related to accommodation and insurance. Long-term care and social care are part of the project. Long-term care is still split between the healthcare system and the social welfare system. Long-term medical care is provided in the stationary part of Homes for elderly persons. All procedures are recorded in DOGMA according to the “Four degrees of geriatric care”. It will be a challenge to connect the now separate IT operations performed through CEZIH and DOGMA into one IT programme, organizationally (many different institutions involved), technically, and financially. At this moment this can be considered a barrier.

## Workforce

New professional roles will be developed from already established professions and must be created with the prefix “geronto” in order to provide specific care to geriatric persons. This must be included in the curriculum of their education. There is lack of educators at the moment. GeroS includes various specialists in the interdisciplinary team. It includes all kind of medical professionals. From non-medical professions, it includes social workers, occupational therapists, nutritionists, anthropologists, informal health care givers, volunteers, foster caregivers, patient associations, clubs, priests, and family. Through 48 geronto workshops, all already included staff (medical and social domain) became familiar with their new professional roles, and this can be taken as facilitating factor. Financing and less developed non-institutionalization are the most relevant barriers when implementing these “new” professional roles in the programme. Even if a geronto housewife already has a place in CEZIH, the need for it is far greater. One social worker from a Home for the elderly told us that they cannot provide service for users with different types of dementia because additional specialists and more working space are needed. One nurse from a Home for the elderly noticed a deficit in staff, especially career physicians. IT personnel see a lack of mobile teams, e.g. a mobile dentist who would go to a Home for the elderly.

## Technologies & medical products

Given the complexity of the whole GeroS system and the large number of entities which will be involved in it, the proposal is implemented in three stages: Phase 1: Installing a central database, web applications, all web services, and then involvement of family doctors, social welfare centres, the Centre for gerontology, the Croatian Health Insurance Fund, the Croatian Institute for Public Health; Phase 2: Ministries (health, welfare), County/regional Centres for gerontology, hospitals, all health institutions, community nurses, and a web portal for the insured persons; and Phase 3: development of advanced reports and the inclusion of entities that bring auxiliary descriptive materials (volunteers, priests, foster parents, associations, etc.).

ICT applications are not yet used in the whole range possible. Some of the documentation, which is predicted to be part of GeroS, is still in paper form. The Reference Centre for Health Gerontology supplies Record sheets No 1 and 4, which are filled out partly on paper and partly electronically and are connected to data in the web service NRS2002 (for nutritional risk screening 2002 – NRS 2002). GeroS is designed as an upgrade of that documentation and connection between different types of documentation. In the Homes for elderly, some of the documentation regarding “Four degrees of geriatric care” or documentation from the social worker domain, which is entered in DOGMA system, is still in paper form which slows down the workflow because data must be entered manually. In relation to DOGMA, GeroS is designed as an upgrade of DOGMA regarding the wide spectrum of data in it and possibility of connectivity under the Central Health Information System of the Republic of Croatia (CEZIH), as declared by non-physician medical staff from the Reference Centre. As GeroS will be integrated in CEZIH, all of the applications used through it (services, waiting lists, status of orthopaedic tools, number of drugs used by each user...) will be visible, some of them as alerts. IT staff from the Croatian Health Insurance Fund (HZZO), which operates in CEZIH, explained that their IT system is constantly upgraded with new applications, e.g. for home care and physical therapy at home, e-medical aids, and e-prescription. This will be the potential part of GeroS. In GeroS, a Patient portal is scheduled as the separate Module 13. The most relevant barrier seems to be how to provide a sustainable financial budget for the full integration of all GeroS Modules in CEZIH, on the national level. One possibility could be usage of Structural EU funds. This is also connected with political, legal, and organizational aspects. IT personnel from HZZO have the opinion that in relation to already existing components (the preventive panel and chronic disease panel) in CEZIH, which can be used by GeroS, a benefit regarding rationalization of costs through will be obtained connection of services. They consider primary

healthcare very well covered by ICT and see possible obstacles for involving GeroS on the hospital level. Furthermore, they advocate computerization of volunteers. Staff cannot see clear relationships in caring for the elderly, because the Homes for the elderly (social welfare) can have different owners, and individuals are insured by HZZO. The most relevant facilitator is the fact that most of the applications intended to be used in GeroS already exist, integrated in its pathways. Upgrading of the existing structure will be needed according to education from the Reference Centre of the Ministry of Health for protection of the elderly.

In addition to this, IT experts from CEZIH have a lot of experience with e-mobile health and medical records which are already exchanged with some European countries. All partners included in the project see that GeroS will be a valuable tool in everyday work and express enthusiasm in building it.

### Information & research/monitoring

There will be systematic data collection within the programme. All health data which already exist in CEZIH for insured persons older than 65 and geriatric patients will be relocated to its subsystem, GeroS, created for persons older than 65. GeroS will be used as the main identifier and identification number of the insured persons. Attributes associated with a person under each ID contain information on the first name, last name, gender, date of birth, personal identification number, and address in a structured format. According to current legislation, monitoring is provided by two types of records (Record sheet No 1 sent from Homes for elderly persons and Record sheet No 4, sent from Gerontology centres. Record sheets are collected and processed in the Reference Centre for Health Gerontology):

**Record sheet No 1** is filled out partially in a paper version and partly electronically. It is filled out by medical staff (nurses and physicians). It is related to the following functional units of **monitoring individual insured persons older than 65**: age, gender, occupation of insured persons older than 65 before retirement, mobility in relation to the physical status (completely mobile, limited mobility, a permanently limited mobility, permanently paralyzed), independence regarding the mental status (completely independent, self-limited, permanently dependent, cannot be determined), negative health behaviour related to smoking and alcoholism, obesity and malnutrition, blood pressure (mmHg), the value of total cholesterol in the blood (mmol/L), glucose in blood, BMI index, body weight, urinary disorders, prescribed medication by the ATC system, the form of prescription, the reason for discharge in case of death, the reason for hospitalization or transfer to another social institution, or relocation.

**Record sheet No 4** includes **monitoring and evaluation of gerontology determinants, using particular geroprofilactic measures in general/family medicine**. It is filled out by social workers.

Data will be grouped and matched for a registry of medical needs and functional capacity of older people (with a sub registry for people older than 100 years); it will be used for analyses, reports, files on the programme's evaluation, and professional-methodological instructions for implementation - in order to prevent gerontology duplication (NO overlapping) and the differentiation of medical procedures of the monitored determinants of insured persons older than 65 and geriatric patients, to give a “signal” to other participants in the whole chain of care for proactive measures. A monitoring system is provided for the programme. According to the Manager and Initiator of the Programme, monitoring is predicted in the form of Quality manual and standardized questionnaires on quality in the social care institutions. The quality assurance system has not yet been established within the programme. Until the programme is established, the Reference Centre for Health Gerontology processes records obtained from Record sheets No 1 and 4, and publishes results in the Health Service Yearbook of Zagreb City for 2015.

### Financing

A representative of the sponsor/funder confirmed that there is no knowledge regarding the financing of GeroS. An IT professional from the Croatian Health Insurance Fund (HZZO) stated that implementation of Geros must be solved by a national consensus, as it was for primary care computerization, probably through an announcement on public tender. The Manager and Initiator of the Programme state that the money exists, although financing is considered a barrier to put GeroS in function.

According to data from the Ministry of Social Policy and Youth, MSPM, the owners of the Homes for elderly persons in Croatia can be states or counties, towns, associations, religious communities, and private physical or legal entities. For all of them it is essential that service providers meet the requirements stipulated by the Ordinance on the minimum requirements and that they are enrolled in the Ministry's (Ministry of Social Policy and Youth, MSPM) registry of service providers. Accommodation is a social service, which may include housing, feeding, caring about health (not health services), social worker services, psychosocial rehabilitation, physical therapy, occupational therapy, and activities in free time, depending on the identified needs and the user's choice. When the service provider provides the accommodation service, it is implied that they provide a full “package” of aforementioned activities. Those providers who have contract with the Ministry are in the network, all others are outside of it. Services outside the network are provided entirely on a free-market basis, and the accommodation

service fee is paid from the users' own income on a monthly basis. The Ministry pays providers for those users who are accommodated on the basis of a social care centre decision. The user has to participate with all their income and properties in paying for their accommodation.

The unit of account is the number of users to which accommodation services are provided, not the number of service activities. The Ministry pays the service provider according to the number of users and the number of days (how many times each user used accommodation services), on the basis of invoices.

MSMP cannot pay the provider for healthcare because the Croatian Health Insurance Fund does not allocate many funds for it. Depending on the service provider (private entity or the state), workers are paid from the funds remitted for accommodation. Doctors' services: Home users are their users in primary healthcare, insured by the National Reimbursement Fund; their visits are considered Home visits. The doctors are not constantly present, and in case they are not working or are not on duty, the Home engages emergency services.

Insured persons older than 65 /patients are insured by the Croatian Health Insurance Fund, regardless of the proprietor (owner) of the Home.

Incentive systems for multi-morbid persons and professionals have not been presented yet.

### 3.10. Appendix – Original Quotes

IP: Ono što sada postoji, postoji u okviru CEZIH-a, postoji na razini PZZ posebna aplikacija u okviru panela koju on ispunjava elektroničkim putem. Istovremeno dok još ne postoji i nije implementiran u okviru CEZIH-a jer taj CEZIH ne živi danas, u ovom trenutku, nije implementiran u sve domove za starije osobe, dakle dio liječnika ga različitim ugovorom o radu ispunjava, dio ne. Dio glavnih sestara u domovima ga ispunjava, dio ne. Ovisi koliko je čisto tehnološki informatizacija prisutna. U tom procesu on ispunjava istovremeno papirnatu evidencijsku listu, sve tražene determinante koje može i elektronički. Mi zasada dobivamo i jednim i drugim putem. Naša aplikacija programa 4 stupnja gerijatrijske zdravstvene njege. Zapravo u mnogim domovima GEROS kroz ta 4 stupnja već živi. Operativno nama već dolaze pokazatelji i možemo danas govoriti o preprojekcijama budućnosti da u Hrvatskoj u okviru gerontološke i gerijatrijske zaštite je neophodan razvoj izvaninstitucijske skrbi za starije - to su Gerontološki centri koji postoje. Dakle razvoj i uključivanje ovih segmenata i drugo kad je nužno gerijatrijsko liječenje, strogo je praćeno pitanje kvalitete nepotrebnog ležanja gerijatrijskih bolesnika u akutnim krevetima nego strogo na gerijatrijskim posteljama. IP01\_1, page 8, line 273-277.



IP: Ja moram priznati da, s obzirom da je GeroS u fazi razvoja, mi nismo vidjeli, zapravo, završni proizvod i definitivno Hrvatski zavod za zdravstveno osiguranje i njegovi djelatnici sudjeluju u razvoju sustava, baš iz tog razloga, da bi povezali sve potrebne i adekvatne podatke tako da, ja vam za sada ne mogu reći koja su očekivanja ispunjena jer se nadamo da će očekivanja, u ovom djelu, vezano uz zdravstveno osiguranje biti implementirana u tijeku razvoja sustava. Koja očekivanja nisu ispunjena? Ja znam, za sada, da nije izravno sve povezano u smislu da liječnici koji rade na bilo kojoj razini zdravstvene zaštite ne moraju dodatno nešto unositi, bilo koji podatak, već da se ti svi podaci generiraju iz onog njihovog kliničkog rada koji oni obično rade, mislim da je to jedno od očekivanja koje bi svi voljeli da se ispuni. Što se tiče evaluacijskih kriterija, koliko ja znam, za sada oni, iz perspektive ove, nisu definirani. Znači, šta bi to bilo, koji bi bio dio ciljeva naše uključenosti i osnovom toga da li smo ih mi ispunili. IP03\_1, page 5, line 162-163.

IP: ....čisto da se nekakva racionalizacija uvede u taj sustav, čisto...Jer mislim da... Mislim da se možda troši previše, više nego što se može, to se sigurno troši. Ja nemam uvid u financijsko stanje Ministarstva zdravstva, ali voljela bi da se poradi prije svega to, da i pacijenti dobiju nekakv drugačiji pristup nama kao pružateljima usluge i cijelom sustavu..... IP06\_1, page 9, line 309-312.

IP: Kada bi se stvarno pokazalo da je i došlo do racionalizacije lijekova, i do bolje suradnje specijalista i primarne zdravstvene zaštite, kada bi se sve to pokazalo, mislim da bi to bilo najveće i najbolje ostvarenje da se ta cijela zdravstvena zaštita digne na neki novi nivo. IP06\_1, page 12, line 412-414.

IP: Kao voditeljica Referentnog centra Ministarstva zdravlja za zaštitu starijih osoba koji je ujedno Centar za, imenovani znači, Centar za zdravstvenu gerontologiju Nastavnog zavoda za javno zdravstvo "Dr. Andrija Štampar" .... IP01\_1, page 1, line 9-11.

IP: Ono što moramo odmah na početku kazati da zapravo smo mi dio tijela koji je povezan funkcijski sa Ministarstvom zdravlja, to znači da smo mi imenovani od njih, dakle na svaki njihov upit mi odgovaramo i šaljemo izvješća. IP01\_1, page 3, line 106-108

IP: U program sam uključena od početka upravo zbog programa Četiri stupnja gerijatrijske njege sa sestrinskom dokumentacijom. Sudjelovala sam na nekoliko radionica. Jedna od tih radionica upravo je bila održana u Domu za starije Centar, Klaićeva, ovdje. IP01\_7, page 1, line 11-12.

IP: DOGMA se uklapa u GEROS, to je moje mišljenje, samo je GEROS širi pojam, obuhvaća više sudionika, a DOGMA se odnosi samo unutar nas, unutar kuće. Zapravo u nekim segmentima nismo povezani ni sa računovodstvom i unutar kuće fali. DOGMA je zamišljena da se nadograđuje. Mi to već imamo, ali GEROS bi bio puno opširniji. IP07\_1, page 5, line 156-159.

IP: Ako bi to bilo sve tako kako GEROS, kako je napravljeno, onda bi....zvoni mobitel...to bilo dobro i za nas djelatnike, a i korisnike jer ne bismo lutali za informacijama jer ako meni neki novi korisnik dođe u kuću ja već od

nekuda imam podatke putem GEROS-a, to je jedno praćenje, kontinuirano, da nemamo više jedno takvo rasulo – mi vodimo ovo, oni vode ono... IP01\_1, page 2-3, line 67-70.

IP: Tužna sam zbog toga jer vidim u GEROS-u da bi se to moglo objediniti jer mi imamo kategorizacijski, kroz sestrinsku dokumentaciju i to je stvarna slika koju uslugu korisnik treba i što mu je potrebno, a da se to ne gleda na taj način u domovima socijalne skrbi jer se korisnici kategoriziraju na osnovi socijalnih usluga po stupnjevima pa je to sad..nema pisani trag o nečemu kao što je to kroz sestrinsku dokumentaciju. U DOGMI imamo puno toga, ja korisniku mogu sutra dati, bilo kojem od njih, u kojem stupnju je njege, što mu se pruža, imamo parametre kroz hranjenje, pa je li samostalan, nije, dobijem zbroj bodova točno na ime i prezime dobijem u kojem stupnju njege je. IP01\_7, page 4-5, line 132-139.

IP: I četvrti stupanj usluge koju mi imamo predviđenu, ali nažalost zbog organizacijskih i financijskih uvjeta ne možemo pružati, ali predviđeno imamo četvrti stupanj usluge su korisnici koji su oboljeli od raznih vrsta demencija. Međutim, evo, za sad ne možemo taj oblik skrbi pružati jer znamo svi da su nam, evo, da je za to ipak potrebno malo više i stručnjaka i znanja i organizacijski prostora, drugačije, koje mi ovdje ne možemo osigurati. IP015-1, page 6, line 189-193.

IP: Pa, problem... problem, ja ću to reći bez obzira što se snima, je manjak osoblja. To je prvenstveno problem koji za sobom vuče ne probleme, tu ne smijemo imati probleme, mi to moramo sve riješiti, ali to je nešto što nama koči puno, puno stvari, koje bi mogle bit na puno boljem i višem nivou nego što su sada. Ja sad govorim za stambeni, jer ja sam dosta dugo sestra dolje na tom sad dijelu. Dolje dvije njegovateljice na tih 60 ljudi, mislim da se nikome ne mora objašnjavati šta te žene dolje proživljavaju. IP014\_1, page 4, line 142-147.

IP: Surađujem sa svim, dakle, eemmm, stručnjacima, koji se bave zaštitom zdravlja starijih osoba, dakle po cijeloj županiji, Hrvatskoj, i to su svakodnevni upiti. Postoje, eemmm, eeemmm, postoje eeemmmm, različite potrebe i poteškoće kako stručnjaka, tako i članova obitelji koji brinu o svojim eemmm, eemmm, o svojim eeemmm, eeemmm, roditeljima, starijim osobama, dakle i tu redovito odgovaramo na, na upite i zaista na jedan kvalitetan način pokušavamo zajedno riješiti te svakodnevne poteškoće. IP013\_1, page 4, line 139-144.

IP: Dakle, ono što sam već maloprije spomenula, znači, najveći dio mog posla GeroS-a su, znači, te Evidencijske liste 1 i 4 za praćenje zdravstvenih potreba u Domovima za starije, dakle, to je jedna evidencijska lista sastavljena od vodeće dijagnoze, prateće dijagnoze, stupnjeva samostalnosti, stupnjeva pokretljivosti, propisivanih lijekova, kroz nju se prati negativno zdravstveno ponašanje, vrijednost kolesterola starije osobe, tlak se prati, zatim, ovoga, nekih osobnih podataka, znači, ovoga, datum rođenja, datum i spol koji je nama izrazito bitan prilikom naših analiza, jer nas kroz te evidencijske liste nikad ne zanima ime i prezime same osobe, nego nas zanima u kojoj je on dobnoj skupini, da li je ranija, srednja ili duboka starost, ovoga, da možemo reći, ne znam, kakva je osoba s 80 godina - da li je funkcionalna, samostalna ili nesamostalna, da li može funkcionirati i to je to. To je recimo moj posao, što sam radila jučer, danas, prekjučer i što ću raditi sutra dok GeroS ne zaživi, a, ovoga apostrofirala bi još i taj Gerontološki

centar, Evidencijsku listu broj 4, on se malo razlikuje od te liste i nju ne ispunjava, recimo, zdravstveni stručnjak, tipa medicinske sestre ili liječnik kao što ispunjava Evidencijsku listu broj 1, nego ju ispunjava socijalni radnik. IP010\_1, page 3, line 83-95.

IP: U sklopu toga, mi vam imamo Evidencijsku listu broj 1, znači za praćenje zdravstvenih potreba u Domovima za starije i Evidencijsku listu broj 4 za praćenje zdravstveno-socijalnih potreba u Gerontološkim centrima odnosno izvaninstitucijskoj skrbi za starije. GeroS je zapravo krenuo od tih evidencijskih lista jer mi smo došli do toga da te evidencijske liste, dvije, što mi pratimo u Domovima za starije i Gerontološkim centrima, svojevremeno to su bili i rehabilitacijske ustanove, Domovi zdravlja i tako, ovoga, da mi bi to željeli proširiti na sve djelatnosti. Znači, da nije samo da nama liječnik ili sestra ispunjava informaciju, nego da nas zanima što socijalni radnik radi sa starijom osobom u Domu, što radi fizioterapeut, što radi njegovateljica, što radi radni terapeut, što radi stomatolog, recimo, da zaista sagledamo stvari sa svih mogućih aspekta gledišta. IP010\_1, page 2, line 43-51.

IP: Znači, ja tu mogu davat čisto svoje savjete, al da, mislim, to se vidi u svakom pogledu, ako pacijent koji je inače stambeni korisnik se ozlijedi ili padne prebacit će se u stacionar do oporavka, pacijent koji ima trenutno neke gastrointestinalne tegobe podesit će mu se prehrana, pacijent koji je trenutno bolestan ili zarazan nosit će mu se obroci u sobu, znači, uvijek se trudi ovisno o individualnim potrebama u tom trenutku i organizirat zdravstvenu zaštitu, znači, pa bilo to onda i posjeti liječnika u sobu, ili, mislim uvijek se tako gleda. IP06\_1, page 3, line 92-97.

IP: Ja svoje pacijente, pogotovo sa kroničnim bolestima, svaki put kad ih vidim, potrudim se ponoviti neke glavne smjernice čisto da oni znaju kako nastupati i mislim da to i je uglavnom i najviše na liječniku obiteljske medicine. Znači, i preventivni programi i primarna, sekundarna prevencija, to bi najvećim djelom trebao raditi liječnik obiteljske medicine jer je on najviše u kontaktu s pacijentom i onda bi on trebao, možda, najviše educirat pacijenta o svemu šta možda fali ili ne znam. IP06\_1, page 7, line 220-226.

I: Da li se koriste individualni planovi skrbi? IP: Da, individualne planove skrbi je moguće vidjeti. IP05\_1, page 2, line 37.

I: Da li se u programu provodi stratifikacija rizika? IP: Moguće je, da. IP05\_1, page 2, line 35.

IP: Ne, što se tiče ovoga mi možemo raditi smjernice ali u ovom programu, ovaj je program namijenjen praćenju i nemamo uvid kroz taj program u osobne ciljeve. IP05\_1, page 2, line 32-33.

IP: Prati od tima liječnika opće obiteljske medicine koji je prvi kontakt s tim gerontološkim bolesnikom jer je glavni nositelj u zaštiti zdravlja starijih osoba, uz svoju gerijatrijsku sestru, oni detektiraju to, potiču, jer ga mi educiramo, taj tim, oni potiču kod ispunjavanja da li je to prisutno ili ne, prate i to je ta uloga GEROS-a. Dakle s podatkom koji dolaze k nama mi izrađujemo upute koje taj osiguranik dobiva, potiče ga na suodgovornost, kao konkretan primjer kada smo izradili preporučene mjere za zaštitu od vrućina starije populacije. Zahvaljujući tom našem programu,

ulozi svih partnera i medija koji jako potiču te preporuke i naš program, mi bilježimo manje poziva u hitnoj pomoći starije populacije. IP01\_1, page 6, line 218-226.

IP: Program je, znači, bar ovaj tu dio koji se već provodi, taj NRS 2002 izvrsno osmišljen, jako sam zadovoljna i ovaj, velim, ako negdje nešto zapne oni to zaista vrlo brzo riješe. Meni je samo znači...ja bi htjela još veći, možda broj tih gerijatrijskih bolesnika ili gerontoloških osiguranika, evo. IP011\_1, page 9, line 281-283.

IP: Znači, mogli bi čisto kroz to kontinuirano praćenje i izbacivati pojedine lijekove. Jer ovako se dogodi, pacijent se pogubi i pije lijekove koje ne znam ni ja, i onda odjednom, za godinu dana, ispadne da ga više nije trebao pit, ali se nikom nije javio i on je mislio da treba i tako dođemo do brojke od 15 lijekova, da, koji su možda u nekom trenutku bili potrebni, ali više nisu, ali se pacijent nije javio na kontrolu pa nisu ni izbačeni. To je onda, ajmo reć... IP06\_1, page 5, line 168-173.

IP: Prednosti, ovaj program bi trebao omogućiti uvid u te multimorbiditete i medikaciju i pomoći da uočimo primjere prakse različitih institucija i na temelju toga otvoriti rasprave i razviti smjernice da se smanji polipragmazija. IP05\_1, page2, line 57-59.

IP: Program koji radimo bi trebao pomoći tome. Dakako, medicina je u zadnjih 20 godina, to se piše po svijetu, otišla još više u tehnički dio i holistički pristup je izazov, generalno, i pristup osobi i upravo smisao programa GEROS je da se dobije uvid i kroz zdravstveni i kroz socijalni sustav i pomoglo tome da se dobije holistički pristup pacijentu, a i druge stvari. Dakle ovaj program će biti samo pomoć tome, neće riješiti problem. IP05\_1, page 1, line 26-30.

IP: Pružamo kroz taj Gerontološki centar, osim te usluge pomoći i njege, postoje i razno razne aktivnosti koje imamo, ne znam, tog fizioterapeuta pa vježbanje u zajednicama, mjesnim zajednicama, pa u mjesnim odborima, ne zna, usluge, mislim da imaju aktivnosti poput slikanja ili glazbe, razno raznih okupljanja kojima se korisnici zajedno druže pa ne znam neka edukativna predavanja o prehrani na primjer u trećoj životnoj dobi, psihološkim promjenama i tako, ovisno o potrebama pružaju se i te dodatne, ajmo reć savjetodavne usluge. IP015\_1, page 8, line 275-282.

IP: GeroS više manje ispunjavaju stručnjaci, interdisciplinarni stručnjaci koji dolaze u kontakt sa samom starijom osobom. Starija osoba može koristiti GeroS, na način da je informatički, recimo, pismena, to je isto još jedna od mogućnosti što će GeroS nuditi, ovoga, i želi se predbilježiti u Dom za starije osobe, znači, ona će upisati podatke, znači, ući će u taj naš sustav i vidjet će, da, ja se želim prijaviti tu i tu, ima tu i tu dokumentaciju, ja ju ne moram fizički nositi tamo, ja ju mogu skenirati, staviti u bazu podataka, i poslat ću ju recimo u Dom za starije Medveščak, tamo će socijalna radnica vidjeti da je zaprimila moje podatke i onda ako je potreban nakon toga inicijalni razgovor, staviti će me na inicijalni razgovor, znači, izbjeći će nekoliko koraka koje je trebala raditi fizički. Može, ako je informatički pismena sve si to riješiti putem kompjutera, laptopa, ili kako god, pametnih telefona, i može u svakom trenutku vidjeti, da ja sam, ne znam, 150. na listi čekanja za ulazak u taj dom, može vidjeti i kako se pomiče taj rang

same starije osobe. Znači, u svakom trenutku, doba dana, može vidjet, recimo, pri tom ulasku u Dom kakvo je stanje, koliko još treba čekati bez da ide fizički tamo, ovoga, jednostavno je taj neki vremenski tijek ušteden putem GeroS-a. IP010\_1, page 8, line 275-287.

IP: Integracija u odnosu na korisnika i njegove potrebe i mislim da bi to bilo odlično za planiranje daljnjih postupaka u gerijatrijskoj zdravstvenoj njezi. Te informacije ovako nam često budu uskraćenje, zapravo nam olakšava i oblik smještaja ako znamo o korisniku da li ide u stacionar ili stambeni dio, mislim da bi to bilo odlično. IP07\_1, page 3, line 79-82.

IP: Pa njihovo mjesto je zamišljeno na taj način da oni, zapravo, osim tog ulaska u Dom, što sam vam objasnila, kako mogu pomoć starijoj osobi, ovoga, oni zapravo, na taj način, a slušajte, i kroz tu našu edukaciju koja će ići putem GeroS-a i sve to, možda mogu i oni pomoći u skrbi za te starije osobe, možda će naučit nešto novo, što nisu, primjerice, znali, ili ne znam, primjerice, kako negovati osobu s moždanim udarom koja je recimo, ne tetraplegičar, ti su obično u instituciji, ali recimo, paraplegičar, pa će, ovoga, nju će liječnik komunicirati, ovoga, o toj starijoj osobi, da se dođe po neki lijek, da se dođe preuzeti, znači direktno na taj način u skrbi starije osobe kroz kontakt s drugim stručnjacima. Ili ne znam, tipa, osoba je imala moždani udar, završila je kod kuće, nema se gdje smjestiti ili ne znam kakve su životne okolnosti i sad živi sa, recimo, sinom ili kćerkom, nije bitno, ovoga, i ti stručnjaci kad dođu u kuću, oni će doći i evidentirati to, ali recimo radni terapeut dođe i on će pokazat toj samoj starijoj osobi kako izvest neki pokret, ali ne samo toj starijoj osobi, nego kako prilagoditi okolinu za tu stariju osobu, što neće moći sama starija osoba za sebe prilagođavati nakon moždanog udara, ali će naučiti obitelj kako olakšat to zajedničko stanovanje s tom starijom osobom. IP010\_1, page 12, line 433-446.

IP: Nisu to samo volonteri. Udruge i zaklade. Udruge registrirane u Hrvatskoj sa velikim brojem udjela, financirane su za pomoć starijih osoba. Te udruge isto prolaze dio edukacije i mogući način pristupa, kako one nogu sudjelovati i one su obuhvaćene GEROS-om. IP01\_1, page 7, line 251-253.

IP..., znači jedan čitav sustav stručnjaka je tu, stvarno, uključen, maksimalno, do razine duhovnika odnosno svećenika, smo taj GeroS obuhvatili. Tako je. Starija osoba dođe, pa joj bude teško, pa se ide posavjetovat sa svećenikom i mi željeli da i taj svećenik nama to unese u naš GeroS, znači, osoba je tražila konzultacije sa svećenikom, duhovnikom ili kako god. Do te razine, znači. IP010\_1, page 6, line 197-201.

IP:...nama jako koristilo je naših 48 gerontoloških radionica jer, recimo, ne znaš što na terenu, recimo, sa samom starijom osobom radi stomatolog, što radi fizioterapeut, ali kroz te radionice mi smo dobili uvid, koliko smo mogli dobiti kroz tih 48 radionica što oni rade s tom starijom osobom, koji je njihov djelokrug rada i to je bio neki vid edukacije da i mi shvatimo povratnu informaciju što oni rade, znači, da nije samo, pokazatelj je nama bitan, ali na koji način doći do tog pokazatelja, kako oni rade svoj posao. Tako da, to je bio, po meni, neki vid edukacije, da malo se približimo njima i upoznamo njihove segmente rada. IP010\_1, page 3, line 71-77.

IP: I psihologija je uključena, i mi smo imali, bez daljnjeg, psihologe smo također, imali smo i nekoliko radionica s njima i psihološka komora je bila uključena. Znači, i psihijatri su bili uključeni. Dakle, bilo je zaista...neurolozi, specijalističku djelatnost smo pokušali obuhvatiti koliko smo mogli, ali ovo interdisciplinarne, a svi koji se bave sa radom starijih osoba smo obuhvatili sve. IP010\_1, page 6, 204-207.

IP: Jednom mjesečno držim predavanja na temu recimo visoki krvni tlak, moždani udar, preventivno, predavanja držim na nivou edukacije kako sami sebi pomoći, što im je najveća opasnost, čega se trebaju pridržavati. Dajem im pisane smjernice npr. za prevenciju padova, svakom isprintam, dam smjernice za prevenciju visokog krvnog tlaka itd. ...vrućine. IP07\_1, page 3, line 91-94.

IP: Preventivno...nama veći dio korisnika i nama je tako lakše raditi s obzirom na kadrovske norme koliko nas ima, oni puno sudjeluje u tome i samostalno. Mi kod dijabetičara mi svakog želimo educirati kako sam sebi aplicirati inzulin i ostale stvari, sve ono što oni mogu. Ja kao glavna sestra znam motivirati, poticati, bez njihove pomoći ne znam kako bi mi to sve uspjeli. Oni nisu svi potpuno ovisni o nama, ima korisnika koji uz pisane upute, uz usmene upute, na bilo koji način, mogu individualnim razgovorima sami sebi pomoći. IP07\_1, page 3, line 84-89.

I: Oni vam pomažu da se obučete? IP: Mislim to je u programu, ja izbjegavam, nastojim se sama obući ujutro kad ustanem.. IP017\_1, page 3, line 74-75.

IP: ima jedan dio korisnika ovdje koji koriste internetski pristup i na taj način komuniciraju sa nama i komuniciraju sa bolnicama, sa liječilištima, sa toplicama i tako. Ima, ima jedan dio. Unazad evo, ja kako sam počela raditi, moje isto prvo radno iskustvo je bilo u jednom drugom staračkom domu, progradirao je broj, odnosno povećao se broj ljudi koji koriste u starijoj životnoj dobi internet i sami se s time, ovaj, sami funkcioniraju, ne trebaju toliko naše usluge. IP015\_1, page 6, line 401-404.

IP: Aha. To je ovako dosta široko pitanje. Neki jesu, a neki nisu. Ima pacijenata koji će se savršeno pridržavat uputa i svega što im se kaže i nekih koji neće, al to je sto ljudi, sto čudi, svi su individualni. IP06\_1, page 6, line 205-207.

I: Da li se u programu postiže osnaživanje pacijenta?

IP: Indirektno da, pacijenti možda neće biti ni svjesni što se radi ali se upravo sagledavanjem različitih praksi će se osnažiti ljude bez njihovog eksplicitnog sudjelovanja u tome. U smislu, da u nekoj ustanovi, u nekom sustavu, imamo više polipragmazije ili nečeg, ćemo intervenirati i to će indirektno osnažiti krajnjeg korisnika. IP05\_1, page 3, line 73-77.

IP: U okviru GEROS-a, kako se u našem Centru za gerontologiju prati negativno zdravstveno ponašanje, jedni smo od prvih koji prate te zdravstvene potrebe, znači determinante negativnog zdravstvenog ponašanja koje su specifične upravo u tog starijeg gerontološkog bolesnika, ali i gerijatrijskog osiguranika. Ako pratimo da li je on tjelesno aktivan, da li je on psihički aktivan, da li je prisutna ovisnost bilo koje vrste, alkoholizam pušenje, ovisnost o lijekovima – uzima više od 3 lijeka dnevno, da se ne pridržava uputa liječenja,... IP01\_1, page 6, line 211-216.

IP: U DOGMI imamo puno toga, ja korisniku mogu sutra dati, bilo kojem od njih, u kojem stupnju je njege, što mu se pruža, imamo parametre kroz hranjenje, pa je li samostalan, nije, dobijem zbroj bodova točno na ime i prezime dobijem u kojem stupnju njege je. IP07\_1, page 4, 137-139

IP: Međusobno sa zaposlenicima, sa tim nekim stručnim timom, od fizioterapeuta, Glavne sestre, kolegica socijalnih radnica, Ravnateljice, ali ovo su sad pitanja koja su vezana uz korisnike, zatim sa članovima obitelji, puno sa članovima obitelji, a sa nekim vanjskim institucijama, najčešće Zavod za zdravstveno osiguranje i Centri za socijalnu skrb ovisno o prebivalištu korisnika. To su mi nekako... U zadnje vrijeme, nešto malo intenzivnije sa MUP-om, pitanje prebivališta, postalo je poprilično aktualno i vjerujem da će se to još sada i aktualizirati jer su predstojeći izbori pa ćemo morati ko nam je gdje na spisku, ali nešto sa MUP-om vezano i uz gubitke osobnih dokumenata i izradu novih dokumenata i pitanje prebivališta, ali uglavnom HZZO i Centri za socijalnu skrb je nekako osnova. E i pardon, krivo, još jedna institucija, to je Gradsku ured za socijalnu zaštitu i osobe s invaliditetom s obzirom da korisnici koji su nam tu smješteni imaju određene cenzus mirovine, neki koji su smješteni i rješenje dobivaju, ostvaruju neka materijalna prava, financijska iz tog Gradskog ureda pa onda i s njima moramo komunicirati kad korisnici preminu ili kad netko treba ostvariti pravo ili bilo kakve statusne promjene njihove, jel. IP015\_1, page 3, line 131-143.

IP: Ono što moramo odmah na početku kazati da zapravo smo mi dio tijela koji je povezan funkcijski sa Ministarstvom zdravlja, to znači da smo mi imenovani od njih, dakle na svaki njihov upit mi odgovaramo i šaljem o izvješća. IP01\_1, page 3, line 106-108

IP: To je sve apsolutno timski rad i tu je teško odvojiti koliko je informacija bitna socijalnom radniku, koliko je bitna medicini jer i medicinskom osoblju je bitno da je, na primjer, ne znam, komunikacija s obitelji bila otežana, jer u slučaju da se nešto ponovno dogodi onda neće zvati članove obitelji, jel, a meni je isto tako, s druge strane bitno da znam da se terapija promijenila, mislim da znam da je možda i to proces prilagodbe na terapiju, nekakve reakcije, pa da i to znam prepoznati, a ne automatski da odmah kažem ništa se nije promijenilo ili još je gore, nego da onda i ja znam prepoznati da je moguće promjena terapije utječe na ponašanje ili slično. Uglavnom je sve timski, teško je raspodijeliti, tako da se mi u maksimalnom povjerenju razmjenjujemo informacije, jer svi znamo da smo dužni čuvati etički kodeks i službene tajne i ne dajemo trećim osobama, ali unutar Kuće mora se znati o čemu se radi. IP015\_1, page 9, line 315-324.

IP: Sestre su u sustavu socijalne skrbi na jedan način, tako su one meni prenijele, da su marginalizirane, da su kontrolirane od stručnjaka koji nisu njihova profesija, eeemmmm... da ih nema dovoljno, da su raspoređene i obavljaju i ono što treba i ono što ne treba. IP013\_1, page 12, line 477-479.

IP: Zahvaljujući upravo GEROS-u ojačala je i jača edukacija iz gerontologije, gerijatrije i gerijatrijske zdravstvene njege, dakle stvaraju se novi profili stručnjaka od gerontologa, gerijatara, to nije naša ideja nego europska jer je medicinska specijalizacija Europe eksplicitno traži medicinsku specijalizaciju gerijatrije, kojom se može Hrvatska

pohvaliti da ju ima i da smo time isto u Europi, jer je to čak bio jedan od ulaska u Europu, dakle do gerijatrijskih medicinskih sestara koje moraju biti posebno educirane i školovane, a sad idemo dalje i sa novim profesijama. Više je nezamislivo u Hrvatskoj da se objavi natječaj u okviru zdravstvenog turizma i razvoja uopće turizma gdje upravo starija populacija i stariji turisti su jako zainteresirani za zdravstveni turizam u Hrvatskoj, pojavljuje se potreba za gerontokineziolozima. Zahvaljujući, kroz taj projekt mi smo uključili i gerontokineziologe, jer na Kineziološkom fakultetu, koji su isto naši partneri, postoji Katedra za gerontokineziologiju. Pa idemo dalje, gerontostomatologija. Gerontostomatološke usluge su u GEROS-u itekako prepoznate jer oralno zdravlje je strahovito važno u starijoj populaciji i znamo koje su to, gerontostomatološke usluge koje se vrednuju i prate. dakle da bismo uopće mogli imati tu determinantu tako u okviru Stomatološkog fakulteta se danas educiraju nova zanimanja i postoji subspecijalizacija gerontostomatologija. Možemo dalje nabrajati sve do jednog novog edukcijskog programa koji smo mi edukacijski napravili, a to su gerontonegovateljice koje su pomoćne djelatnice gerijatrijskog medicinskoj sestri pa sve do programa gerontodomačice koje pričaju pomoć starijoj osobi koja je isto uključena u GEROS do volontera do gerontoservisa do geročuvalica – zamjenske bake i djede, do praktički na koji način je moguće u svim poveznicama, do dnevnog boravka za Alzheimerovog bolesnika gdje sudjeluju i gerontoantropolozi, kreatori, dramske sekcije, znači on mora biti praktički i taj fizioterapeut, glumac, mora znati koje su to determinatne, na koji način će prikazati moguće rješenje gerontološkog problema, a to je opet unapređenje i očuvanje zdravlja. IP01\_1, page 5, line 172-192.

IP: Naše gerontodomačice mislim da idu po dva sata ili po jedan sat tjedno kod nekih, jer imaju puno korisnika pa treba spojiti to u satnicu, jel, pa tako da je brojčano to zasad malo, a za zapošljavanje još jedne gerontodomačice opet nemamo dovoljno korisnika, jer ta osoba ide na teret našeg Doma, naše ustanove, a nama su financijska sredstva na raspolaganju koliko nam Grad doznačuje tako da da bi zaposlili još jednu osobu, da bi onda češće bila kod korisnika potrebno nam je dodatno razvijati tu vaninstituciju, posebice ovaj dio di ljudi sami plaćaju tu uslugu i prema načelu deinstitutionalizacije da ostaju u svojim kućama, svojim stanovima, primarnim, primarnoj, nekakvoj, svojoj okolini koliko god maksimalno mogu, a tek onda dolaze na smještaj što i je načelo deintitucionalizacije kojim se vodimo unazad 10-15, 20 godina u Hrvatskoj u Sustavu socijalne skrbi. IP015\_1, page 7, line 250-257.

IP: To mi zovemo tako. U jednom pravom trenutku u gradu, Gradska uprava, koji su za domove, su išli na informatizaciju tih nekih usluga koje se pružaju i obavljaju u domu. Onda smo svi imali priliku dati ono što nam treba u elektronskom obliku a u tom trenutku smo mi sestre iz socijalne skrbi bile na završetku sestrinske dokumentacije ova 4 stupnja gdje sam bila i ja i tim od nekoliko sestara i ja sam u tom trenutku iskoristila dobro vrijeme i gurala cijelu dokumentaciju i tako da je to nama ušlo jako puno u odnosu na prostor socijalnih radnika gdje imaju samo osnovne bilješke i to, mi imamo jako puno. IP07\_1, page 5, line 146-152.

IP: Unutar kuće mi imamo sustav pomoći, mi imamo u svakoj sobi zvono na koje korisnik može pozvoniti u slučaju da mu to treba. To se nama na stacionar javlja na jednoj ploči, imamo 2 pagera koje nose sestre u službi 24 sata, dakle nije nam bilo potrebno više, uspijemo se pokriti, tako da sestra tijekom rad odlazi na poziv, ne mora biti



negdje u ambulanti da gleda poziv i bilježi, imamo svjetleće po kući da je to na tom određenom katu, koja soba i na taj način smo povezani putem kompjutera. Imamo program da se može vidjeti kad je netko pozvonio, kad je došla sestra na poziv. Imamo jedan dio soba sa sistemom tableta, dakle više nadogradnja da korisnici iz sobe mogu dojaviti u kuhinju pritiskom na tablet, nekih 10 soba.

IP: Zapravo, ja u Centru za gerontologiju radim na radnom mjestu Voditelja Odsjeka za gerontološkojavnozdravstveni menadžment i onda u sklopu tog Odsjeka, velik dio mog posla, između ostalog, odnosi se i na komunikaciju sa drugim stručnjacima, ovoga, koje smo uključili u sam projekt GeroS, tako da je moja pozicija, iz te perspektive bila, znači, osim komunikacije sa svim tim stručnjacima, socijalnih radnika, stomatologa, liječnika, radnih terapeuta, fizioterapeuta, sestara dobiti povratnu informaciju od njih, što oni zapravo žele, što je njima bitno da oni prate, znači, stvaranje tih nekih njihovih obrazaca, recimo. Uz to, ovoga, moj posao vam se odnosi i dosada, kao i prije samog GeroS-a, i dan danas, odnosi se i na praćenje zdravstvenih potreba u Domovima za starije i Gerontološkim centrima. U sklopu toga, mi vam imamo Evidencijsku listu broj 1, znači za praćenje zdravstvenih potreba u Domovima za starije i Evidencijsku listu broj 4 za praćenje zdravstveno-socijalnih potreba u Gerontološkim centrima odnosno izvaninstitucijskoj skrbi za starije. GeroS je zapravo krenuo od tih evidencijskih lista jer mi smo došli do toga da te evidencijske liste, dvije, što mi pratimo u Domovima za starije i Gerontološkim Centrima, svojevremeno to su bili i rehabilitacijske ustanove, Domovi zdravlja i tako, ovoga, da mi bi to željeli proširiti na sve djelatnosti. Znači, da nije samo da nama liječnik ili sestra ispunjava informaciju, nego da nas zanima što socijalni radnik radi sa starijom osobom u Domu, što radi fizioterapeut, što radi njegovateljica, što radi radni terapeut, što radi stomatolog, recimo, da zaista sagledamo stvari sa svih mogućih aspekta gledišta. IP010\_1, page 2, line 32-51.

IP: Onda, šta još sad radimo. Sad smo informatizirali njegu u kući i fizikalnu terapiju u kući. Znači, te osobe sa multimorbiditetom vrlo često imaju potrebu njege u kući. Sad ćemo bilježiti svaki dan šta je kome rađeno. Koji postupci i kako napreduje ili ne napreduje. Onda smo informatizirali eemmm... to bi do kraja godine, za sva pomagala, koja odobrava primarni liječnik, eeemmm.... Ide aplikacija e-pomagala, to je jednako kao i recept. Recimo jednako, složenije je jer ima liječničkih povjerenstava i tako. IP19\_1, page 2, line 58-63.

IP: Znači, pacijent s više bolesti neće morati više ići kod svog doktora po potvrdu, nego će ga nazvat, a ovaj će u CEZIH pustiti eemmm...potvrdu za pomagala koju će onda isporučitelj moći dohvatiti i isporučiti. Znači, neće morat bezveze hodati okolo. To nam je dobro jer su nam uključene ljekarne, koje već sada rade s receptima i ljekarnici vide benefit od toga, znači neće projekt propasti zato što netko ne želi radit. IP19\_1, page 2, line 65-69.

IP: To je znači, šta god radiš u zdravstvu, uključene su i osobe sa multimorbiditetom, bilo koje poboljšanje, a pogotovo ovo kad će nam krenuti mobilno zdravlje, to nam sad ne kreće, fali nekih 100 000 kuna za, za licence nekakve, za baze, što mi je jako, jako žao. IP019\_1, page 2, line 79-82.

IP: Znači, eemmm... u primarnoj zdravstvenoj zaštiti postoje preventivni paneli i kronični paneli. Od preventivnih je pušenje, alkohol, debljina, a od kroničnih to je KOPB, eemmm, to je opstrukcija pluća, onda je tlak, šećer i još nešto... Ne mogu se sjetiti. Znači, u koju su oni uključeni. Znači, stariji su uključeni sa multimorbiditetom, uz nacionalne preventivne koji su po... eemmm... se ne odnose na osiguranike zdravstvene, nego na bilo koga tko živi, ima prebivalište u Hrvatskoj i ovo sve što se radi kroz to. Znači, dio GeroS-a je de facto gotov, i od njega je sve što se tiče primarne i sekundarne zdravstvene zaštite. GeroS nam šteka na mobilnim timovima, eemmm... recimo, mobilna stomatolog, mobilni ne znam... oftalmolog ili tako nešto, koji bi išli onda u domove za starije. IP019\_1, page 3, line 94-102.

IP: Nije slučaj, volonteri će posebno biti informatizirani kroz ovaj projekt GeroS, jel ti ne znaš, ja... nemamo sad informacija ako je sad netko volonter ili je duhovnik ili je nešto, da li je njegova posjeta poboljšala psihičko, fizičko stanje tog pacijenta, ili pogoršala. Možda on svaki put kad ode volonter se rasplače, razumiješ, zato što mu nije drag. Ili krivo čita, ili ne znam šta već radi. Znači, trebalo bi ih informatizirati, odnosno anketirati pacijenta da li bi htio nekog drugog, možda neće ženu, možda hoće muškarca, možda ne znam, ne... i druga stvar, treba bilježiti koliko su educirani ti volonteri, a specijalno educirani za komunikaciju sa... osobama s multimorbiditetom. IP019\_1, page 5, line 174-180.

IP: Treće, kod starijih osoba, uvijek je unutra upetljan i grad, sredstva nekog grada, pa sredstva neke županije, pa sredstav HZZO-a, odnosno Ministarstva, pa sredstva HZZ-a i tako. Znači, trebalo bi napraviti aplikaciju u kojoj bi to sve bilo povezano i točno bi se znalo, ovako ti ne znaš koliko daje grad, koliko daje, ovoga, pojedini od tih subjekata, koji su unutra uključeni za skrb kod starijih osoba. Znači, to je jedno od strašno, strašno važno. Baš je jako važno. Znači, da bi mi možda onda kad bi ta sredstva bila negdje u nekakvom budžetu, gdje se svaki konto od toga vidi, možda bi mi mogli priuštiti tim starijim osobama i da odu toplice i da ne znam šta, šta je sad uskraćeno. Znači, poboljšat, definitivno. A, ovako, kad svak drži svoje, u svojem balončiću i nema zajedničkog povezivanja, niti znaš tko šta dobiva, ni za koje novce. To definitivno bi donijelo veliki, veliki, ja mislim uštede i prvenstveno dobrobit za pacijente. IP019\_1, page 7, 254-263.

IP: Ovaj dio koji sad radimo, za sve stanovnike, pa tako i za starije i za emmm, emmm.... starije od 65 godina, to se već koristi. Ali je potrebna ogromna nadogradnja da bi zaokružili i napravili cjelinu. Znači, to će biti sigurno raspisano na javni natječaj. IP019\_1, page 7, line 276-278.

IP: Po meni, ovo kako je GeroS zamišljen, jako je dobro, to bi mi čak mogli napraviti takvu aplikaciju da ju može koristiti pola Europe. Europa nije tako dobro informatizirana kao mi. Znači, mi smo jako visoko na ljestvici po informatizaciji. A, ovoga... mogli bi napraviti takvu aplikaciju, s obzirom da smo Europa, da to svi u Europi mogu koristiti. Pa, bila ta, pogotovo što sad su ti međunarodni programi što radimo, kao eemmm... razmjena kartona, da svak može vidjeti naš karton, to ćemo sad ići raditi sa Austrijom. Sa Švedskom smo radili razmjenu E-recepta. IP019\_1, page 4, line 128-134.

IP: Ono što je bitno kazati je da mi istovremeno provodimo standardizirani upitnik praćenja kvalitete u zdravstvenoj i socijalnoj skrbi za starije osobe i da mi dobivamo koje obrađujemo, kad kažem mi, kao Referentni centar koji smo sunositelji, upravo sa vašom Agencijom, kada smo izradili priručnik kvalitete, konkretno u ustanovama skrbi za starije koji je u ovom momentu nedostatan. Koji u ovom momentu traži od nas kao RC i od vas kao partnera u tom poboljšanju i sudionika u GEROS-u, zahtijeva uvođenje novih elemenata praćenja te kvalitete upravo iz ovih pokazatelja koje smo dosada napravili. Sigurno da je implementiran i da je u okviru samoga GEROS projekta i to je još jedna komponenta koja zapravo govori o samoj kvaliteti GEROS projekta. Ali da ga treba i da nije u potpunosti prisutan i da nije implementiran u današnjem sustavu govori upravo i taj podatak što mi po ispunjenim upitnicima provođenja, mi nismo dobili otpor za neispunjavanje nego smo zapravo dobili jedna odmak, oni koji ne provode te standarde su zapravo motivirani sada s našim edukacijskim pristupom da to primjene što opet traži i kod nas jedan kontinuiran, stalan proces praćenja i uključivanja još više vas kao Agencije za praćenje kvalitete upravo da se to omogući što više i ja u svojstvu voditelja i mi kao RC čak tražimo da u registraciji tih ustanova određenih u skrbi za starije bilo u institucijskoj ili izvaninstitucijskoj koja je jako prisutna da bude kod registracije obilježavajući zakonski faktor da se ne može registrirati ako nema taj standard kvalitete osiguran. IP01\_1, page 10, line 382-397.

IP: Znači, projekt je dosta zaokružen, sam o treba novaca za to, i političke volje. Definitivno, jel ako to ne bude, eemmm, ne donese odluku vlada, pa da svi segmenti u vladi, znači čak od poljoprivrede, od bilo čega, jel je različito ako je starija osoba u poljoprivrednom domaćinstvu, ako je ovdje, ak je ondje, znači morat će se napraviti prilagodbe za određene načine, stilove života i to. IP019\_1, page 8, line 297-300.

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## 4. Programme 2: “Palliative Care System”

### 4.1. Basic information

The **Palliative Care System** is an integrated care programme specifically designed for palliative care patients; it is based on the National Healthcare Strategy and the Strategic Plan for Palliative Care 2014–2016. It is estimated that a minimum of 20% of cancer patients and 5% of non-oncological patients need palliative care in the last year of their life (1,2).

Table 4.1.1: Basic information about the programme

Information category	Description
Programme name	<p>The <b>Palliative Care System</b>, according to the Strategic plan for the Development of Palliative Care in Croatia for the period 2014-2016, and the National Healthcare Strategy, 2012-2020, specifically priority 4: Reorganisation of the structure and activities of healthcare institutions and Priority 8: Cooperation with other sectors and the society in general</p> <p><a href="https://zdravlje.gov.hr/UserDocImages/dokumenti/Programi,%20projekti%20i%20strategije/National%20Health%20Care%20Strategy%202012-2020.pdf">https://zdravlje.gov.hr/UserDocImages/dokumenti/Programi,%20projekti%20i%20strategije/National%20Health%20Care%20Strategy%202012-2020.pdf</a>  <a href="https://zdravlje.gov.hr/UserDocImages/dokumenti/Programi,%20projekti%20i%20strategije/Strateški_plan_razvoja_palijativne_skrbi_u_RH_za_razdoblje_2014-2016.pdf">https://zdravlje.gov.hr/UserDocImages/dokumenti/Programi,%20projekti%20i%20strategije/Strateški_plan_razvoja_palijativne_skrbi_u_RH_za_razdoblje_2014-2016.pdf</a></p>
Contact details, programme management	<p>Head: Croatian Ministry of Health  Ksaver 200a, 10 000 Zagreb  Sector for Ambulatory Healthcare and Community Care</p> <p><i>Contact: Danica Kramarić, <a href="mailto:danica.kramaric@miz.hr">danica.kramaric@miz.hr</a>; Sanja Predavec, <a href="mailto:sanja.predavec@miz.hr">sanja.predavec@miz.hr</a></i></p> <p><i>For county or hospital level projects and implementation</i></p> <p><i>Contact: Professor Karmen Loncarek, MD, PhD, Clinical Hospital Centre Rijeka, <a href="mailto:palijativa@kbc-rijeka.hr">palijativa@kbc-rijeka.hr</a></i></p> <p><i>Dr Ante Ivančić, Director of Primary Care Centres of the Istrian region, <a href="mailto:ante.ivancic@idz.hr">ante.ivancic@idz.hr</a></i></p>
Starting date of the programme	<p>2005, starting with palliative care on a voluntary basis at the regional level in Istria;</p> <p>2011, starting with the official project at the regional level in Istria (palliative care on the primary healthcare level was established at the Primary Care Centres; an innovative mobile specialist palliative care team started to work);</p> <p>2011, Centre for Coordination of Palliative Care in Zagreb was been established</p>

	<p>(Informal caregiver, IP15_2, page 3, line 92-93);</p> <p>December 2013, the Strategic plan for the Development of Palliative Care in Croatia for the period 2014-2016 was accepted by the Croatian Government;</p> <p>2014, a proposal for a legal framework was developed, organisational changes were started, as well as an initiative for the development of Guidelines for palliative care and Catalogue for palliative care competence, as well as implementation of MKB-10 Z51.5 for palliative care patients;</p> <p>2014, national official pilot projects of mobile palliative team were started: 6 funded by the Croatian Health Insurance Fund (Primorsko-goranska, Istarska, Međimurska, Osječko-baranjska, Vukovarsko-srijemska, and City of Zagreb counties) and two pilots funded by counties (City of Zagreb, Primorsko-goranska);</p> <p>November 2014, the Committee for Palliative Care (appointed by the Ministry of Health) was established, responsible for the monitoring of the activities and achieving the main expected results determined with the Strategic Plan.</p>
Geographical scope	<p>Republic of Croatia;</p> <p>Currently on the pilot project level in different parts of Croatia (counties) with different levels of implementation of the palliative care system, please see above.</p>
Target group of the programme	<p>People who need palliative care (it is estimated that a minimum of 20% of cancer patients and 5% of non-oncological patients need palliative care in the last year of their life).</p> <p>Patients in palliative care but also their families were mentioned during interviews (Manager of the programme, IPO3_2, page 5, line 160-162; Manager of the programme, IPO2_2, page 3, line 88-90).</p>
Number of patients treated in the programme	<p>Around 26,000 - 46,000 patients/year need palliative care (~50-89% oncologic patients and ~20% non-oncologic patients with multi-morbidity). The estimated number of palliative beds in Croatia ranges between the 349 and 429.</p> <p>According to the data from the Croatian Health Insurance Fund, in 2014 general/family physicians made 7,290 first visits and 17,465 home visits for palliative patients, while medical care in the home for extremely difficult patients and patients in the terminal stage of the disease was provided in 26,509 cases.</p> <p>In 2015, around 10,000 patients, according to the ICD-10: Z51.5</p>
Aim of the programme	<p>Organization and implementation of the palliative care system in a systematic way on the national level, improving the quality and appropriateness of care, following the examples of such care in well-developed European countries, and a good practice experience in the Istria County;</p> <p>The main goal: to organize palliative care on three levels: home care (provided by</p>

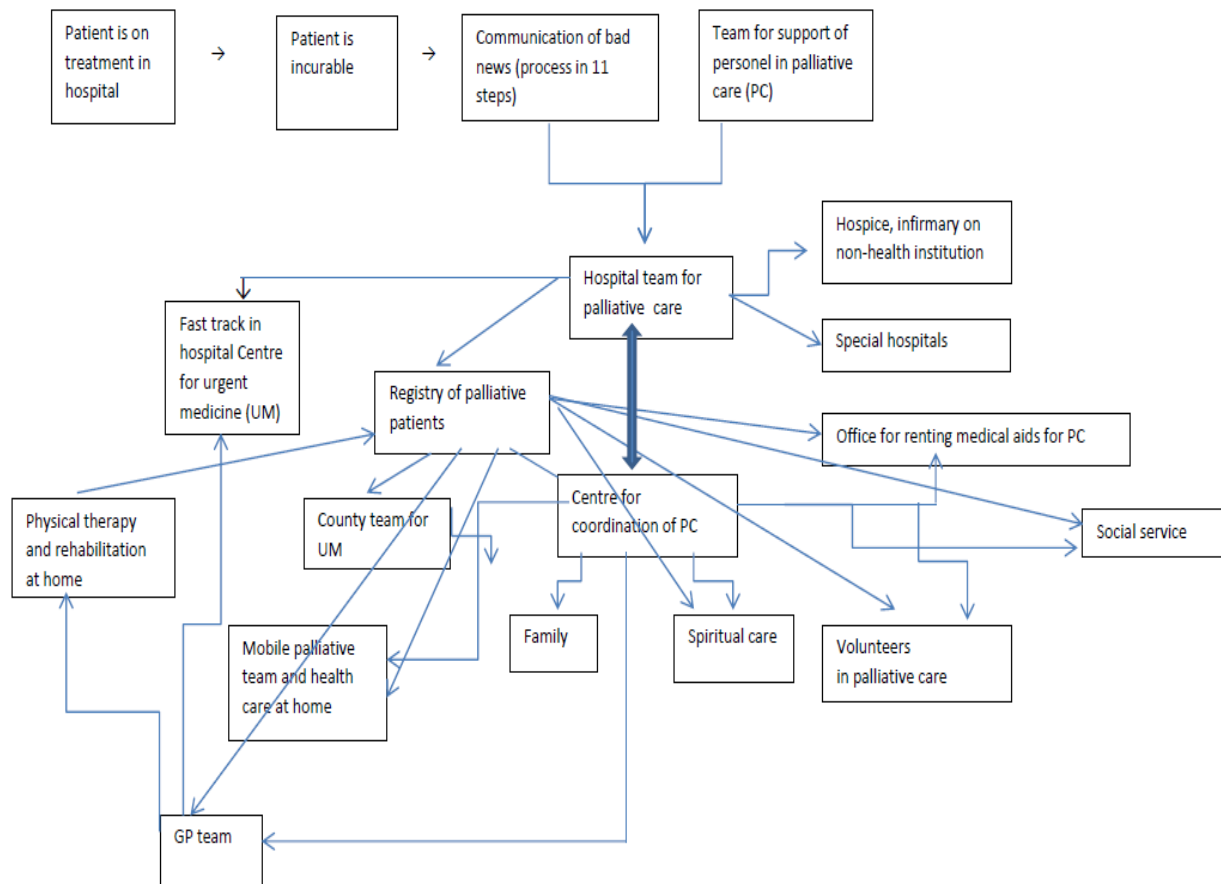
	<p>family medicine physicians, community nurses, and home care); extended palliative care (provided by social services); and hospital care. A special centre, the so-called Coordination Centre for Palliative Care, coordinates care at county levels between hospitals, ambulatory palliative care, specialized palliative care teams, the mobile palliative care team at the primary care level, and social care, providing vertical, horizontal and intersectoral cooperation and collaboration. An institution/office for renting medical aids/devices is included as well.</p> <p>In the interviews, different stakeholders involved in the project confirmed the abovementioned aims of the programme (Manager of the programme, IPO3_ page 2, 5, line 166-167; Representative of the funding organisation, IPO7_2, page 3, line 85-87; Representative of the funding organisation, IPO7_2, page 6, line 191-193; Manager of the programme, IPO1_2, page 2, line 61-64; Manager of the programme, IPO1_2, page 2, line 52-54).</p>
Definition/understanding of “integrated care”	<ol style="list-style-type: none"> <li>1. An integrated model of care with core holders that are already existing elements of the healthcare system at the primary and hospital level and social welfare (institutions, centres, social workers ...);</li> <li>2. Not primarily established as a new/additional system, but organized by conversion of existing physical resources, with empowerment and training of professionals, and by establishing new procedures and standards of work;</li> <li>3. Additional or new systems and models may be developed;</li> <li>4. Includes the effects of other sectors which can contribute to better care for palliative care users (volunteers, civil society, educational system, religious communities, the for-profit sector, etc.) in a continuous partnership;</li> <li>5. Organization of palliative care involves, encourages, and supports all forms of vertical and horizontal cooperation and strong inter-sector connections.</li> </ol>
Definition/understanding of “multi-morbidity”	No definition of multi-morbidity was found.
Definition/understanding of “patient-centredness”	<p>The decision on which form of palliative care will be provided shall be made on the basis of several criteria: the needs of the patient, treatment options in home/day hospital institutions, existing services, the needs of the family, etc.; Particular attention is given to vulnerable groups such as children, psychiatric patients, people in demographically endangered areas, prisoners, etc.;</p> <p>A palliative patient should be placed in a palliative bed closer to the patient's place of residence in order to better preserve social contacts and the possibility of visitation.</p>
Definition/understanding of “self-management”	No definition of self-management was found.
Organisational form and	The Ministry of Health (all three levels of healthcare), the Ministry of Social Policy and Youth, the Croatian Health Insurance Fund and their services at the national



ownership (Please see Figure 4.1.1 below)	and county levels, Universities.
Involved partner organisations	<p>The Ministry of Health (all three levels of healthcare), the Ministry of Social Policy and Youth, the Croatian Health Insurance Fund and their services at national and counties levels, Universities.</p> <p>In the Istria County, partner organisations that were mentioned during the interviews were: Centres for Social Care, Homes for the elderly, the Istria County Body, local self-government units, the League against Cancer Pula, the Volunteer Centre of Istria, the Pula General Hospital, the Emergency Medical Centre, the Muscular Dystrophy Society of Istria, the Croatian Centre for Palliative Care (Manager of the programme, IPO3_2, page 5, line 176-172; 180-182)</p> <p>In Zagreb, the Secular Franciscan Order and the Centre for Coordination of Palliative Care are involved in the programme (Informal caregiver, IPO16_2, page 1, line 10-11; Manager of the programme, IPO1_2, page 4, line 125; Informal caregiver, IPO15_2, page 2, line 39).</p>
Involved disciplines and professions	Physicians (GPs, specialists such as paediatricians, oncologists, psychiatrists, anaesthesiologists, and physiatrists), nurses at different health institutions, community care nurses, psychologists, social workers, volunteers, mobile teams, family, university staff, priests.

Source: 1-4

Figure 4.1.1 Organisational framework of the Palliative Care (PC) System in Croatia



## 4.2. Service delivery

### 4.2.1. Design of delivery of care

Currently, the Palliative Care System is not fully integrated in the national healthcare system; it is based on pilot projects level in different parts (counties) of Croatia. Changes in the legal framework are waiting for full implementation on the national level (2,5,6, Manager of the programme, IPO1\_2, page 2, line 41-42).

Palliative care should be organized **on three levels**: *home care* (provided by primary healthcare centre staff: family medicine physicians, community nurses, mobile palliative care teams, and other social care); *extended palliative care* (provided by social services); and *hospital care*.

*Hospital care* of palliative care patients could be provided through general or special hospitals, hospital day care, and hospices. Hospital palliative care departments and hospital specialist teams for palliative care should be established, to coordinate palliative care and to provide integration, support, and logistics for such care. Planned discharge of palliative care patients as a very important activity should be implemented as well. *Extended palliative care* could be provided through permanent accommodation in social institutions; when a palliative care patient needs healthcare, a primary care physician or emergency physician could come to provide healthcare on call (the so-called Home visits, paid through the Croatian Health Insurance Fund) (2).

*Special centres*, so-called *Coordination Centres for Palliative Care*, coordinate care between hospitals, ambulatory palliative care, specialized palliative care teams, mobile specialist palliative care teams at the primary care level, and social care, providing vertical, horizontal, and intersectoral cooperation and collaboration, at the county and national levels. *Informal care givers/volunteers* are included, as well as *institutions/offices for renting medical aids/devices*. A *registry of palliative care patients* at the national level is necessary (2-4).

The Programme is partly embedded in the healthcare system. The health system should be reorganized, and new network between health institutions must be constituted. Better links to social services (the Ministry of Social Policy and Youth) must be formed. Political support has been obtained (1,2). According to the information from the interview partners, the importance of palliative care was recognized by the relevant decision-maker institutions despite the political situation in the country and frequent changes

of Government (Manager of the programme, IPO3\_2, page 10, line 344-350; Manager of the programme, IPO1\_2, page 2, line 41-42).

Clinical guidelines, such as the National Guideline for working with palliative patients in emergency centres, were published in 2015 (7).

The palliative care programme includes all kinds of professionals, such as physicians (GPs, specialists such as paediatricians, oncologists, psychiatrists, anaesthesiologists, and physiatrists), nurses at different health institutions, community care nurses, psychologists, social workers, volunteers, and family and university staff. The care process supports and/or improves continuity, comprehensiveness, and coordination of care for multi-morbid persons by linking three levels of healthcare, social care, and informal caregivers (1,2,4).

*“The team has two permanent members who are full-time employees in palliative care, and we have a wider team consisting of about 15 people of all kinds of profiles - including a priest, psychologist, social worker, and nutritionist.” (Physician, IP10\_2, page 1, lines: 21-23)*

CEPAMET was established for educational activities at the Medical School of the University of Zagreb and provides workshops on palliative care for different stakeholders (Manager of the programme, IPO2\_2, page 6-7, line 233-236; Physician, IP09\_2, page 9, line 303-304). There is also a European White Book on education in palliative care. Education is divided into 10 domains.

*IP10\_2: “There is a European White Book on education in palliative care. Education is divided into 10 domains. All of the people in our hospital working with palliative patients, those are mainly “old cats” who know their job well. A nurse who works in the emergency room I cannot teach anything about care, but I can teach her a lot about legal issues, social issues, about the spiritual needs of these patients and their families, so I can teach them and I can send them to the education for everything, apart from their core business which is being a doctor or nurse.” (Physician, IP10\_2, page 8-9, lines: 314-325)*

In the Palliative Care programme, 24/7 care at the national level is planned, as is the necessary infrastructure but with increased costs (e.g. new organisational structure, equipment of new teams, additional workforce). In the Istria County, the Mobile Specialist Palliative Care Team operates on working days from 7 AM to 9 PM and can be contacted by phone on weekends as well; it cooperates

with the Emergency Centre and hospital doctors before discharge of palliative care patients (Manager of the programme, IPO3\_2, page 10, line 344-350; Physician, IP09\_2, page 12, lines 439-445; Physician, IP09\_2, page 2, lines 61-65; Physician, IP09\_2, page 10, lines 337-338). For now, 24/7 care cannot be obtained, but it is planned (8).

*“... When a hospital doctor decides to no longer apply the curative approach, that means he no longer thinks that it is possible to cure a person; in the discharge letter he usually recommends engaging a palliative team in Istria County, that's us. I try to make it so that I go to the hospital before this patient is discharged from the hospital, no, so that I can get to know him, get to meet the family, that in some ways I take over the care as painlessly as possible, while the person is still in the hospital.” (Physician, IP09\_2, page 2, lines 61-65), Situation in Istria County*

*“The whole programme is made on the basis of the Strategic Plan for the Development of Palliative Care in Croatia and according to the instructions from the Ministry of Health through its Committee for palliative care. Since the Clinical Hospital Dubrava does not have beds for palliative care and given that we do not have a younger population in our care, we have a large number of palliative patients, we opted for a programme that we have put together in Clinical Hospital Dubrava, made a working structure that is specifically in charge of this matter, we created teams which have passed a part of the education in CEPAMET in Zagreb, and in that way we organized the care for patients who need palliative care.” (Physician, IP11\_2, page 1, lines 24-30)*

The care process is based on patient-centred care, organised around a palliative care patient. It is based on a holistic assessment of the palliative care patient – in addition to healthcare; it includes social care, spiritual care, and family.

In the programme, an individual's characteristics, values, preferences, and personal goals are considered as well (Manager of the programme, IPO3\_2, page 13, line 467-471; Manager of the programme, IPO3\_2, page 13, line 474-476; Non-physician medical staff, IP13\_2, page 3, lines 90-100). Users and their families are not lost in the system, they can obtain information and adequate care at home and in the institution in a simpler way (Physician, IP09\_2, page 4, lines 112-118; 121-124; Physician, IP10\_2, page 2, lines 69-71; 75-77; Physician, IP10\_2, page 3, lines 82-85; 91-94; 101-104). Families are actively included as well (Physician, IP10\_2, page 4, lines 119-120).

*"...The person's wishes, their needs, their pain, and their torments are more important than the treatment protocols. It is more important to respect that than to get the result that using some medicine can prolong the patient's life for 7 or 15 days which can be published in conferences. We really care about the person." (Manager of the programme, IPO3\_2, page 19, line 665-668)*

*"The aim is a holistic approach and teamwork. There is not only one person in the care process, a lot of professional roles and different experts from the health system are included who manage and provide the patient's symptoms, considering their needs." (Manager of the programme, IPO1\_2, page 3, line 178-180)*

*"I: Regarding the individual needs of patients, how do you assess them, is there a comprehensive approach to assessment or ..? IPO9\_2: Yes, we use, we use the, uh, the tables, we use the protocols which are generally accepted and were just recently compiled into the National guidelines for the work of the Croatian Department of Emergency Medicine, there are tables, which we apply daily starting with a performance status, this means general status, in what state is the patient, should we continue with the current therapy or the treatment should change, but the approach is always, and it must be, individual. Because our patients are no longer patients who can be on curative, therefore schematic, routine, and preventative care therapy, but they are patients who have certain problems such as this patient, who had water in the stomach, which needed to be extracted...." (Physician, IPO9\_2, page 3, lines 82-88)*

*"So, first of all in palliative care, the base of palliative care is the involvement of the patient in their own care. In a way that, a person who knows that their disease is progressing is given an opportunity for them to speak about their illness, is given an opportunity that they eemmmm ... say what they want with regards to treatment and care and what they do not want, and through working with them to try to see what of it is possible to enable or isn't possible, it means, the base for palliative care is that a person knows that we will help them to finish their life in a way that they want. This, of course, is not always possible, but it is something our project is based on, because when you look at ordinary healthcare, the patient is not entitled to say a word; they are not the one who decide. In palliative care, they, with our support and guidance of course, are always and foremost given an opportunity to express what they want, and, and the way they would like to finish their life and where they would want to finish their life. And they, although this is a project, and it may not have any security, we hope it will have, but patients only and*

*always accept our visit with welcome, our initiative, because in the final stages of the disease they often feel abandoned, without professional support.” (Non-physician medical staff, IP13\_2, page 3, lines 90-100)*

*“I: When it comes to your treatment and your care, you have a say in that personal plan of yours, you discuss it with the doctors ...? IP18\_2: Well, normally. Here, a moment ago, you heard my conversation with this gentleman and so on. There is nothing without agreement. We have to be, to cooperate, if I want to achieve something, he has the knowledge, I need to listen, to follow what he says, take the appropriate medication which they recommend to me and so on.” (Patient, IP18\_02, page 5, lines 151-155)*

One important issue in palliative care is to recognize and deal with polypharmacy in palliative care patients. All unnecessary drugs should be removed with clear explanation to the patient and families. In the interviews it was mentioned that some doctors and nurses do not think about the limited life span of the patient; they should have to think about how much sense there is to give different drugs to a palliative care patient (Physician IP10\_2, page 5, lines 190-195; 197-200; Physician, IP11\_2, page 3, lines 70-73).

Informal caregivers are involved in the programme as a family members or volunteers.

The role of the informal caregivers (beyond that of the health system), predicted by establishing and achieving the Strategic Plan for the Palliative Care is, for example, that when the patient is being released from the hospital, the nurse should contact the coordinator and the family. The coordinator should check the conditions in which the patient will live and if there are any family members to take care of them.

Family is included in the care process and represents the basic unit of care. Family members provide 80-90% of the care and take part in the therapy process. Instructed by the members of the mobile palliative care team, the family is 100% included. Experts evaluate the physical, psychological, and emotional state of the family members to determine who can be the caregiver. They even evaluate whether the caregiver is in a possible conflict of interest. The family should be included throughout the whole period process of dying; they should get the support and adequate information to prevent them from being lost in the system. During the visit in their homes, informal caregivers or volunteers could talk with the patients, give them psychosocial support, some information about their rights provided by the social

care system and the health system, and sometimes even help them in the process of achieving these rights.

The first task of non-medical caregivers is to spend time with patient, to see what their needs are in that moment so that the family members who take care of the patient can peacefully go somewhere and relax a little without being concerned. The volunteer will talk if the patient wants to talk, they will be quiet if the patient wants to be in the silent, they will go to the pharmacy if there is a need for that, they will do whatever is necessary. The volunteer is at the service of the patient and their family, when it comes to their needs. Patients often need a conversation because they are in a very delicate situation, close to dying, and they are dealing with spiritual issues, social issues, and fears (Manager of the programme, IPO3\_2, page 13, line 491-499; Manager of the programme, IPO1\_2, page 6, line 196-200; Representative of the funding organisation, IPO7\_2, page 1, line 14-16; Informal caregiver, IP15\_2, page 2, line 31-36; Informal caregiver, IP15\_2, page 2, line 31-36; Informal caregiver, IP15\_2, page 4, line 124-130; New professional role, IP14\_2, page 15, lines 546-554; Physician, IP11\_2, page 2, lines 58-60).

*“Well, the first thing when we get called to the Department is for us to ask who does the patient have, even before we see a patient we need to know who takes care of them because if we do not know who takes care of them we cannot keep working on plan for their care at all. The first thing is to see who they have because to take care of them at their home there must be three adults in the same house, one of whom must be at home for 24 hours a day. This means one younger pensioner and two adult children. Without this, we will not be able to organize quality care. So, the first question is who the family is and then we see what their needs are. There on that cabinet you will see, on the middle shelf [points], we have about 15 different types of leaflets. These are the info leaflets which we give to the family after the conversation, depending on their needs. If they need something about diet, if they need to learn how to empty the urine bag, how to change the urine condom, how to feed and nurture patients with percutaneous gastrostomy. Such patients have a vast number of needs and it would take us at least 20 different types of flyers to help the family to become better engaged in care. Mostly well-arranged families do want to care for the patient, but do not have the knowledge, and we constantly forget that the highest number of beds in palliative care are located in patient homes and that there we have a significant number of willing caregivers who only need to be strengthened with specific knowledge and medical aids.” (Physician, IP10\_2, page 6, lines: 221-233)*



*“... Some of them are dealing more with education and support, some of them are dealing with visits to the patients in their homes eemmm ... he, we mostly work with the Secular Franciscan Order and they really are a serious group of volunteers, they have a social worker employed, a social worker who regularly monitors volunteers, guides them, supervises, they have joint meetings, have official educations...” (Non-physician medical staff, IP13\_2, page 5-6, lines: 194-199; 204-208)*

#### 4.2.2. Self-management interventions

According to the available documents, self-management interventions are not known. The target groups for the self-management interventions in the programme are patients and their families who need palliative care. Different stakeholders from the programme can support the patients with the self-management interventions. Education and special training for the patients and the families are needed. Different stakeholders from the programme which were interviewed have different thoughts about the self-management interventions depending on their position in the programme. They think that self-management is a reality, but education is needed to be able to overcome the everyday problems, of course with the support of the experts (Manager of the programme, IPO3\_2, page 6, line 186-188; Manager of the programme, IPO1\_2, page 2, line 65-67; Patient, IP18\_02, page 6, lines 171-180; Manager of the programme, IPO1\_2, page 5-6, line 187-189; Physician, IP10\_2, page 7, lines: 253-259; Physician, IP09\_2, page 7, lines 250-258; Patient representative, IP17\_2, page 8, lines: 271-278; 291-292).

Self-management interventions could support and/or improve continuity, comprehensiveness, and coordination of care for multi-morbid persons and could be accepted by multi-morbid persons as important (Physician IP11\_2, page 4, lines: 103-112; social staff, IP12\_2, page 3, lines 73-77; Physician, IP09\_2, page 7, lines 232-239; New professional role, IP14\_2, page 7, lines 232-239; Physician, IP11\_2, page 3, lines 81-88).

Challenges which arise in the context of self-management initiatives with respect to the training of healthcare system/medical professionals, clinical setups, especially regarding primary care, payment mechanisms, and characteristics of the individual that influence adherence, and access to such interventions (education, physical states, social backgrounds, financial situation, access to information) are described below.

*IP11\_2: "As we carry out this training verbally, my experience is that for each patient, the family must get it in writing too, in printed material because the situations are such that they often forget, do not understand well, this should be transferred to the written form." (Physician, IP11\_2, page 4, lines: 103-112)*

*"... It all comes down to knowledge, the lack of information. Lack of information. The patient, when the patient comes home from the hospital, they have no idea that they have cancer, for example." (Physician, IP09\_2, page 8, lines 272-274)*

*"In palliative care you have developed schemas to bypass it. There must be no conflict because if you do not gain the trust of the patient immediately, you won't ever again. The first question when we talk with the patient about their illness is: "What have you learned so far about your illness?" And then they tell us what they know, what they think they have. Another question: "Do you want to ask us something? Whatever you ask, we will answer honestly." That is how you form relationships, first we find out what they know, secondly we gain their trust. And if they ask: "How long before I die?", I'll form a response for them. Provided that the truth is being treated as a drug, this means ... to the right person, at the right time, in the right dose, and at regular intervals, because the bad news are not communicated as a one-time event but as a process. So, there is a scheme for how it is done." (Physician, IP10\_2, page 8, lines: 286-294)*

*"I: Do you have some ideas, maybe what would be good to improve this program? What would any other ... IP17\_2: Only the infirmary. There. Only the infirmary, because you really have people, and I now put myself in a situation, I always think, maybe I'll call you when I'm ... I am alone, there are no ... When I one day, well I will be seriously ill one day. When I get sick one day, who will... The infirmary is necessary, necessary. And, I hear that there will be one in the new hospital." (Patient's representative, IP17\_2, page 6, line 206-210)*

### 4.3. Leadership & governance

Governance structures are appointed by the Ministry of Health. The motivation for and purpose of the relationship/partnership is to organise palliative care in the country in order to rationalise healthcare spending and to give an opportunity to patients and their families to obtain the defined rights and not feel insecurity. Long-term care and social care are parts of the palliative care programme. They are predetermined as a part of the palliative care network. Special centres, the so called Coordination

Centre for Palliative Care, coordinate care between hospitals, ambulatory palliative care, specialized palliative care teams, mobile specialist palliative care teams at the primary care level, and social care, providing vertical, horizontal, and intersectoral cooperation and collaboration, at the county and national levels. Informal care givers/volunteers are included as well. The Institution/Office for renting medical aids/devices is also included (2,4,5,8, Manager of the programme, IPO3\_2, page 4, line 130-132; Manager of the programme, IPO2\_2, page 13, line 506-507; Manager of the programme, IPO1\_2, page 5, line 148-150; Manager of the programme, IPO3\_2, page 12, line 409-410). The most relevant barrier is the undefined legal framework which causes uncertainties in financing of care and does not define the level of services.

The most relevant facilitators are cooperation with patient associations and cost reductions of palliative care when such care is provided in an organized system in comparison with a non-organized system.

*“We developed a plan for the engagement of the social care system in which the social care system reacts according to priority and the social staff comes to the patient's home the very next day. Social staff are informed of the fact that if the mobile palliative care team phone them, then they have to react immediately, not in 15 days, because that could be too late. The social worker's visit is financed by the Istria County.” (Manager of the programme, IPO3\_2, page 5, line 170-174)*

*“Regarding spiritual palliative care, we are in the contact with the Diocese and we work together on the project of hospice construction in Istria County. We are trying to develop spiritual palliative care and we are trying to find priests who are willing to enter in the project and as a part of a mobile palliative care team visit patients in their homes and provide that aspect of the care.” (Manager of the programme, IPO2\_2, page 4, line 132-136)*

*“I: Tell me, what is communication or cooperation with providers of non-medical services like? IP10\_2: We nourish them. We included them slowly and explained to them how important they are to us. They are informal but very active members of our hospital team for palliative care. Their word is respected and we have provided them, the social workers, we formalized their work in the way that we persuaded the management to enable them to write their findings in a way that a physician, psychologist, or speech therapist write them and they can access the hospital information system and they have their own social worker's clinic as an organizational unit, and*

*a social worker receives a referral from the department and prints its findings. They can read the findings from us, the palliative care.” (Physician, IP10\_2, page 4, lines: 137-144)*

*“The coordinator should represent a connection between the health system and the other systems involved. They should organize the registration of the volunteers; manage the office for renting medical aids/devices. They should obtain all the relevant information, the contacts, and have an advisory and support role at the primary healthcare level for the patients and their families who can contact them to get the relevant answers about their needs.” (Manager of the programme, IPO1\_2, page 4, line 143-148)*

*“Our office for renting medical aids/devices is a great help for the patients and their families. Anti-decubitus mattresses, good care, and explanation on what to do, really facilitate the whole care process. And the other aids/devices as well: toilet chairs, electrical beds...” (Manager of the programme, IPO2\_2, page 14, line 517-520)*

#### 4.4. Workforce

As already mentioned, the Palliative Care Programme includes **different kind of professionals**, such as physicians (GPs, specialists such as paediatricians, oncologists, psychiatrists, anaesthesiologists, and physiatrists), nurses at different health institutions, community care nurses, psychologists, social workers, volunteers and family, mobile teams, university staff, and priests.

**Mobile multidisciplinary specialist palliative care teams**, an example of a new innovative role in the Croatian palliative care model, are established at the county level (at the primary care level) (they also include different physician specialists). The first mobile team was established in Istria County. It consists of a specialist in radiotherapy-oncology and two nurses as full-time permanent employees; the external part-time experts are an oncologist, neurologist, surgeon, psychiatrist, physiatrist, stomatologist, psychologist, pharmacist, GP, and social worker. In the period of 2012 to 2015, they provided different interventions/procedures for palliative care patients in the Istria County, such as urethral and suprapubic catheter insertion, necrectomy and polishing, abdominal and pleural puncture, as well as parenteral therapy (8).

*“The appearance of the mobile palliative care team is one new role. A mobile team of specialists who enter the patient's home, their family, has never existed in Croatia.” (Manager, IPO3\_2, page 11, line 397-399)*

*"... I am otherwise radiotherapist oncologist ... I worked at a hospital, now I am working in Primary Care Centres for the Istrian region as a field doctor and head of the Department of Palliative Care and the mobile palliative team." (Physician, IP09\_2, page 1, lines 1, 18-19)*

**Palliative care coordinators** are predicted to work in the Coordination Centre situated in the healthcare institutions established by the state or local/regional government units. The coordinator is a health or social worker with at least a minimal level of *Baccalareus* education, with 5 years of working experience, and with additional palliative care education. The predicted tasks for the coordinator are: coordination and empowerment of the existing healthcare system in the field of palliative care through the 24/7 model; coordination and empowerment of the social care system for providing palliative care; coordination and connection of healthcare on every level and of social care and other stakeholders; maintaining the palliative patient registry; coordination of the mobile teams; coordination of the office for renting medical aids; coordination of the education in the area of palliative care, and informing citizens about palliative care (2, Manager, IPO3\_2, page 11, line 408-410; Non-physician medical staff, IP13\_2, page 1, lines 17-19; 20-21; Non-physician medical staff, IP13\_2, page 2-3, lines 75-84).

*"Now is the time for the establishment of the head of the new office for renting medical aids/devices which should start working soon." (Manager of the programme, IPO3\_2, page 11, line 411-412)*

**Informal caregivers/volunteers** have important roles as well (Manager of the programme, IPO1\_2, page 4, line 143-144; IPO1\_2, page 8, line 287). Explanations of their role can be found in the chapter "Design of the delivery of care".

*"Volunteers have an important role." (Manager of the programme, IPO1\_2, page 8, line 262)*

*"A volunteer is an equal member of the multidisciplinary team, and if the doctor and a nurse are required to have palliative care education then the volunteer must have the same education, too. Of course, the education has to be adapted for the parts of the care that volunteer can and should do." (Informal caregiver, IP15\_2, page 3, line 106-108)*

There is a need for the creation of task shifting and skill mix catalogues and defining a network of centres of excellence, training centres, and cabinets. Task shifting and skill mix programmes should be

gradually introduced in the healthcare system by redistributing tasks among professions horizontally or vertically, from the level of primary healthcare to the clinical institutions (9).

Old professions must be upgraded for palliative care. There is a lack of doctors in the health system and professionals will probably need to take over some of their duties. New professionals must be educated and trained to give specific care to palliative care patients. This must be included in the curriculum of their education. The abovementioned centre CEPAMET, at the Medical School University of Zagreb, provides workshops on palliative care for different stakeholders, but other form of educations are needed as well. The levels of education, knowledge, and skills have to be customized to the authorization level of every specific stakeholder (medical and social) who provides palliative care with, the possibility of expanding and officially approving authorization according to the education level gained (1,4, Manager of the programme, IPO2\_2, page 6-7, line 233-236; Informal caregiver, IP16\_2, page 4, line 140-142; Manager of the programme, IPO2\_2, page 9-10, line 352-357; Non-physician medical staff, IP13\_2, page 1, lines 28-32).

*“Three levels of education are important - basic education of all medical and non-medical staff, education for the medical staff on the immediate palliative care level, and a specialist, narrow specialization, knowledge.” (Manager of the programme, IPO1\_2, page 8, line 262-264)*

*“The basic requirement for someone to be a part of the palliative care team is to have education in the area of palliative care. This is a minimal requirement. We need to have a registry of the appropriate educators who can provide the educations to others. CEPAMET provides educations. There are some sporadic educators, too. There is an announcement from the Catholic University of Croatia that they formed a Chair for palliative medicine.” (Manager of the programme, IPO1\_2, page 4, line 156-160)*

The most relevant barriers are the lack of educated doctors and nurses in the health system and some legal and organizational issues. The most relevant facilitators could be recognition of needs and willingness of different stakeholders to participate.

#### 4.5. Technologies & medical products

Computerization of health and social care and e-Health are recognized as a priority in Croatia. The Strategic Plan for Development of e-Health in the Republic of Croatia exists since 2014 (10).

ICT applications such as electronic health records (EHR), internet, cellular phones/devices, and telemedicine will be used in the palliative care system in a sustainable way. The electronic health record e-card is being released in a test phase in September 2016.

Target groups for ICT applications are not yet defined. They will probably consist of patients or members of his/her family, volunteers, the GP, hospital teams for palliative care, the Centre for Coordination of Palliative Care, mobile palliative teams, and hospices. ICT applications are already used in some parts of the country – for example in the region of Istria, but under individual organisation. They use cellular phones, tablets in connection with the GPs, hospitals, mobile palliative teams, volunteers, and patients; lately, in agreement with the General Hospital Pula, smartphones are used for telemedicine. Sometimes a photo is taken or a video about patient is made and they are then sent to the emergency centre (Manager of the programme, IPO1\_2, page 6, line 211-213; Manager of the programme, IPO3\_2, page 14, line 505-509; Manager of the programme, IPO3\_2, page 14, line 509-512).

The Centre for Coordination of Palliative Care in the City of Zagreb has developed an application which allows data storage on common users in Zagreb which enables following of user needs. This is necessary in order to see how many users need palliative care in Zagreb and what their needs are. According to this information, the Centre calculates how many volunteers are needed, preventing the situation in which there are 30 users and 20 volunteers (Informal caregiver, IP16\_2, page 5, line 184-186). In Rijeka, special software for the identification and monitoring of such patients exists; it finds potential candidates for palliative care (Physician, IP10\_2, page 2; lines: 51-53).

*“It was developed by a hospital computer expert, a wonderful electrical engineer who, according to my requirements, made a piece of software that allows me to have both a virtual clinic and my own virtual department. So, in our hospitals, there are a total of 43 roofs, 1200 beds. I have the software, up on the screen all my patients who are currently in the hospital are listed, I have their diagnosis, their last letter of discharge, the patient category, the strength and category of pain. And the rehospitalisation during the given period as well, either 3, 6 (op. months), depending on the calibration of my tool. It is a magnificent platform that allows you to move on with the inclusion of education in palliative care as well. Because you cannot hold classes on palliative care in hospices or the infirmary where every new face causes alarm in a patient, where the patient is in the hospice alone or there are two of them in a room and in general people do know why they came to the hospice, they came to die. And for our patients, where*

*there is a non-stop spinning of white or blue coats, and pink and grey, two more coats do not mean anything. According to our software we know exactly which patient is capable of accepting students and for how long.” (Physician, IP10\_2, page 8, lines: 302-313)*

*“I: Do you use, in your work, some special ICT applications, programmes? IP11\_2: Yes, for assessment of the remaining life span. These are applications PIPS- A and -B. We are now at the stage in which our computer scientists could create a short programme where we, based on the review of health condition due to the diagnostics that have been performed, could quickly assess which patients are dying patients so that we do not have to wait for an announcement from the department.” (Physician, IP11\_2, page 8, lines 95-99)*

It is necessary to establish a unified information system for collecting, monitoring, and management of information on palliative care, which includes the establishment of a national Registry of palliative patients. The Centre for Coordination has developed its own registry of patients and uses that registry for entering the visits of their volunteers (Informal caregiver, IP15\_2, page 5, line 192-193).

Continuous linking of the palliative care network will assure more efficient and better quality care and active engagement of the patients as well (IT expert, IP19\_2, page: 3; lines: 96-101; IP19\_2, page: 3; lines: 108-111).

*“So, in September we should start a Portal for patients, where patients can obtain their medical findings and so on, and probably in the future they will be able to write some of their measurements or they will do that through applications for mobile health, and that's all associated with the E-citizen programme and authentication via NIAZ and so on.” (IT expert, IP19\_2, page 4; lines: 132-136)*

It is not known how these ICT applications are accepted by the multi-morbid persons. The most relevant barrier seems to be financing and IT education. The most relevant facilitators are not known.

*“I: You mentioned the obstacles for the introduction of applications for patients, what you would say are the barriers to the introduction of applications for other users in the programme, from nurses and doctors to the ... IP19\_2: Money.” (IT expert, IP19\_2, page 4; lines: 137-140)*



#### 4.6. Information & research/monitoring

Palliative care is still not implemented in sustainable way in the Croatian healthcare system. At the beginning of the implementation of the Strategic Plan for the Development of Palliative Care in Croatia for the period of 2014-2016, analyses of resources and needs were done according to the results from Questionnaires sent to primary care hospitals and counties. After the changes in the Network of Public Health Service, in which stakeholders of palliative care (coordinators, mobile palliative teams, institutions for palliative care, hospitals) are now included the network and there is an Ordinance on the minimal standards for healthcare performance, counties are faster in the process of negotiation for such care. For full implementation, a new Law on Healthcare is needed, which is currently in process. The Committee for Palliative Care, appointed by the Ministry of Health, is responsible for the further activities and suggestions on further implementation of palliative care and the development of new a Strategic Plan for the Development of Palliative Care in Croatia for the period after 2017 as well, with the aim of improving the quality of life of palliative care patients and their families (11). Indicators used to assess the performance of integrated care systems are not yet established at the national level (2).

The monitoring system is not yet fully established. Continuous systematic data collection within the Palliative care programme is planned, as well as the establishment of a Registry of palliative care patients. Data for financial calculations for the Croatian Health Insurance Fund will be collected (such as the number of procedures, etc.). The Committee for Palliative Care, which is appointed by the Ministry of Health, is responsible for the monitoring of the activities and achieving the main expected results determined by the Strategic Plan (2,11). Currently, different data are collected, for example elements important for palliative care monitoring through questionnaires at primary healthcare centres and hospital institutions at the county level, with the aim of improving and developing palliative care (some of the monitoring elements are connected with organizational issues, structures for providing palliative care, continuity of care, educational issues, recognition and patient monitoring, care in patient homes, communication and psychological care, and technologies of care) (5).

In 2015, a questionnaire for evaluating the work of the mobile palliative care teams was sent to the Primary Healthcare Centres which are conducting pilot projects (Primary Healthcare Centre Zagreb - Centre, Primary Healthcare Centre Čakovec, Primary Care Centres of Istria, Primary Healthcare Centre Vukovar, Primary Healthcare Centre of Primorsko-goranska County, and Primary Healthcare Centre of Osječko-baranjska County). The questionnaire about the development of the elements of palliative care

was sent to the primary healthcare centres and hospitals which have contracted beds for palliative care (the results can be seen in Table 4.6.1 and 4.6.2). A questionnaire about executed tasks related to palliative care was sent to 21 counties (the results can be seen in Table 4.6.3) (5). In the analysis, pilot projects were rated as one of the stages of development of palliative care with recommendations for further strengthening of the existing resources of the health system and investment in further education in the area of palliative care (3).

**Table 4.6.1: Elements of palliative care establishment within a certain level for 49 primary healthcare centres**

Elements of palliative care establishment within a certain level for primary healthcare centres	Number of primary healthcare centres which established certain elements, N
<b>Organizational level</b>	
Cooperation with other institutions	25
Inclusion of the voluntary organizations	12
Formed a directory with the contacts for the relevant stakeholder	13
Available plan for development of palliative care or other document	10
Existence of a palliative care team (stationary or mobile)	6
Existence of an ambulance or service directed towards palliative patients	6
<b>Educational level</b>	
The educational plan was completed	9
An educational plan for patronage nurses was made	9
Some of the employees have education in palliative care	22
Some of the patronage nurses have education in palliative care	22
<b>Recognition and patient monitoring</b>	
System recognition of the patients who are candidates for palliative care is being applied	24
The number of patients included in palliative care is being monitored	12
The institution has its own registry of palliative patients	6
ICD-10 Z51.5 is being applied	11
The patronage service recognizes ICD-10 Z51.5 for palliative patients in its work	4
<b>Care in patient homes</b>	
External catheters in patient homes are being used	10
Subcutaneous infusion in patient homes is being applied	5
Educational materials about palliative care for patients and families are being used (care plans, preferences, communicating)	9
There are patients with PEG who are in home care	13
Elastomeric pumps are being used in home care	1
The existence of a formal written consent form to be signed by the patient or legal representative for inclusion in palliative care	3

Note: The survey questionnaire was sent to 49 primary healthcare centres. The number of primary health centres that answered was 41.

Source: (5)

Table 4.6.2: Elements of palliative care establishment within a certain level for 44 hospital institutions

Elements of palliative care establishment within a certain level for hospital institutions	Number of hospitals which established certain elements, N
<b>Organizational level</b>	
A plan for the development of palliative care or other document available	12
The existence of an official document for decision-making and sending patients to palliative care	6
The existence of clear practice related to who and how is responsible for the decision that further curative treatment is not professionally justified and that only palliative care is indicated	11
The institution has its own registry of palliative patients	10
ICD-10 Z51.5 is being applied	11
The number of patients hospitalized in the institution or already involved in palliative care on the day of completing the questioner is known	11
<b>Structures for palliative care provision</b>	
A hospital team for palliative care has been established	10
A supporting palliative care team has been established	12
Establishment of an ambulance for pain	14
Establishment of an ambulance for chronic wounds	7
Establishment of a palliative care ambulance (or palliative medicine)	7
Establishment of a palliative care unit	9
Establishment of a palliative care unit for children	2
Establishment of organized support for family during the patient's illness and during mourning	11
Establishment of a clinic for nutrition (or another form of organized advice about nutrition)	9
<b>Continuity of care</b>	
Establishment of cooperation with other institutions	16
Establishment of special programmes or cooperation with other colleagues in the area of palliative care	13
Inclusion of voluntary organizations	7
A directory with the contacts of the relevant stakeholders in the hospital and on the field	16
Establishment of the service/person responsible for the planned discharge of patients	16
The obligation to organize a meeting with the patient's family or caregivers before the patient is discharged	13
<b>Educational level</b>	
An educational plan about palliative care is available	13
Some of the employees have education on palliative care	17
<b>Communication and physiological care</b>	
The existence of a standard procedure for communicating bad news	9
The existence of adequate space for conversation with the family at each department	14
The existence of the "silent room"	9
The existence of a standard procedure for informing family members about death	14
Educational materials about palliative care for patients and families are being used (care plans, preferences, communication)	7

The existence of a formal written consent form to be signed by patient or legal representative for inclusion in palliative care	7
<b>Technology of the care</b>	
External catheters are being used	14
Elastomeric pumps are being used	2
PEGs are being placed	14
Form lists of monitoring problems designed specifically for palliative patients are being used	7

Note: The survey questionnaire was sent to 44 hospitals. The number of hospitals which answered was 23.

Source: (5)

Table 4.6.3: Tasks for palliative care establishment for 21 counties

Tasks for palliative care establishment on the county level	Number of counties which performed certain tasks, N	The task has not been performed or there is no data about it
Establishing a county project team for the development of palliative care	12	9
Adopting development of palliative care as one of the county council for health priorities	9	12
Development of a public health needs assessment for the region (county IOPH)	6	15
Detecting and systematizing existing resources and capacities for palliative care in the county	11	10
Developing an address book with the contacts of all the stakeholders relevant for providing palliative care	7	14
Developing a county plan and programme for the development of palliative care	5	16
Making a plan about a county network for renting medical aids/devices for people with severely limited mobility	6	15
Making a plan about a county network for pain treatment	2	19
Establishing an emergency line for palliative patients in the welfare centre	4	17
Establishing a county coordination centre for palliative care in some of the health institutions in the state/local property on the primary care level	5	16

Note: The survey questionnaire was sent to 21 counties.

Source: (5)

*“So, each patient is led by their chosen family medicine physician. All data that doctor has are sent to a central healthcare system. We said that we will use NKB Z .51 or 55 for palliative, this is what I was ... anyway, this diagnosis so that the patient would be recognized everywhere in the system as palliative. If such a patient goes to the hospital, some care is provided there for them,*

*eemmm... A hospital doctor can equally eemmm... each finding, and their letter of discharge is also placed in CEZIH, where it can be reached by a GP or the doctor who needs it. In the same way, meaning starting from September, emergency medicine should work the same way. So, everything what is done with the patient, and if it concerns health, and, or contractual health, that means not private clinics, not polyclinics and so on, is being recorded in a central healthcare system. I think somewhere around 90% of the data is recorded. So we already have all that recorded in the central healthcare system.” (IT expert, IP19\_2, page: 4-5; lines: 146-155)*

*“Because we are a hospital department, our documentation is managed through an integrated hospital information system. Both my and my nurse’s findings are one of the findings in the medical records just like one of the findings is the social worker’s finding, also. Along with that we have a registry for palliative patients where we record things that cannot be easily monitored through the hospital information system, for example, the patient’s desired place of death and the actual place of death. For now, as we have patients only temporarily, for just a part of the care or in some sort of intervals, with each new hospitalization we cannot systematically monitor their quality, so for now, the only indicator that we are tracking is the desired and the actual place of death. And again, we do not manage to do that with all of our patients, because we very often do not know that our patient died, and no one except us, well, the coroner documents it, but this is not displayed in our information system which we obtain from CEZIH. So we do not know if our patient died at the nursing home, in private social care, at home, or in a hospice. We can only know if they died in the hospital or if they did not die in the hospital.” (Physician, IP10\_2, page 11, lines: 398-409)*

*“We maintain a registry of our patients which are included in palliative care from the date of inclusion. We try to get feedback through the Centre for Palliative Care in Zagreb on when our patients leave the hospital so that we know what is going on. Basically, we try to follow them all the time.*

*Although it is still very difficult, I do not know what term I would use, due to the failure to establish a more comprehensive cooperation with primary healthcare.” (Physician, IP11\_2, page 5, lines: 148-152)*

*"I: How are they, and are they at all assessed and evaluated your results, is there a system of monitoring and quality assessment? IP13\_2: Well, I think that, that it is not very developed. We*

*are a pilot, a pilot project which is still being paid, funded by the city of Zagreb. So, we act as part of the institution for healthcare, which is the official institution that reports to the HZZO and to the city of Zagreb. However, as we are a pilot project, which is being paid by the city of Zagreb, then our reports are directed towards, towards the Office of Health of the City of Zagreb. So, we try to summarize these, our, our results, but as I am saying, since we are a pilot project, this is the only way ...” (Non-physician medical staff, IP13\_2, page 6, lines: 235-242)*

*“We have done the financial impact assessment on the health system and we saw that the charges on the primary level instead of on the hospital level bring healthcare and financial savings. Although this is not the priority, not in the first line of the care for the patient, but there were evident cost savings...*

*... Evaluation of the 10 pilot projects which are financed by the Croatian Health Insurance Fund was done to see if this model was appropriate for further work.” (Initiator of the programme, IPO4\_2, page 9, line 320-322; 324-325)*

*“Some elements of the self-evaluation we do continuously and we are trying to get as much data as we can, and we get it. We follow what is happening, what we have done, is this too little or too much, is the work we have done enough—that are the statistical elements. We have our informatics programme in which we enter the data and we can follow different elements: the time length of the palliative care, the number of patients, the number of families, the number of calls, the number of phone calls, the number of communications with the GPs, the percentage of the GPs who contact us, the percentage of the families who contact us...*

*...the number of the interventions of the emergency centre for the palliative patients; ...the number of hospital admissions...; ...the engagement of the palliative care by the cities... all that is the evaluation data that we collect.” (Manager of the programme, IPO3\_2, page 6-7, line 214-221; 226; 232; 238)*

In Istria County, the main county body monitors the parts of the services which are under its funding. For example, the number of patients/users and home visits of the mobile specialized palliative care team from 2012 to 2015; interventions/procedures of the mobile specialized palliative care team in patient homes from 2012 to 2015, and the costs of such care (Table 4.6.4 and 4.6.5).

*“Everything what was done can be found in our application. We have six-month and one-year reports in which the data about the number of the visits, the number of the procedures by type, the number of kilometres that the mobile palliative care team has crossed, the number of communications with the doctors, the number of phone calls from the patients, the number of rented medical devices, the number of times advice was given, the number of contacts with social care, the number of the visits of the social care staff in the patient's home, can be found. All that data is what we collect.” (Manager of the programme, IPO3\_2, page 17, line 612-619)*

**Table 4.6.4: Number of patients/users and home visits of the mobile specialized palliative care team from 2012 to 2015**

	Year			
	2012	2013	2014	2015
Number of patients/users, N	259	500	643	843
Number of home visits, N	732	2236	2308	2525

Source: (8)

**Table 4.6.5: Interventions of the mobile specialized palliative care team in patient homes from 2012 to 2015**

		Type of procedure					
Year	Number of patients, N	Urethral and suprapubic catheter	Necrotomy and polishing	NGS-PEG	Abdominal puncture	Pleural puncture	Parenteral therapy
2012	259	46	40	40	64	52	14
2013	500	335	136	128	67	11	57
2014	649	353	214	161	76	28	113
2015	843	305	346	162	60	13	124

Source: (8)

A quality assurance system will be established. The quality assurance system is still in the process of establishment (Manager of the programme, IPO1\_2, page 8, line 277). The selection of appropriate quality indicators will ensure standardized information on the beneficiaries of palliative care. At this time, they do not exist at the national level.

#### 4.7. Financing

The system of palliative care in Croatia is not being established as new or additional one; it is being established on the basis of the conversion of the existing resources, by the empowerment and training of professionals and the appointment of the new procedures and work standards (9).

The sustainability of funding of palliative care will be ensured through the same mechanism applied for the whole healthcare and social system in Croatia. The financing and payment scheme is presented partially: although one of the goals of palliative care is to enable care for incurable patients in their own home until the last day, the number of palliative care beds should be harmonized with EU standards. The public health service network has provided 206 beds for palliative care, of which 113 beds are in general hospitals, 79 are in special hospitals, and 14 beds are in the Institution for Palliative Care Hospice “Marija Krucifiksa Kozulić” (12).

The capital investments in some palliative care institutions are already presented in a macro-level description. The Croatian Health Insurance Fund (HZZO) is constantly increasing the capacity and expanding the network of hospital palliative beds. Thus, from the current 10 institutions, palliative beds are to be extended to 13 new hospitals, and in beds are to be converted to palliative care 9 health centres. Ten mobile palliative team pilot projects, contracted with the Croatian Health Insurance Fund, are currently being conducted (in the Primorsko-goranska, Istarska, Međimurska, Osječko-baranjska, Vukovarsko-srijemska, Požeško-slavonska, Dubrovačko-neretvanska, Koprivničko-križevačka, and City of Zagreb counties). They are being financed from the funds for special programmes (3). Palliative care is being contracted within the Croatian Health Insurance Fund as an activity in line with the Network for the Hospital Institutions and Primary Healthcare Centres. It is being contracted at the level of hospital healthcare and as specialist/conciliar healthcare at the Primary Healthcare Centres. Palliative care on the hospital level refers to the palliative beds whose number is determined by the Healthcare Network and it is being funded as hospital days under chronic healthcare. Until changes happen in the Healthcare Act, palliative care is funded as pilot projects.

Pilot projects have been developed for 10 Primary Healthcare Centres, which is 1/3 of the total number of Croatian Primary Health Centres. Mobile palliative care teams which are being funded by HZZO include one general practitioner and one medical nurse which is being funded through fixed resources in the form of doctor and nurse salaries. Additional staff, such as specialists in the Istrian mobile palliative



care team, are being funded by the County (Representative of the funding organisation, IPO7\_2, page 2, line 37-42; 49-57; Representative of the funding organisation, IPO7\_2, page 2-3 line 72-76; Representative of the funding organisation, IPO7\_2, page 8, line 281-287).

*“The Croatian Health Insurance Fund is open to the establishment of the system and there are no barriers present. Currently, 10 pilot projects in different Croatian counties are being funded. The funding is available at the primary healthcare level and for agreed-upon palliative beds. We developed procedures which are being followed, and we do not expect problems with the funding, we got the green light. When we were making changes in the public health network we listed all the subjects involved, the service providers and the funds from the County bodies are welcome for the above standard, for everything beyond the minimal requirements.” (Manager of the programme, IPO1\_2, page 7, line 225-230)*

*“Whereas the legal basis for contracting palliative care services on the primary healthcare level based on the published network and realised contracts do not exist, the Act did not recognize and regulate the issue of palliative care development as it is written in the National Strategy, which refers to a mobile palliative care team and a coordination centre.” (Representative of the funding organisation, IPO7\_2, page 2, line 49-57)*

The Croatian Health Insurance Fund can only fund health services according to the Healthcare Act. Non-medical stakeholders are funded only through healthcare services, as associates. It is important that the Committee for Palliative Care define all the stakeholders which have to be included in the team, so as to be able to develop funding schemes for all the stakeholders involved. For the development of payment schemes for all non-medical staff, the Ministry of Health must form an agreement with the Ministry of Social Policy and Youth. (Representative of the funding organisation, IPO7\_2, page 9, line 308-310; 318-322; Representative of the funding organisation, IPO8\_2, Page 1, Lines: 24-34).

*“So, the way that the Croatian Health Insurance Fund is conceived at this time, in terms of mandatory health insurance, is that it covers only medical services. So, in that sense at this point ... Financing, with regards to the cooperation with non-medical institutions, is not possible.” (Representative of the funding organisation, IPO8\_2, page 5, lines: 163-165)*

*“HZZO participated in the Committee for palliative care in terms of the designing of the entire programme, but as far as the actual implementation, we are responsible for that part of the*

*funding, because the policy maker is the Ministry which issues these basic legal regulations and the public health services network which defines providers of certain services.” (Representative of the funding organisation, IPO8\_2, page 2, lines 59-62)*

According to the results of existing model, future improvements of the organizational units for the palliative care will be provided.

*“Throughout the pilot project we noticed that the model of the GP doctor and a medical nurse is insufficient. The pilot resulted with the development of a new model which includes coordination nurses on the county level and the mobile specialized palliative team. A new model needs to be implemented in the regulation and acts.” (Representative of the funding organisation, IPO7\_2, page 2, line 60-64)*

Based on the volunteer work, published epidemiological studies, and the sensibilities of the community, in 2011 the Istria County made a decision to finance the project of palliative care. Palliative care was included as one of the 7 county priorities (8). The overall planned resources of the Istria County for palliative care priorities in 2014 were 900,000 HRK (13).

*“Before the National Strategy for palliative care was made, we succeed, with the support of the Directors of the Primary Care Centres of the Istrian region, to introduce palliative care activities in the Primary Health Centres. At the beginning this was a pilot programme, and in 2011 we got the funding from the Croatian Health Insurance Fund for one team which included one doctor and a nurse whose role was to coordinate the whole work. At the same time the Istria County started to fund the other members of the mobile palliative care team including the doctors who are an oncologist, neurologist, surgeon, psychiatrist, physiatrist, psychologist... (Manager of the programme, IPO2\_2, page 6, line 199-208)*

The incentive systems for multi-morbid persons and professionals are not presented.

*“... The financial simulation model is only part of the story of the entire system, so it is definitely necessary to create a lot of other preconditions so that the financial stimulation would have an effect. It certainly is a useful tool in motivation, but ... No, it cannot be the only one. And, as we have ... some problems with which were faced, since now in development, we are financing teams and everything, but of course these teams need to develop themselves, in terms of*

*knowledge and human resources and organization, in which the County's governments and other stakeholders certainly participate, who are outside the healthcare system so that ... now, funds have been allocated, and now we have a system. I think, unfortunately, this is not happening, but I think that this financial part, which is ensured, is certainly an incentive for local governments to go in that direction. I mean, the needs are recognized and are not questionable, I think we are all aware of that, but I said ... there will be some problems because securing human resources is not so simple." (Representative of the funding organisation, IP08\_2, the fourth lines: 128-138)*

*"We in the Croatian healthcare system in general don't have a developed incentive system for the patients at all." (Representative of the funding organisation, IP08\_2, the fourth lines: 140-141)*

#### 4.8. Implementation process

The main goal was to build a palliative care system which will be tightly structured and provide organized, appropriate care for terminally ill people and support their family members; to organize palliative care on three levels: home care (provided by family medicine physicians, community nurses, and social care), extended palliative care (provided by social services), and hospital care.

The Strategic Plan for the Development of Palliative Care in the period of 2014-2016 was prepared according to the White Book on Standards and Norms for Hospice and Palliative Care in Europe - Recommendations of the European Association for Palliative care and recommendations Rec (2003) 24 of the Committee of Ministers of the Council of Europe to the member states on the organization of palliative care. The term "palliative care" is used and it includes the definition of the European Society for Palliative Care (European Association for Palliative Care) and the World Health Organization (2,14-17).

The concept and the possible ways of the development of palliative care were discussed on several expert meetings. The Croatian Health Insurance Fund estimated the costs of care for palliative patients (2).

Cultural changes were not mentioned. In the implementation process, the Ministry of Health appointed the Committee for Palliative Care, which includes experts from clinical hospitals, GPs, the School of Public Health, the Medical Faculty, the University of Zagreb, the Croatian Health Insurance Fund, the

Ministry of Social Policy and Youth, and the Ministry of Health. Different stakeholders on county levels such as physicians (GPs, specialists such as paediatricians, oncologists, psychiatrists, anaesthesiologists, and physiatrists), nurses at different health institutions, community care nurses, psychologists, social workers, volunteers, and family and university staff were also involved in the implementation process (2).

There is a high level of political commitment to supporting the implementation of the programme, according to the Strategy and Plan mentioned above (1,2). The most relevant barriers and facilitators during the implementation process and afterwards (e.g. reservations of one or more stakeholders, acquirement of (financial) resources, unclear/conflicting responsibilities) are described below (2,4,8,11).

#### Barriers:

- The legal framework needs to be revised and amended, to enable the living will document and a document to allow natural death to be prepared and included in palliative care.
- Undeveloped norms, definitions, standards, criteria, protocols, and guidelines in palliative care.

These documents are under development and will specify the following required elements and areas in the system of palliative care: organization, human resources, education, knowledge, skills, attitudes, space, equipment, data for the registry of palliative patients, price lists, the documentation, the contents and scope of palliative care services by level of health and social care, procedures, drugs, criteria to determine which patients need palliative care, competence and authority, quality standards, and quality indicators.

- Non-existence of developed forms for monitoring palliative patients and their families to determine how much need there is for palliative care until the end of the mourning period.
- Absence of specific training for palliative care on a continuous basis; it is necessary to revise the curriculum of higher educational institutions in order for the contents of palliative care to be adequately represented in the training of healthcare professionals.
- Some private health or social institutions, in terms of the absence of systematic care for palliative patients, are doing well by placing their care services for such patients on a commercial basis. They will probably resist to the development of a state-funded system that provides free palliative care for users.

- Voluntary and non-profit organizations previously worked in palliative care. After the constitution of systematized, structured, regulated, and professionalized palliative care, they will gain a form of “competition” that can take away the exclusivity of their work. This can cause some resistance to the systematic development of palliative care.
- The lack of doctors in the health system.

In addition to the abovementioned barriers, stakeholders involved in the programme pointed out additional issues from their point of view: lack of coordination, non-cooperation between the institutions involved, lack of unified diagnoses for palliative patients, introduction of the palliative patient diagnosis code, Z51.5., undefined evaluation criteria, absence of specific education and training, absence of a unified IT platform, administration barriers... (Representative of the funding organisation, IPO7\_2, page 3, line 94-96; Representative of the funding organisation, IPO7\_2, page 9, line 324-327; Representative of the pay funding er organisation, IPO7\_2, page 4, line 132-133; Representative of the funding organisation, IPO7\_2, page 6, line 223-226; Manager of the programme, IPO1\_2, page 6, line 211-212; Informal caregiver, IP16\_2, page 4, line 141-145; Informal caregiver, IP15\_2, page 2, line 61-62; Manager of the programme, IP02\_2, page 13, line 489; Manager of the programme, IPO3\_2, page 9, line 301-302; 305-306).

The most relevant facilitators are that our political support has finally recognized the enthusiasm of healthcare professionals and patients associations; the main strategic documents and plans related to palliative care have already been described above.

#### 4.8.1. Historical information

##### National level

The Croatian Government, on December 27, 2013, accepted the Strategic Plan for the Development of Palliative Care in Croatia for the period of 2014-2016. The Strategic Plan was prepared according to the White Book on standards and norms for hospice and palliative care in Europe - Recommendations of the European Association for Palliative care and recommendations Rec (2003) 24 of the Committee of Ministers of the Council of Europe to the member states on the organization of palliative care (14,15).

On November 26, 2014, the Minister of Health made the decision to establish the Committee for Palliative Care (appointed by the Ministry of Health), responsible for the monitoring of the activities and achievement of the main expected results determined by the Strategic Plan (5).

In 2014, multiple national official mobile palliative team pilot projects were started, 6 funded by the Croatian Health Insurance Fund (in the Primorsko-goranska, Istarska, Međimurska, Osječko-baranjska, Vukovarsko-srijemska, and City of Zagreb counties) and two pilots funded by counties (City of Zagreb, Primorsko-goranska County) (5). The City of Zagreb funded one voluntary mobile palliative team in Zagreb (5,18).

In 2014, meetings with the Representatives of the county bodies were held regarding the implementation of the Strategic Plan for the Development of Palliative care in Croatia for the period 2014-2016 and the establishment of the centres for the coordination of palliative care. Members of the Committee for Palliative Care conducted a series of field visits, meetings, and workshops with different stakeholders. An assessment of the need for palliative care and resources was performed as planned (5).

In 2014, a proposal for the legal framework, organisational changes, initiative for the development of Guidelines for palliative care, and the Catalogue for palliative care competence were developed as well as implementation of MKB-10 Z51.5 for palliative care patients (2,3,4).

In 2015, the amendments of the Network of Public Health Services ("Official gazette" 113/2015) and the Regulation on minimum requirements in terms of space, staff, and medical technical equipment for health activities (Official gazette 124/2015) were completed (3).

The guideline for acute situations in palliative care and the guideline for working with palliative patients in emergency centres were published in 2015 (7).

During the whole process, meetings with the representatives of the county bodies were held. County teams for palliative care were established, with the main role of designing palliative care on the county level according to specific local factors, needs, and possibilities (4).

### The regional level - Istria County

In 2005, the organization of palliative care in the Istria County started on a voluntary basis and lasted for 6 years. In 2011, based on the volunteers' work, published epidemiological studies, and the sensibilities of the community, the Istria County made a decision to finance the project of palliative care. Palliative care was included as one of the 7 county priorities. The County Team for Palliative care was established with the purpose of coordination of the organizational activities on the local level and cooperation with the regional and governmental institutions. The team includes representatives of a wide range of structures included in palliative care: representatives of the county administrative departments for health and social care, Directors of the hospitals and primary care centres of the Istrian region, GPs and hospital doctors, nurses, representatives of home healthcare, social care, volunteers, educational institutions, and the church. The decision was made to establish outpatient palliative care which included a mobile palliative care team. In 2011, palliative care was established in the primary care centres of the Istrian region on the primary healthcare level. The Director of the primary care centres of the Istrian region was the project leader. Before the start of the programme, a one-day education for the GP doctors and patronage nurses was organized (8, Manager of the programme, IPO3\_2, 2, 41-50; IPO3\_2, page 2, line 65-66; 67-68).

*"Before the National Strategy for the palliative care was made, we succeed, with the support of the Directors of the primary care centres of the Istrian region, in beginning palliative care activities in the primary health centres. At the beginning it was a pilot programme, and in 2011 we got the funding from the Croatian Health Insurance Fund for one team which included one doctor and a nurse whose role was to coordinate the whole work. At the same time, the Istria County started to fund the other members of the mobile palliative care team including the doctors who are an oncologist, neurologist, surgeon, psychiatrist, physiatrist, psychologist..." (Manager of the programme, IPO2\_2, page 6, line 199-208)*

#### 4.8.2. Present information

The system of palliative care in Croatia is not being established as a new or additional one; it is being established on the basis of the conversion of existing resources, by the empowerment and training of professionals and the appointment of the new procedures and work standards.

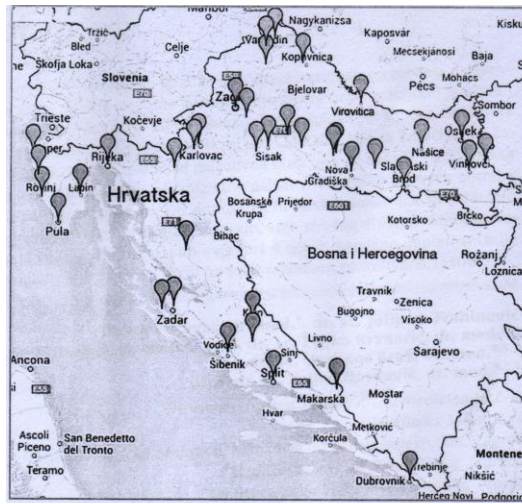
In Croatia, outpatient palliative care is managed through general/family practice healthcare, patronage healthcare, and healthcare in patient homes. Stationary palliative care is being carried out in hospitals, primary health centres, and daily hospitals.

According to the Network of Public Health Services, 206 palliative beds (113 in general hospitals and 79 in special hospitals), are predicted (5).

According to the amendments of the Network of Public Health Services, 333 palliative beds (215 in general hospitals and 103 in special hospitals) are planned. On the primary healthcare level, according to the amendments of the Network of Public Health Services, 47 coordinators for palliative care, 67 infirmaries in the primary health centres, and 14 beds in the institution for palliative care, are planned (3). In Croatia, from the adoption of the Strategic Plan for the Development of Palliative care in 2014 until 2016, 10 mobile palliative care teams, funded by the Croatian Health Insurance Fund (10 pilot projects on the primary healthcare level), 14 hospital teams for hospital palliative care, 31 clinics for pain, 43 offices for renting medical aids/devices (free of charge), 16 volunteer organisations, 5 county teams for the development of palliative care on the county level, 4 coordination centres on the county level, 1 centre for education (CEPAMET), and 1 hospital Department for Palliative Care (KBC Rijeka) were established (4).



Figure 4.8.2.1 Network of the existing organizational units of palliative care in Croatia (including counselling offices, offices for renting medical aids/devices, voluntary mobile palliative teams, mobile palliative care teams, and voluntary civil society associations) (4)



Ten mobile palliative team pilot projects, contracted with the Croatian Health Insurance Fund, are currently being conducted (in the Primorsko-goranska, Istarska, Međimurska, Osječko-baranjska, Vukovarsko-srijemska, Požeško-slavonska, Dubrovačko-neretvanska, Koprivničko-križevačka, and City of Zagreb counties). They are being financed from funds for special programmes (3).

In the Istria County, a model for palliative care was adapted according to the patient's needs, staff capacity, and financial resources. The most appropriate model for Istria was a mobile specialized palliative care team. The members of the team can activate the social care system which facilitates social problem solving. The development of the information system for patient monitoring has been started. The Registry of palliative patients has been established at the county level. An office for renting medical aids/devices has been established in the Istria County area. The specialized mobile palliative care team cooperates with the General Hospital Pula, the Clinical Hospital Centre Rijeka, and the League against Cancer Pula, and with the volunteer institutions as well. Video link networking with smartphones, notebooks, and tablet PCs is in the process of development. The team permanently employs one oncologist-radiologist and two medical nurses. The team also includes external associates. The mobile specialized palliative care team comes to the patient home after receiving a call from a GP, from the patient, or their family, or by the recommendation of hospital doctors. In cases when the

family or patient make the call, the GP is contacted by the team members to give the approval for the mobile specialized palliative care team to be included in the care process.

(8, Manager of the programme, IPO3\_2, page 4, line 122-124; Manager of the programme, IPO3\_2, page 4, line 128; Manager of the programme, IPO3\_2, page 7, line 266-268; Manager of the programme, IPO3\_2, page 8, line 281-282; 287-289).

#### 4.8.3. Future implementation/development

The Strategic Plan for the Development of Palliative Care in Croatia for the period of 2014-2016 will end in 2016. From it, according to former experience and possibilities and in line with the recommendations of the EU, European Association for Palliative Care, and the Prague Declaration, the Croatian model of palliative care needs to be completely established.

It is necessary to continue with the initiated development of the catalogue of the competencies for the health professionals and volunteers who are involved in the process of palliative care. The criteria for determining who is a palliative patient need to be defined, and the unified diagnosis, Z51.5, should be introduced. The Registry of palliative patients needs to be established. Hospital palliative care and outpatient palliative care should be developed uniformly and coordinated with the development of the county coordination centres. In the care for terminally ill patients, a unified model of healthcare and social care has to be found, in which the patient and their priorities will be respected and the holistic approach applied (4).

Coordinators for palliative care and the mobile palliative care team, which are planned in the Strategic Plan for Development of Palliative Care in the Republic of Croatia for the period of 2014-2016, should be implemented in the Healthcare Act. Establishment of the organizational forms of palliative care in counties (the coordinator for palliative care and a mobile palliative care team, an office for renting medical aids/devices, and hospital specialist teams for palliative care) should be done.

Defining the criteria for palliative patients, production of standardized documentation and forms to establish high-speed lines in healthcare facilities for palliative patients, systematic introduction of the Z 51.5 diagnosis, and nursing discharge notices are planned. It is important to encourage general/family practice doctors to make palliative home care visits and to encourage patronage services and facilities for healthcare in further participation in palliative care for patients and their families.

Adoption of the National Guideline for early recognition of palliative patients, proposed by the professional societies of the Croatian Medical Association, which should include the criteria and procedures for the inclusion of patients in palliative care for certain groups, needs to be done. Until the adoption of the National Guideline, the Ministry of Health recommends the application of GSF-PIG (Gold Standards Framework - Prognostic Indicator Guidance) as a fundamental tool to support early recognition of patients who are approaching the end of life, and SPICT, Cristal, and QUICK GUIDE as auxiliary tools (6,16,17).

*“In the field of education a lot of things have to be done, and this is one of the tasks of the Committee. The procedure has to be done to determine who is a palliative doctor, which education do they need to have, and palliative nurses as well. Only in that way can the system in the whole country be standardized. We have to know who a palliative patient is and how to access them and how to make the things easier for them and their family. We are dealing with a lack of standards, a lack of the same quality of the care in the whole country, and those cannot be achieved without appropriate education.” (Representative of the funding organisation, IPO7\_2, page 10, line 351-358)*

## 4.9. Discussion

### 4.9.1. General discussion

Palliative care is still not implemented in a sustainable way in the Croatian healthcare system. The Committee for Palliative Care, appointed by the Ministry of Health, is responsible for further activities and suggestions on the further implementation of palliative care and development of a new Strategic Plan for the Development of Palliative Care in Croatia for the period after 2017 as well, with the aim of improving the quality of life of palliative care patients and their families (11).

The motivation for and the purpose of the relationship/partnership is to organise palliative care in the country in order to rationalise healthcare spending and give an opportunity to patients and their families to obtain their defined rights and not feel insecurity.

The most relevant barrier when establishing relationships/partnerships with long term care, social care, and other partners outside the healthcare system is the undefined legal framework which causes uncertainties in the financing of care and does not define the level of services. The most relevant

facilitators are cooperation with patient associations and cost reductions of palliative care when such care is provided in an organized system in comparison with a non-organized system.

Evaluation reports are carried out continuously from the very beginning of the development process. In the future data will be systematic collected within the programme. Establishment of a national Registry of palliative patients is planned.

A quality assurance system will be established. The quality assurance will be important to encourage networking and cooperation with the World Health Organization, the Council of Europe, International Society for Hospice and Palliative Care, the European Association for Hospice and Palliative Care, and the Working Group on Palliative Care in Central and Eastern Europe.

At the 1<sup>st</sup> National Workshop, the question was raised regarding the existence of the planned discharge of patients from hospitals. It was pointed out that some hospitals have well-organized planned discharge of patients but that it is often hampered because of the lack of recognition for the need for planned discharge of patients. Practical problems related to the planned discharge of patients from hospitals were mentioned in the work of a mobile specialist advisory team for providing outpatient palliative care. The need for cooperation for a painless transition from curative palliative hospital care to outpatient palliative care was highlighted. The experience of good functioning of the planned discharge in the Clinical Hospital Dubrava was shared. The existence of a nurse for planned discharges and the importance of nursing discharge letters were pointed out. The practice of outpatient palliative care in the Istria region was concisely described. In Istria, a consensus was achieved, according to which there is a need to solve the patient needs pre-hospital admission, in the house of the patient. Palliative patients needed a team that would be available for 24 hours, but due to lack of staff at this time, this is not possible. A good result of the integration of hospital and outpatient systems of palliative action in cooperation with neighbouring counties is hoped for. The need to introduce digital e-cards (electronical medical records) to facilitate the planned discharge and integration of care for patients was expressed. Factors which complicate the process were mentioned: the problem of patients' resistance related to potential violations of their privacy which can happen during the inspection of their individual medical records by all healthcare professionals, and, on the other hand, the physicians' resistance due to possible public expert reactions to their notes in the patient card. It was pointed out that viewing only the basic information about the palliative patients should be enabled in the system, as well as instructions for transferring key information in order to mark patients receiving palliative care with the

Z51.5 diagnosis. The opportunities provided by European funds which could be a significant help in the field of computerization were mentioned. A lack of understanding for the resistance of institutions to use mark Z51.5 was expressed. Hospital facilities are encouraged to create notes in order to avoid patient exposure to the unnecessary tests, to alleviate the symptoms, and to release them in an organized system. Nevertheless, there is still resistance to the recording of the diagnosis which prevents the creation of a true and clear picture of palliative patients. As a possible solution, active work i.e. conversation with each hospital team and with each department or clinic, which requires a lot of time, was mentioned (19).

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

As stated by Leiten et al., the SELFIE framework can be used as a starting point to systematically describe the Palliative Care Model, as an integrated care programme for multi-morbidity (*micro-meso*) and their respective target groups (*the core*) within their respective contexts (*meso-macro*) (20).

##### Holistic assessment

The care process is person-centred, organised around the palliative care patient. It is based on a holistic assessment of the palliative care patient; in addition to healthcare, it includes social care, spiritual care, and family.

Individual characteristics, values, preferences, and personal goals are considered in the programme as well. Users and their families are not lost in the system; they can obtain information and adequate care at home and in the institutions in a simpler way. Families are actively included as well.

##### Governance and leadership

The motivation for and the purpose of the relationship/partnership is to organise palliative care in the country in order to rationalise healthcare spending and give an opportunity to the patient and their family to obtain their defined rights and not feel insecurity. Long-term care and social care are parts of the palliative care programme. They are predetermined as a part of the palliative care network. Special centres, the so called Coordination Centre for Palliative Care, coordinate care between hospitals, ambulatory palliative care, specialized palliative care teams, mobile specialist palliative care teams at the primary care level, and social care, providing vertical, horizontal, and intersectoral cooperation and collaboration at the county and national levels. Informal care givers/volunteers are included, as well as institutions/offices for renting medical aids/devices.

## Delivery system

Currently, the Palliative Care System is not fully integrated in the national healthcare system; it is based on pilot projects in different parts (counties) of Croatia. Changes in legal framework are waiting for full implementation on the national level.

Palliative care should be organized **on three levels**: *home care* (provided by primary healthcare centres staff: family medicine physicians, community nurses, mobile palliative care team and other social care); *extended palliative care* (provided by social services); and *hospital care*. *Special centres*, so called *Coordination Centres for Palliative Care*, coordinate care between hospitals, ambulatory palliative care, specialized palliative care team, mobile specialist palliative care teams at the primary care level, and social care, providing vertical, horizontal, and intersectoral cooperation and collaboration at the county and national levels. *Informal care givers/volunteers* are included, as well as *institutions/offices for renting medical aids/devices*. *Registry of palliative care patients* at the national level is necessary.

## Health and social care financing

The system of the palliative care in Croatia is not being established as new or additional one; it is being established on the basis of the conversion of existing resources, by the empowerment and training of professionals and the appointment of new procedures and work standards. The sustainability of the funding of palliative care will be ensured through the same mechanism applied for the whole healthcare and social system in Croatia. The financing and payment scheme is partially presented.

The Croatian Health Insurance Fund is constantly increasing the capacity and expanding the network of hospital palliative beds. Ten pilot projects of mobile palliative teams, contracted with the Croatian Institute for Health Insurance, are currently being conducted (in the Primorsko-goranska, Istarska, Međimurska, Osječko-baranjska, Vukovarsko-srijemska, Požeško-slavonska, Dubrovačko-neretvanska, Koprivničko-križevačka, and City of Zagreb counties). They are being financed from funds for special programmes.

## Workforce

Palliative care programme includes *different kind of professionals*, such as physicians (GPs, specialists such as paediatricians, oncologists, psychiatrists, anaesthesiologists, and physiatrists), nurses at different health institutions, community care nurses, psychologists, social workers, volunteers and family, mobile teams, university staff, and priests.

*Mobile multidisciplinary specialist palliative care teams*, an example of a new innovative role in the Croatian palliative care model, are established at the county level (at the primary care level) (they include different physician specialists as well). The first mobile team was established in Istria County. It consists of a specialist in radiotherapy-oncology and two nurses as full time permanent employees; external part time experts are an oncologist, neurologist, surgeon, psychiatrist, physiatrist, stomatologist, psychologist, pharmacist, GP, and social worker.

*Palliative care coordinators and informal caregivers/volunteers* have important roles as well.

There is a need for the creation of task shifting and skill mix catalogues, defining a network of centres of excellence, training centres, and cabinets. Task shifting and skill mix programmes should be gradually introduced in the healthcare system by redistributing tasks among professions horizontally or vertically, from the level of primary healthcare to the clinical institutions. Old professions must be upgraded for palliative care. There is a lack of doctors in the health system, and it will be probably be necessary for other professionals to take some of their duties. New professionals must be educated and trained to give specific care to the palliative care patient. This must be included in the curriculum of their education.

The most relevant barriers are the lack of educated doctors and nurses in the health system and some legal and organizational issues. The most relevant facilitators could be the recognition of needs and willingness of different stakeholders to participate.

### Technologies and pharmaceuticals

Computerization of health and social care and e-Health are recognized as a priority in Croatia. The Strategic Plan for the Development of e-Health in the Republic of Croatia exists since 2014. ICT applications such as the electronic health records (EHR), internet, cellular phones/devices, and telemedicine will be used in the palliative care system in a sustainable way. The electronic health record, the e-card, was released in a test phase in September 2016. It is necessary to establish a unified information system for collecting, monitoring, and management of information on palliative care, which includes the establishment of a national Registry of palliative patients.

### Information and research

Palliative care is still not implemented in sustainable way in the Croatian healthcare system. The Committee for Palliative Care, appointed by the Ministry of Health, is responsible for further activities

and suggestions on the further implementation of palliative care and development of a new Strategic Plan for the Development of Palliative Care in Croatia for the period after 2017 as well, with the aim of improving the quality of life of palliative care patients and their families. The Indicators used to assess the performance of integrated care systems have not yet been established at the national level. A monitoring system has not yet been fully established. Continuous systematic data collection within the palliative care programme is planned, as well as the establishment of a Registry of palliative patients. Currently, different data are collected, for example, elements important for palliative care monitoring through questionnaires at primary healthcare centres, hospital institutions, and at the county level, with the aim of further improving and developing palliative care. The selection of appropriate quality indicators will ensure standardized information on the beneficiaries of palliative care. At this time, they do not exist at the national level.

#### 4.10. Appendix – Original Quotes

“Onda je 2011. formiran Centar za koordinaciju palijativne skrbi Grada Zagreba.” (IP15\_2, stranica 3, redak 92-93)

“Ciljana skupina vašeg rada su svi oni kojima je potrebna palijativna skrb? Da. Aha. Svi pacijenti. I obitelj.” (IPO3\_2, stranica 5, retci 160-162)

“Ciljana skupina pacijenata u palijativnoj skrbi svakako jesu ti pacijenti koji jesu proglašeni ili bi trebali biti proglašeni, a nisu jer je još to ono problem i nova stvar i liječnicima je neki puta teško definirati pacijenta i reći mu da je palijativan.” (IPO2\_2, stranica 3, retci 88-90)

“Dakle, cilj je da im se pruži apsolutno sva medicinska i socijalna i duhovna i psihološka palijativna skrb.” (IPO3\_2, 5, 166-167)

“Ideja je zapravo došla iz evidentnih potreba za jednim, jednim timom, za jednim sustavom koji će se baviti specifično potrebama palijativnog bolesnika na način da poveže postojeće elemente u sutavu.” (IPO7\_2, stranica 3, retci 85-87)

“Pa najvažniji aspekt, bi bila pravovremenost pružanja kvalitetne usluge. Dakle, da palijativni pacijent dobije uslugu koju treba kada treba, jer to je upravo takvim pacijentima najvažnije. Bilo to zdravstvena usluga, bilo to psihološka, socijalna, volonterska.” (IPO7\_2, stranica 6, retci 191-193)

“Osnovni cilj je unaprijeđenje kvalitete života umirućih i njihovim obitelji, ono ne završava smrću pacijenta, potrebno je proraditi i fazu žalovanja, pomoći obitelji i da se suoči sa gubitkom voljene osobe...” (IPO1\_2, stranica 2, retci 61-64)



“Pa specifičnost se sastoji upravo u uključivanju više dionika i više razina unutar zdravstvenog sustava a isto tako i sustav povezanosti i sa sustavom socijalne skrbi, duhovnicima, psiholozima, fizioterapeutima, radnim terapeutima, svim onima koji mogu doprinijeti kvaliteti života umirućih.” (IPO1\_2, stranica 2, retci 52-54)

“Ako bi govorili o institucijama, dakle, Centri za socijalnu skrb su sustavno unutra, dogovorno. Od institucija, dobro tu su, imamo dobru suradnju sa Domovima za starije i nemoćne, dobro, s nekima više s nekima manje, ali sa svima, u smislu jedne više suradnje, dakle gdje oni znaju za mobilni palijativni tim, pozivaju ljude da se... Dakle, Domovi za socijalnu skrb u Istri, svi su u tome. Dobro, Županija Grada i to je to od institucija. Jedinice lokalne samouprave; Liga protiv raka u Puli kao jedna nevladina organizacija, oni su jako u tome sa nama zajedno; Volonterski Centar Istre s kojima surađujemo i tako.” (IPO3\_2, stranica 5, retci 176-182)

“Radim u Franjevačkom svjetovnom redu unutar mobilnog tima volontera u palijativnoj skrbi.” (IPO7\_2, stranica 1, retci 10-11)

“Suradnju smo imali, apsolutno, to je Franjevački svjetovni red.” (IPO1\_2, stranica 4, redak 125)

“Mi koordiniramo rad s Centrom za koordinaciju palijativne skrbi u Gradu Zagrebu.” (IP15\_2, stranica 2, redak 39)

“Da bi mogli ugovarati sadržaje PS potrebno je još dopuniti, doradit zakon o zdravstvenoj zaštiti i to nam je neizmjereno važno, to nam je baza, temelj.” (IPO1\_2, stranica 2, retci 41-42)

“Pa čak i tad, ta prva neka, kada smo dobili tih 800 000 kuna 2011 g... ta...znamo da je, ovaj, donešena na prijedlog neke oporbene stranke, a bila je prihvaćena jednoglasno. I koliko je meni poznato, na Županijskom nivou odluke koje se donose se donose jednoglasno kad je u pitanju palijativa tako da nismo iskusili tu neku...da je oko toga došlo...da je iskorištena problematika palijativne skrbi da to bude područje nekog konfrontiranja političkih nekih ideja. Nije.” (IPO3\_2, stranica 10, retci 344-350)

“Mislim da ovo nadilazi političku privrženost, da zapravo su sve vodeće strukture podržale od početka, znači i prije ovog strateškog plana, 2013. kad je on usvojen, od početka početaka je postojala i načela i više od načelne podrške.” (IPO1\_2, stranica 2, retci 94-97)

“U timu nas je dvoje stalnih članova koji smo u punom radnom vremenu zaposleni u palijativi i imamo širi tim kojega čini jedno 15-tak osoba svih profila – od duhovnika, psihologa, socijalnoga radnika, nutricioniste.” (IP10\_2, stranica 1, retci: 21-23)

“...ali isto tako i sa CEPAMET-om sa Medicinskog fakulteta u Zagrebu smo surađivali, tako da ovdje lokalno evo u Medicinskoj školi, gdje se školuju buduće medicinske sestre i tehničari razvijamo programe, edukacije, čak i na Fakultetu, na Sveučilištu ovdje, gdje se otvara studij programe, edukacije, čak i na Fakultetu, na Sveučilištu ovdje,

gdje se otvara studij..to je...postdiplomski, ja mislim, za medicinske sestre, također, ulazimo s edukacijom te palijativne skrbi..." (IPO2\_2, stranica 6-7, retci 233-236)

"Dio nas, pa, ja bi rekao da svi, smo bili na tečajevima, eem, većina nas je prošla onaj tečaj u CEPAMETU u Zagrebu..." IP09\_2 (Stranica 9, Retcis 303-304)

"I: Vi ste prošli edukaciju. Da li se i za drugo osoblje pružaju treninzi, edukacija, za koje kategorije? Da li vi sami sudjelujete u pružanju edukacije? IP10\_2: Šaljemo ih na vanjske tečajeve i sami organiziramo tečajeve. I: To su tečajevi – čega-njege ili? IP10\_2: Palijative. I: U čemu se sastoje ti tečajevi, što je obuhvaćeno njima? IP10\_2: Postoji Europska bijela knjiga za edukaciju u palijativi. Edukacija je podijeljena u 10 domena. Svi ljudi koji rade u našoj bolnici s palijativnim pacijentima, uglavnom su vam to stari mačci koji dobro znaju svoj posao. Ja sestru u šok sobi ne mogu ništa naučiti o njezi, ali ju mogu naučiti štošta o pravnim problemima, o socijalnoj problematici, o duhovnim potrebama takvih pacijenata i njihovih obitelji, dakle mogu ih naučiti i slati na edukaciju iz svega, osim njihovog core bussinessa, a to je liječništvo odnosno sestrinska njega." (IP10\_2, stranica 8-9, retci: 314-325)

"Dakle, pacijenti znaju broj telefona. Sve što im fali ili bilo šta što ih muči mogu nazvati od jutra, od 7 ujutro do 9 navečer, radnim danom. Sad imamo i suradnju sa Hitnom medicinom i vikendima se poziva naš doktor Brumini...navečer do 8 sati ako ga zove Hitna pomoć ga može zvati na broj mobitela koji postoji koji smo im dali." (IPO3\_2, stranica 13, retci 446-452)

"Naime, kada zovu subotom ili nedjeljom, ako je nešto važno, ja idem u kućnu posjetu. Ja ne mogu reći ja ne radim subotom i nedjeljom. Eh. Jedino po noći ne mogu raditi, telefon ostavim na jednom mjestu, ja idem spavati na drugo mjesto, tako da po noći, ako i zvone... Ali, u pravilu, jedanput su zvali koliko se sjećam ili dvaput, dvaput su zvali po noći sve ove godine. U pravilu nastojim napraviti posao tako da nas ne zovu." (IP09\_2, stranica 12, retci 439-445)

"... kada liječnik u bolnici, bolnički liječnik dakle, odluči da više ne može primijeniti kurativni pristup, to znači, više ne ide za tim da će izliječiti čovjeka, obično preporuča u otpusnom pismu da se angažira palijativni tim Istarske županije, to smo mi. Ja nastojim da to bude tako da ja uđem u bolnicu prije nego što se tog pacijenta otpusti iz bolnice, ne, tako da ga upoznam, da upoznam porodicu, da ga na određeni način onako bezbolno, recimo, preuzmem još dok je u bolnici." (IP09\_2, stranica 2, retci 61-65)

"Naravno. Apsolutno. Koliko pacijentu treba, toliko sam ja u kući. To obično bude sat, nešto malo manje od sata kada ide prva kućna posjeta, ako nije komplicirano. A, koji puta bude i po tri sata." (IP09\_2, stranica 10, retci 337-338)

"... kada liječnik u bolnici, bolnički liječnik dakle, odluči da više ne može primijeniti kurativni pristup, to znači, više ne ide za tim da će izliječiti čovjeka, obično preporuča u otpusnom pismu da se angažira palijativni tim Istarske

županije, to smo mi. Ja nastojim da to bude tako da ja uđem u bolnicu prije nego što se tog pacijenta otpusti iz bolnice, ne, tako da ga upoznam, da upoznam porodicu, da ga na određeni način onako bezbolno, recimo, preuzmem još dok je u bolnici.” (IP09\_2, stranica 2, retci 61-65)

“Cijeli program je napravljen temeljem Strateškog plana razvoja palijativne skrbi RH te uputama iz Ministarstva zdravlja preko njihovog Povjerenstva za palijativnu skrb. S obzirom da KB Dubrava nema kreveta za palijativnu skrb i s obzirom na to da nemamo mlađu populaciju u skrbi, imamo veliki broj palijativnih pacijenata, odlučili smo se za program koji smo sastavili u KB Dubrava, napravili radnu strukturu koja se posebno time bavi, imenovali timove koji su prošli jedan dio edukacije u CEPAMET-u u Zagrebu te na taj način organizirali brigu o pacijentima kojima je potrebna palijativna skrb.” (IP11\_2, stranica 1, retci 24-30)

“Puno se gleda na osobne ciljeve. Smisao te... i doktrina tog našeg... članova mobilnog palijativnog tima je individualna prilagodba potrebama. To je smisao palijativne medicine. Dakle, da je sve individualno. To i jest razlika od kurativne i od ove je da se polazi od čovjekovih potreba i njegovih želja, i njegovih...nisu to možda neki puta ni njegove potrebe, to nije njegova potreba, ali je njegova želja, to se uvažava, uvijek.” (IPO3\_2, stranica 13, retci 467-471)

“To je apsolutno smisao palijativne medicine da je čovjek i njegove želje i potrebe su u centru, a ne neke sheme ili nekakvi algoritmi gdje bi njemu sad trebalo to i to...” (IPO3\_2, stranica 13, retci 474-476)

“Znači, prije svega u palijativnoj skrbi, baza palijativne skrbi je uključenost bolesnika u samu njegovu skrb. Na način da se čovjeku koji zna da mu je bolest uznapredovala da prilika da on razgovara o svojoj bolesti, da prilika da on eemmmm... veli što želi u liječenju i u skrbi i ne želi, i da se u radu s njim proba vidjeti što se od toga njemu može omogućiti ili ne, znači baza palijativne skrbi je da čovjek zna da ćemo mu mi pomoći da završi svoj život na način koji bi on želio. To naravno uvijek nije moguće, ali na tome se zasniva i naš projekt, jer kad pogledate običnu zdravstvenu skrb, u njoj bolesnik nema pravo riječi, nije on koji odlučuje. U palijativnoj skrbi se njemu, naravno uz našu podršku i vodstvo, uvijek i prvo daje prilika da on izrazi ono što on želi i, i način na koji bi htio završiti i gdje bi htio završiti svoj život. I oni, mada je to projekt, i možda nema neku sigurnost, nadamo se da će imati, ali bolesnici samo i uvijek s dobrodošlicom prihvaćaju naše posjete, našu inicijativu jer u završnim fazama bolesti oni se često osjećaju napušteni, bez profesionalne podrške.” (IP13\_2, stranica 3, retci 90-100)

“I: Da li u programu obavljate i stratifikaciju rizika? IP09\_2: Stratifikaciju...? I: Rizika, za svakog pacijenta. IP09\_2: eeemmmm... Da, u pravilu, u pravilu da. Eemmmm... Naime, pokušavamo, znate palijativni pacijent nije, nemaš dva ista. Šta se mora napraviti? Mora se napraviti, ako čovjek kao pojedinac, član tima to može sam napraviti, napravi, ako ne onda ja šaljem, kako sam rekao prije, svog kolegu onkologa koji je kurativac, a ja sam palijativac...I kada je situacija takva da ja procijenim da bi se pacijentu više moglo pomoći jednim agresivnijim, dakle aktivnijim

pristupom, kurativnim, onda ja njega pošaljem. A, ako ne, idem ja. A koji puta imamo stručne sastanke, jedanput mjesečno, koji puta i diskutiramo o takvim pacijentima zajedno..." (IP09\_2, stranica 4, retci 112-118; 121-124)

"Obavezno holistički pristup, bez njega nema palijative. Procjenjujemo u 4 ključne dimenzije. To su zdravstvene, psihološke, socijalne i duhovne potrebe. To bi bila ona jezgra potreba a onda su to još, ne znam potrebe, ...hm..., pravne ili ...praktične. (IP10\_2, stranica 2, retci 69-71)

"I: Da li i kako je u palijativi moguće uzeti u obzir pacijentove osobne ciljeve? IP10\_2: S time uvijek krećemo. To su gotovo prva pitanja. Krećemo od toga: „Što vas najviše brine“, „Čega se najviše bojite?“ "To obično bude među prvim našim pitanjima. "(IP10\_2, stranica 2, retci 75-77)

„I: Kako se u programu radi stratifikacija rizika? IP10\_2: Za procjenu pacijenata postoji veliki broj alata i skala koje mi koristio. Postoje tablice s postocima koji nam pomažu da nešto procijenimo, a s vremenom sve je izoštriji klinički osjećaj tako da više i ne moram gledati u neku skalu tako da zaključim da će nam pacijent uskoro umrijeti..." (IP10\_2, stranica 3, retci 82-85)

"... Dakle, pravilo je u osnovi jednostavno, ako je pacijentu lošije od mjeseca do mjeseca, očekivani životni vijek je u mjesecima, ako mu je lošije iz sata u sat, očekivani životni vijek može se mjeriti u satima. Iz cjelovite procjene pacijentovih potreba, vidimo koji su mu rizici. "(IP10\_2 (stranica 3, retci 91-94)

"I: Da li se koriste i ako se koriste, kako izgledaju ti individualni planovi o skrbi? IP10\_2: To su razrađeni obrasci u kojima radimo procjenu, a onda na osnovu procjene se izrađuje plan skrbi, na osnovu individualnih ciljeva, na primjer, ako pacijent odbija neku vrstu terapije, naš je zadatak da ga zaštitimo od prisile zdravstvenih radnika da se nešto učini." (IP10\_2, stranica 3, retci 101-104)

"IP10\_2: Postoje tzv. obiteljske konferencije gdje uključujemo pacijenta i obitelji ili samo obitelj ako pacijent nije više kadar iznijeti svoju volju..." (IP10\_2, stranica 4, retci 119-120)

"Važnije su čovjekove želje, njegove potrebe, njegovi bolovi, njegove muke itd. Nego da mi izvršimo naše protokole, da čovjeku produžimo život zato što ćemo mi to prezentirati na nekom kongresu da ovaj lijek produžuje život za 7 dana il 15 dana muka, a mi ovdje stvarno gledamo čovjeka." (IPO3\_2, stranica 19, retci 665-668)

"Cilj je holističkog pristupa i timskog rada, nije u pitanju jedna osoba koja sudjeluje u zbrinjavanju, tu je više profila stručnjaka unutar zdravstvenog sustava, svih djelatnosti koje smiruju i zbrinjavaju simptome pacijenta uključujući i njegove potrebe." (IPO1\_2, stranica 3, retci 178-180)

"I: Što se tiče individualnih potreba pacijenata, kako ih procjenjujete, da li postoji nekakav cjeloviti pristup procjeni ili....? IP09\_2: Da, služimo se, služimo se, ovaj, tablicama, služimo se protokolima koji su opće prihvaćeni koji se baš

nedavno evo tu i objedinjeni u Nacionalnim smjernicama za rad Zavoda za hitnu medicinu Hrvatske, tu su tablice koje, koje mi primjenjujemo pa svakodnevno počevši od performans statusa, to znači od općega stanja, kakvog stanja je pacijent, dal ćemo nastaviti sa tom terapijom ili ćemo promijeniti terapiju, ali pristup je uvijek, i mora tako biti, individualan. Jer naši pacijenti nisu više pacijenti kojima možemo kurativno, dakle shematski, šablonski i preventivno davati terapiju nego to su pacijenti koji imaju određene tegobe kao na primjer ovaj pacijent koji je imao vodu u trbuhu pa je to trebalo vaditi...." (P09\_2, stranica 3, retci 82-88)

"I: Kad se radi o Vašem liječenju i o Vašoj skrbi, Vi imate pravo glasa u tom Vašem osobnom planu, dogovarate sa liječnicima...? IP18\_2: Pa, normalno. Evo, maloprije Ste čuli naš razgovor s gospodinom i tako dalje. Bez dogovora nema ništa. Moramo bit, surađivat, ako ja želim nešto da postignem, on ima znanje, ja trebam slušat, slijedit ga što mi kaže, uzimat medikamente koje mi preporučuju i tako dalje." (IP18\_02, stranica 5, retci 151-155)

"I: Kako se postupa sa polipragmazijom? IP10\_2: Isto tako diplomatski. Neki puta samo diskretno ukažemo da molimo, da se smanji, da se isključe nepotrebni lijekovi, a negdje, kad je situacija malo tvrđa, onda molimo da se ukinu neki lijekovi sa jasnim stručnim argumentima, npr. ako je pacijent nepokretan i živjet će još par tjedana, nema nikakvog razloga da mu se daje lijek za osteoporozu čije je djelovanje tempirano na dugi rok..." (IP10\_2, stranica 5, retci 190-195)

Većina lijekova koji postižu učinak tek dugotrajnim davanjem se kod naše klijentele može slobodno ukinuti jer pacijent neće doživjeti dobrobiti od toga lijeka. Moramo polako razlagati barijere u glavama liječnika i sestara koji ne razmišljaju o tome da je pacijentov vijek ograničen i da moraš razmisliti koliko ima smisla davati takav lijek." (IP10\_2, stranica 5, retci 197-200)

„I: Kako se postupa sa polipragmazijom u liječenju? IP11\_2: Hm, na to mi je teško odgovoriti. (Smijeh). Susrećemo je svakodnevno. Moram ipak reći da kad se radi o palijativnom bolesniku, kolege su počeli u zadnje vrijeme smanjivati polipragmaziju, na tome inzistiramo. Ne opterćujemo pacijenta sa svim onim što mu je nepotrebno. " (IP11\_2, stranica 3, retci 70-73)

"Mi ulazimo u kuće samo gdje je obitelj aktivna, jer ako nije onda niti nas zovu niti je to nešto gdje imamo neku...ili je on on već u Domu ili u bolnici, da nema netko o njemu brinuti ili ne želi o njemu brinuti, ali ako imamo situaciju, ako imamo situaciju da ovaj...tu suprotnu, dakle, a imamo, dakle da je obitelj jako uključena, temelj njege je obitelj. Ona pruža 80-90% njege bolesniku, sudjeluje u terapijama, dakle instruirana od strane mobilnog palijativnog tima obitelj je uključena 100 %. Tu je, pazite, tu vam je i procjena stručnjaka koji procjenjuje tko je u obitelji osoba koja može biti njegovatelj, tko to nije, zbog fizičkih, psihičkih, emocionalnih stanja i procjenjuje da li je tu netko tko ima neki konflikt interesa pa onda to gleda ne bi li iz svega toga izvuko neke koristi..." (IPO3\_2, stranica 13, retci 491-499)

“Neformalni pružatelji skrbi (i izvan sustava zdravstva, obitelj, volonteri) su predviđeni u provedbi i uspostavi strateškog plana u palijativnog skrbi na način, na primjer pacijent se otpušta iz bolnice, sestra za otpust bi morala kontaktirati i tog koordinatora i obitelj i koordinatori bi bio produžena ruka da vidi koji su uvjeti u koje se pacijent vraća, da li postoji netko tko će brinuti za pacijenta, a onda kroz cijelo to razdoblje umiranja bolesnika apsolutno treba obitelj uključiti, dati im podršku, dati im savjete da pacijent i obitelj ne luta...” (IPO1\_2, stranica 6, retci 196-200)

“U kućnim posjetama razgovaram s bolesnicima, pružam im psihosocijalnu podršku, dio pravnog savjetovanja u smislu koja prava imaju unutar socijalne skrbi i pomaganja u ostvarivanju tih prava...” (IPO16\_2, stranica 1, retci 14-16)

“Ja sam nezdravstveni volonter, znači ne mogu se patljati u medicinska pitanja i u probleme iako smo mi obučeni i u smislu da znamo okrenuti pacijenta, da znamo promijeniti pelenu i tako možemo pomoći i to napraviti ali prvenstvena svrha mene kao nezdravstvenog volontera je boraviti s bolesnikom, znači biti s njim u tom trenutku i vidjeti što njemu treba da bi se u tom času obitelj, odnosno netko tko inače brine o njemu malo odmorio, nešto napravio za sebe, otišao i da je siguran da je njegov član obitelji u sigurnim rukama, znači on je tu miran.” (IP15\_2, stranica 2, retci 31-36)

“Mislim, službeno liječnik će dati injekciju, lijek i to, a volonter će, ako bolesnik želi pričati, on će pričati, ako želi šutiti, volonter će šutiti, ako će morati otići u ljekarnu, otići će u ljekarnu, ako će morati nešto napraviti, on će nešto napraviti, znači volonter je tu za tog pacijenta, tu obitelj i konkretno za njihove potrebe. Znači, tu smo već malo biliže, ulazimo ipak u njihov prostor. Pacijentima često treba baš razgovor jer tosu vrlo osjetljivi trenuci, to je znači pred smrt, to su vrlo često i duhovna pitanja i znači nekakve dileme oko socijalnih pitanja, strahovi, svašta su tu događa i takva pitanja.” (IP15\_2, stranica 4, retci 124-130)

“Ma, volonteri nisu nikako uključeni zbog toga što volonteri... ih je malo, to je prva stvar. Drugo je što, eeemmm, nemaju prijevoz, pa bi onda trebali ići sa nama, to onda nama remeti naš posao jer... volonter ima ulogu da daje suport, eeemmm, porodici odnosno oboljelome. To znači, mi ćemo plaćati račune, ili će bit sa njime i čitati mu, ako je još zdravstveni radnik onda će mu neke savjete, čak će ga previti ako treba i tako... mi to nemamo. Nama se posao sa ne... nemedicinskim osobljem se svodi na to da sa porodicom surađujemo. I onda sa porodicom imamo, imamo tako jedan odnos... oni su, oni su naši volonteri ustvari, ono što bi trebali biti volonteri, to je porodica, a što nije dobro jer porodica, ovaj, se osjeća jako eeemmm... opterećenom i vrlo često nam izgaraju, ne, mislim, premoreni su.” (IP14\_2, stranica 15, retci 546-554)

“U Dubravi je prisutna volonterska udruga koja obilazi prema planu pacijente, to je Franjevački svjetovni red. U Dubravi imamo svećenika, kapelana, zaduženog samo za Dubravu, jako puno surađujemo i s njim.” (IP11\_2, stranica 2, retci 58-60)

“Pa, prva stvar kad nas pozovu na odjel je da pitamo koga pacijent ima, čak prije nego vidimo pacijenta moramo znati tko brine o njemu jer ako ne znamo tko brine o njemu ne možemo uopće nastaviti raditi plan skrbi. Prvo je da vidimo koga ima jer za skrb u kući mora imati tri odrasle osobe od koje jedna mora biti 24 sata u kući. Znači jedna mlađa penzionerka i dvoje odrasle djece. Ako toga nema nećemo moći organizirati kvalitetnu skrb. Dakle, prvo pitanje je tko je obitelj i onda vidimo koje su njihove potrebe. Tamo na ormaru ćete vidjeti, na srednjoj polici, (pokazuje), imamo jedno 15 vrsta letaka. To su info leci koje nakon razgovora damo obitelji, ovisno o njihovim potrebama. Ako im treba nešto o prehrani, ako moraju naučiti kako se prazni urinska vrećica, kako se mijenja urinski kondom, kako se hrani i njeguje perkutana gastrostoma. Takvi pacijenti imaju ogroman broj potreba i nama bi trebalo još najmanje 20 vrsta info letaka kako bismo pomogli obitelji da se bolje uključe u skrb. Uglavnom dobro posložene obitelji žele skrbiti za pacijenta, ali nemaju znanje i mi neprestano zaboravljamo da najveći broj kreveta u palijativi je u kućama pacijenata i da tamo imamo znatan broj gotovih njegovatelja koje treba samo osnažiti određenim znanjima i medicinskim pomagalicama.” (IP10\_2, stranica 6, retci: 221-233)

“Volonteri ne rade zdravstveni dio. Znači, sve ono vezano za simptome, to i oni volonteri koji jesu zdravstveni ne mogu raditi kao volonteri, davati infuziju i slično. Volonteri su ti koji, na kojima i u drugim zemljama počiva početak i razvoj palijative, pa tako i u Hrvatskoj. I sada postoji puno različitih udruga koje su se uključile na ovaj ili onaj način, većinom su to ljudi ili koji su sami izgubili nekog svog i vidjeli da nema dovoljno pomoći ili su profesionalci željni pomoći više, pa ne mogu na svom radnom mjestu...” (IP13\_2, stranica 5-6, retci: 194-199)

“...Neke od njih se bave više edukacijom i podrškom, neke od njih se bave posjetama bolesnika u kući eemmm... on, mi najviše surađujemo sa franjevačkim svjetovnim redom i oni su zaista jedna ozbiljna grupa volontera, koji imaju zaposlenog socijalnog radnika, socijalnu radnicu koja volontere redovito prati, vodi, vrši superviziju, imaju zajedničke sastanke, imaju službene edukacije...” (IP13\_2, stranica 5-6, retci: 204-208)

“Da, čujte, hm hm... samozbrinjavanje je, ako ga shvatimo da se obitelj i bolesnici samostalno snalaze u sutavu, mislim da je to kod nas jednostavno prisutno...” (IPO3\_2, stranica 6, retci 186-188)

“Osoba koja interjuira: Da li se u PS koristi koncept samopomoći, samozbrinjavanja? IP01\_2: Ne koristi se, ali je naša želja da do jedne razine osposobimo i pružimo potrebno znanje obiteljima da uz, naravno stručne i kvalificirane osobe, mogu prebroditi te svakodnevne probleme.” (IPO1\_2, stranica 2, retci 65-67)

“I: Možete mi malo detaljnije opisati tu Vašu ulogu u Vašem liječenju, znači što se od Vas očekuje na neakvoj... IP18\_2: Pa, čujte, ja trebam bit svjestan da sam ja glavni faktor ako želim sebi dobro. Ne može ona meni ništa napraviti, meni je liječnik reko taj... X lijek popij, ona mi da, ja ga bacim ili... ga koristim. Ako mislim da je dobro, ću ga koristiti, ako sam blesav, kako se ono kaže, ako nemam namjeru uzet, onda ću ga nekako... i tako dalje... Znači, ja imam s time da slušam savjete liječnika, bilo kojeg, da li palijativnog, da li gore onkologa, da li liječnik opće

medicine i tako dalje. I: Znači, ako imate, ako ste u bilo što nesigurni, zatrebate pomoć, uvijek se možete obratiti liječnicima... IP18\_2: Da, zasada da. Dalje, o tom potom.” (IP18\_02, stranica 6, retci 171-180)

“Osoba koja interjuira: Ranije smo govorili o samopomoći, samozbrinjavanju pacijenta, kakvu pomoć mu možete pružiti za to? IP01\_2: Prvo ga moramo podučiti, pripremiti ga sa stanjem.” (IPO1\_2, stranica 5-6, retci 187-189)

“I: Da li u palijativi i koliko, pacijenti mogu preuzeti osobnu odgovornost za svoje zdravlje, liječenje? IP10\_2: O zdravlju se tu govoriti ne može, oni će umrijeti, ali je naša važna zadaća da zagovaramo njihova prava i njihove odluke. I: Kako osnažujete pacijente? IP10\_2: Oni vrlo često ne mogu niti govoriti. Vrlo često komuniciraju stenjanjem ili pogledom. Najvažnije je objasniti obitelji, koja je često vrlo paternalistička i autoritarna i nameće svoju volju pacijentu, kako da razlikuju vlastite želje od želje pacijenta.” (IP10\_2, stranica 7, retci: 253-259)

“Da bi, da bi naš, naša pomoć bila adekvatna i svrsishodna, na kraju i korisna, trebate imati suradnju s pacijentom. Kao što sam rekao, pacijent i njegova porodica, odnosno skrbitelj su ravnopravni članovi tima. Jedan dio je na nama i to je onaj teži dio, gdje moramo, pretpostavljam da je teži dio, gdje moramo čovjeku objasniti njemu razumljivim rječnikom, koji se ne sastoji samo u riječima nego i u gestama i našim posjetama opetovanima koliko god treba, dakle da čovjek osjeti da je on praćen, da on ima, da se netko skrbi za njega. Ako zatreba da će opet doći tako, ali da on ima isto tako obavezu da se pridržava nekih naših uputa. I sada imam jednoga krasnoga pacijenta, krasnoga u smislu suradnje, koji je jako suradljiv i koji upravo radi ono što mu ja preporučim i... i rezultati su pozitivni uprkos porodici koja zastupa drugačije mišljenje...” (IP09\_2, stranica 7, retci 250-258)

„I: Još jedno pitanje, samo za kraj. Da li mislite da Vas je sustav, i Vas i Vašega supruga, dok je on to bio u mogućnosti, poticao na samozbrinjavanje, na vlastitu... na brigu samog sebe o vlastitom liječenju? IP17\_2: Pa, ne mislim o sustavu, ja, ja sam... to shvaćala kao moj odnos s njim, uopće nisam o tome razmišljala. Razmišljala sam da smo cijeli život skupa i da mi moramo sad bit skupa.... (IP17\_2, stranica 8, retci: 271-278)

... Tako da, tu sustav nema ništa, tu imaš, ono osjećaj. Obavezu svoju prema suprugu. “(IP17\_2, stranica 8, retci: 291-292)

„I: Da li se pružaju određene edukacije, treninzi u skrbi usredotočenoj na osobu s više bolesti? IP11\_2: Da, obavezno, svi koji su u mogućnosti sudjelovati, kod svakog pacijenta. I: Tko provodi tu edukaciju? IP11\_2: Sestre. Te su edukacije više vezane uz njegu i provođenje skrbi nakon izlaska iz bolnice, npr. u slučaju respiratora, dodatnih pomagala. Edukacija o načinu brige o sebi, koji su u mogućnost, ako ne pacijentu, onda obavezno obitelji. I: Kakva su vaša iskustva s tim edukacijama? IP11\_2: S obzirom da mi te edukacije provodimo usmeno, moje je iskustvo da ih svaki pacijent, obitelj uz to mora dobiti i pisano, pisani materijal jer situacije su takve da se često puta zaboravi, ne shvati se dobro, trebalo bi preći na pisani oblik.” (IP11\_2, stranica 4, retci: 103-112)



„Oni bi bili voljni preuzeti odgovornost, ali im moraju biti dostupne informacije i mora biti razvijena mreža da oni znaju u svakom momentu, da se čovjeku pojasni, ova odluka može biti ovako i ovako, može imati ishod, da se napravi strategija – u slučaju da se dogodi to, primjenit će s to i to.“ (IP12\_2, stranica: 3; retci: 73-77)

„I: Sami pacijenti su voljni preuzeti vlastiti dio odgovornosti za svoju skrb ili tu ima poteškoća? IP09\_2: Pa, tu ima malo poteškoća, znate, mi živimo na Balkanu, koliko god htjeli da ne živimo, ali živimo na Balkanu i vrlo često... palijativni pacijent je vrlo težak pacijent i vrlo često se okrivljuje sustav i ... teško je priznati svoju osobnu krivicu, ne. Pušio sam cijeli život, sada... sad sam bolestan, imam KOBP, karcinom pluća i tako. Mislim, nitko mi nije kriv, sam sam si kriv. Dijabetičar koji se nije pazio... ne možeš sad njemu reći, a tko ti je kriv. Nego mu trebaš pomoći, naravno. A, da će oni baš preuzeti... Imali smo jednoga, nedavno, jednoga pacijenta, gdje smo se svi začudili kako je on pozitivno prihvatio svoju bolest.“ (IP09\_2, stranica 7, retci 232-239)

„I: S obzirom da taj program zahtjeva i donekle aktivno sudjelovanje samih pacijenata, kakvo je Vaše iskustvo vezano uz to, kako pacijenti reagiraju na činjenicu da i oni trebaju biti aktivno uključeni? IP14\_2: Ha, u većini slučajeva nakon nekoliko razgovora, nakon nekoliko posjeta kućnih, u većini slučajeva prihvaćaju, prihvaćaju savjete.“ (IP14\_2, stranica 7, retci 232-239)

„I: Da li u palijativi možemo govoriti o osobnoj odgovornosti samog pacijenta za svoje liječenje, o samopomoći? IP11\_2: Nažalost da ih u ovom razdoblju koje je iza nas obično dobijemo u onom krajnjem stadiju...ne, ne. Ne mogu odgovoriti jer nemam temeljem čega. I: Da li ih u tom stanju uopće možete osnažiti za samopomoć bilo kakvim nuputcima? IP11\_2: One koji su u kontaktu, da. Oni dobiju sve preporuke, ali s obzirom. Što sam rekla, na vrijeme kada dolaze kod nas, mi se više oslanjamo na obitelji. Obitelji i skrbnici su ti nositelji skrbi kad pacijent izlazi iz bolnice.“ (IP11\_2, stranica 3, retci 81-88)

IP11\_2: S obzirom da mi te edukacije provodimo usmeno, moje je iskustvo da ih svaki pacijent, obitelj uz to mora dobiti i pisano, pisani materijal jer situacije su takve da se često puta zaboravi, ne shvati se dobro, trebalo bi preći na pisani oblik. “ (IP11\_2, stranica 4, retci: 103-112)

“U palijativi imate razrađene sheme kako se to zaobilazi. Ne smije doći do konflikta jer ako smjesta ne steknete povjerenje pacijenta, nećete ga više nikada. Prvo pitanje kad razgovaramo s pacijentom o njegovoj bolesti je: “Što ste vi dosada doznali o svojoj bolesti?” I onda nam on kaže što zna, što misli da mu jest. Drugo je pitanje: “Da li nas nešto želite pitati? Što god pitate mi ćemo vam iskreno odgovoriti.” Tako se formira, prvo doznamo što on zna, drugo dobivamo njegovo povjerenje. I ako on pita: “Za koliko vremena ću umrijeti?”, ja ću mu formirati odgovor. S tim da se s istinom postupa kao s lijekom, to znači... pravoj osobi, u pravo vrijeme, u pravo dozi i u pravilnim razmacima jer se loše vijesti saopćavaju ne kao jednokratni događaj nego u procesu. Dakle, postoji shema kako se to radi.” (IP10\_2, stranica 8, retci: 286-294)

„I: Imate nekakve ideje možda što bi valjalo unaprijediti u tom programu? Što bi nekim drugim... IP17\_2: Jedino stacionar. Eto. Jedino stacionar, jer imate stvarno ljudi, i ja sad sebe stavljam u situaciju, uvijek mislim, možda ću vas ja zvat kad budem... Ja sam sama, njih nema... Kad ja jedan dan, pa ja ću jedan dan bit teško bolesna. Kad ja jedan dan se razbolim, tko će mene... Treba stacionar, treba. A, to čujem da će bit u bolnici novoj.” (IP17\_2, stranica 6, retci 206-210)

“Istovremeno smo gledali da se povežemo i sa bolničkim sustavom i da u toj suradnji...dakle da surađujemo i povezujemo i taj bolnički dio i primarni dio.” (IPO3\_2, stranica 4, retci 130-132)

“Taj ulaz Sustava socijalne skrbi u palijativnu priču se razvija kroz zadnjih par godina.” (IPO2\_2, stranica 13, retci 506-507)

“Osim na toj primarnoj razini, imamo palijativne postelje koje su sada i u općim i u specijalnim bolnicama, psihijatrijskim bolnicama, a isto tako su predviđeni i u stacionarima domova zdravlja i to prenamjenom postojećih kapaciteta općeg stacionara.” (IPO1\_2, stranica 5, retci 148-150)

“Naše medicinske sestre su koordinatori palijativne skrbi. Oni koordiniraju i socijalnu i medicinsku i svaku drugu skrb o tom bolesniku.” (IPO3\_2, stranica 12, retci 409-410)

“...imamo razrađeni model angažmana socijalne skrbi, dakle, gdje se poziva socijalna skrb po jednom prioritetu i dolazi drugi dan, dolazi socijalni radnik u tu kuću, jer znaju, već su informirani da ako ih zove mobilni-palijativni tim da onda trebaju doći ne za 15 dana, što će možda biti kasno nego odmah i tu smo čak razradili model da iz Županijskih sredstava se dodatno plaća dolazak takvog osobno njemu ko jedan mali honorar, socijalnom radniku.” (IPO3\_2, stranica 5, retci 170-174)

“Što se tiče duhovne palijativne skrbi, u kontaktu smo s Biskupijom i zajedno sa njima sad radimo taj projekt otvaranja hospicija u Istarskoj županiji. Pokušava se razviti zapravo i puno bolje ta duhovna palijativna skrb gdje smo u potrazi zapravo za svećenicima, i to ne samo znači glavne Crkve nego i drugi koji bi se onda uključili u rad na način kako radi mobilni palijativni tim znači da idu kod pacijenta u kućnim uvjetima i da pružaju taj dio skrbi.” (IPO2\_2, stranica 4, retci 132-136)

“I: Recite mi kakva je komunikacija, odnosno suradnja sa davateljima nemedicinskih usluga. IP10\_2: Mi ih njeđujemo. Polako smo ih uključivali i objašnjavali koliko su nam oni važni. Oni su neformalni, ali vrlo aktivni članovi našeg bolničkog tima za palijativu. Njihova se riječ uvažava i osigurali smo im, socijalnim radnicima, njihov rad smo formalizirali tako da smo naveli ravnateljstvo da im omogući pisanje nalaza kao što pišu liječnik, psiholog ili logoped. I oni mogu ući u bolnički informatički sustav i imaju svoju ambulantu socijalnog radnika kao organizacijska jedinica i socijalni radnik dobiva uputnice sa odjela i ispisuje svoje nalaze. I može čitati nalaze nas iz palijative.” (IP10\_2 stranica 4, retci: 137-144)

“Koordinator koji bi trebao biti poveznica unutar zdravstvenog sustava i poveznica prema drugim sustavima, koji bi trebao voditi bazu podataka volontera, posudionicu pomagala i koji bi trebao biti jedinstveno prepoznatljivo mjesto na primarnoj razini kojemu bi se svi izvan domova zdravlja, znači pri otpustu iz bolnice i socijale, obitelj, mogli javiti i koji bi trebao raspolagati svim potrebnim podacima, kontaktima i mogao odgovoriti na potrebe pacijenta i njegove obitelji.” (IPO1\_2, stranica 4, retci 143-148)

„Zatim posudionice, ono što pružaju naše posudionice, mislim da je to veliki dobitak za pacijente i obitelji gdje se sad sve iše ide ne samo na taj antidekubitalni madrac koji onda uz dobru njegu ili objašnjenje što treba raditi olakša jako tu njegu. Tu su i različita pomagala: toaletne stolice, tu su u zadnje vrijeme i kreveti...” (IPO2\_2, stranica 14, retci 517-520)

“Već sama pojava mobilnog palijativnog tima je jedna nova uloga. Dakle, mobilni... tim specijalista koji ulazi u obitelj bolesnika, u kuću bolesnika nije nikada postojao u Hrvatskoj.” (IPO3\_2, stranica 11, retci 397-399)

“Koordinator koji bi trebao biti poveznica unutar zdravstvenog sustava i poveznica prema drugim sustavima...” (IPO1\_2, stranica 4, retci 143-144)

“Jedinstveno mjesto vidimo kroz koordinatora, mobilni palijativni tim...” (IPO1\_2, stranica 8, retci 287)

“S druge strane, koordinator palijativne skrbi, koji je kasnije ušao u taj Nacionalni plan, on je prvo kod nas u stvari ispitivan i naše medicinske sestre su koordinatori palijativne skrbi. Oni koordiniraju i socijalnu i medicinsku i svaku drugu skrb o tom bolesniku.” (IPO3\_2, stranica 11, retci 408-410)

“...Od 2012. radim kao koordinator palijativne skrbi u gradu Zagrebu, u Centru za koordinaciju, koji je smješten unutar Gradske ustanove za zdravstvenu njegu u kući....kao koordinator, posao mi je povezivati sve važne dionike u razvoju palijativne skrbi u gradu Zagrebu.” (IPO13\_2, stranica 1, retci 17-19; 20-21)

“Znači, koordinator palijativne skrbi ima svaka, koordinatora ima svaka županija. I moj posao je, eemm, razvijati sustav skrbi u toj županiji, konkretno u Gradu Zagrebu. A to uključuje više različitih razina. Znači, uključuje to da je moj posao povezivati sve profesionalce i institucije koje i na bilo koji način sudjeluju u skrbi za bolesnike. A, to su one postojeće službe u primarnoj zdravstvenoj zaštiti, ali isto tako u bolničkoj zdravstvenoj zaštiti, eeemmm... znači stalna suradnja, sastanci, radionice sa profesionalcima kako bi se što više povezali, kako bi i oni shvatili da, da, da palijativa mora biti cjelovita i kontinuirana skrb, znači, kao što sam rekla, edukacija, radionice, susreti, telefonski razgovori, ljudi zovu i traže pojašnjenje što je palijativna skrb, koje službe postoje u gradu Zagrebu, znači to je taj rad sa profesionalcima i službama. Drugi, drugi dio mog rada je rad sa specijalističkim timovima. Znači svi oni timovi, dva mobilna tima, tim volontera u palijativnoj skrbi, rad sa njima, opet redoviti sastanci zajednički, susreti i razgovor o pacijentima i njihovoj skrbi, da bi mogli kao jedan multidisciplinarni tim raditi zajedno, zajedno s bolesni...eeemmm... zajedno za bolesnika. To je opet, znači, suradnja sa zdravstvenim radnicima, dalje to je posjeta

bolesnicima, znači meni bilo tko da javi da postoji palijativni bolesnik, ja, ja već telefonom odrađujem svoj posao. Radim jednu trijažu i podršku članovima obitelji koji me nazovu, i kad ja vidim telefonom što je njima potrebno, ja ili ih usmjerim na drugu... na mobilni tim ili slično, ili ja sama odem u posjetu i vidim što je toj obitelji potrebno. Znači, to je rad sa samim korisnicima. Velik dio tog rada je podrška, 70%, uputiti čovjeka što mu je potrebno, uključiti mobilni tim, kontaktirati liječnika opće prakse, to je taj rad sa obitelji i bolesnikom. Znači, i dalje imamo grupe podrške za članove obitelji koji njeguju bolesnike i imamo grupe podrške za žalujuće članove. To su susreti koji su jednom mjesečno ili povremeno. Isto tako imamo individualne susrete sa obitelji u žalovanju. Vidite, to je veliki aspekt rada sa korisnicima. Osim toga imamo veliku posudionicu pomagala, gdje besplatno posuđujemo pomagala koja je kupio grad Zagreb. Isto tako svakodnevno imamo obitelji koje mi dolaze po pomagala koja besplatno posudimo, u to vrijeme ja njima pružam podršku, to je jedan razgovor sa obitelji. Kad oni vraćaju pomagalo, oni su u žalovanju, pa je uvijek opet potreban razgovor sa tim familijama. Znači, svakodnevno vodim posudionicu pomagala. Onda dalje, organiziram različite oblike edukacije, za volontere, za laike, za profesionalce, u bolnicama, u primarnoj zdravstvenoj zaštiti eeeemmm.... I... evo, to, to su te osnovne razine. Znači, moj dan nekad počinje dolaskom u ured, i odrađivanjem tih stvari, kako se javljaju konkretno pacijenti i obitelji kroz dan, bilo da je to prvi poziv, bilo da je odlazak u posjetu, bilo da je to dolazak u našu posudionicu pomagala, uz to imam redovito svaki dan desetine ili više poziva od profesionalaca koji se zanimaju za naš rad, ponekad imam organiziran susret i sastanak u bolnici, u primarnoj zdravstvenoj zaštiti, nekad odlazim u medicinske škole, fakultete gdje održavamo predavanja, znači koordinator ima jako, jako širok opseg posla. Eeemmm... i pošto smo mi pilot projekt, mi razvijamo ove usluge i centar za koordinaciju, onako kako se pokaže, pokaže potreba. Ali, to je nek, nekih par osnovnih grupa i zadataka koordinatora palijativne skrbi. U županiji.” (IP13\_2, stranica 2-3, retci 50-84)

“Volonteri su važna karika.” (IPO1\_2, stranica 8, redak 262)

“...volonter je ravnopravni član tima, multidisciplinarnog tima i sad, ako je liječnik mora imati kompetencija, sestra, onda i volonter mora imati iste takve kompetencije ako se bavi palijativnom skrbi, naravno prilagođeno onome što volonter smije i treba raditi.” (IP15\_2, stranica 3, retci 106-108)

“Sad je na redu, nam je, voditelj posudionice ortopedskih pomagala koja bi uskoro se trebala formirati.” (IPO3\_2, stranica 11, retci 411-412)

“...ali isto tako i sa CEPAMET-om s Medicinskog fakulteta u Zagrebu smo surađivali, tako da ovdje lokalno evo u Medicinskoj školi, gdje se školuju buduće medicinske sestre i tehničari razvijamo programe, edukacije, čak i na Fakultetu, na Sveučilištu ovdje, gdje se otvara studij programe, edukacije, čak i na Fakultetu, na Sveučilištu ovdje, gdje se otvara studij..to je...postdiplomski, ja mislim, za medicinske sestre, također, ulazimo s edukacijom te palijativne skrbi...” (IPO2\_2, stranica 6-7, retci 233-236)

“Tako je, više treninga, specijaliziranog od onih koji znaju palijativnu skrb, koji imaju iskustvo, koji rade u palijativnoj skrbi jer sve ove edukacije koje kod nas postoje su više teoretske...” (IP16\_2, stranica 4, retci 140-142)

“...u potrazi smo na neki način za mlađim kadrovima i shvaćamo da bi ti kadrovi, u jednom trenutku kada ih dobijemo, da bismo ih trebali educirati da to budu zbilja specijalisti palijativne skrbi - taj kadar ne postoji još u Hrvatskoj - sve su to neke doedukacije, nešto tako, i ono odlično naši rade; svaka čast, ali baš pravi specijalista palijativne skrbi koji postoji u drugim zemljama Europske Unije kod nas ne postoji, tu kod nas se ne možeš školovati za tako nešto, znači to je nama stvarno nedostatan kadar.” (IPO2\_2, stranica 9-10, retci 352-357)

“... znači cijeli magisterij baziran je samo na palijativnoj skrbi. To su moduli na kojima, koji su bili predavanja i uz to pisanje znanstvenih eseja, znači bilo je sve bazirano na palijativnoj skrbi. I to je dodatna edukacija uz moje školovanje za medicinsku sestru. Ali, bila sam uz to i na brojnim tečajevima, eeemmm.... Eemmm... i hands-on edukaciji, znači... radila uz stručnjake u palijativnoj skrbi.” (IP13\_2, stranica 1, retci 28-32)

“Isto tako edukacija na tri razine - osnovna edukacija svih - zdravstvenih i nezdravstvenih djelatnika, onda ona koja se tiče medicinske struke na razini koja sudjeluje u neposrednom palijativnom zbrinjavanju i specijalistička, uska specijalizacija, znanje.” (IPO1\_2, stranica 8, retci 262-264)

„Osnovni preduvjet je, da bi netko bio član palijativnog tima, to je definirano minimalnim uvjetima, da mora imati završenu edukaciju iz PS. Znači mi moramo imati bazu edukatora koji bi mogli onda educirati dalje, koje imamo sada pri KBC Zagreb, CEPAMET, koji provodi između ostalog edukacije. Ima tu i sporadičnih edukatora, sad najava je isto tako Katoličkog sveučilišta koje je oformilo Katedru za palijativnu medicinu...” (IPO1\_2, stranica 4, retci 156-160)

“Međutim mi još nemamo jedinstvenu platformu, trebamo je tek razviti. U planu je dugo najavljivani e-karton gdje bi imali uključene sve koji sudjeluju u zbrinjavanju pacijenta...” (IPO1\_2, stranica 6, retci 211-213)

“Mi smo sami isfinancirali i imamo svoj informatički program koji nije idealan jer je teško naći idealnog informatičara koji će to prilagoditi, ali mi imamo tu aplikaciju, toj aplikaciji se, tom programu, s obzirom da je on na serveru mogu pristupiti članovi mobilnog tima lozinkom ulaze iz bilo kojeg djela, iz kuće mogu ući i to odraditi. To je nama temelj, bez toga ne bi funkcionirali.” (IPO3\_2, stranica 14, retci 505-509)

“S druge strane imamo te, imamo mobitele, i u zadnje vrijeme eto u dogovoru s Općom bolnicom koristimo smartphone za praktički onu telemedicinu gdje se onda neki puta i poslika i snimi filmić o bolesniku i šalje onda dalje na objedinjeni hitni prijem.” (IPO3\_2, stranica 14, retci 509-512)

“Centar za koordinaciju je razvio aplikaciju gdje vodimo evidenciju zajedničkih korisnika tako da možemo pratiti potrebe korisnika na razini grada da ne bi bilo mi 20, oni 30, nego da vidimo koliko ljudi treba palijativnu skrb na razini grada i koje su im potrebe.” (IP16\_2, stranica 5, retci 184-186)

„...imamo poseban software radi prepoznavanja i praćenja takvih pacijenata. Dakle taj software nam pronalazi potencijalne kandidate za palijativnu skrb...” (IP10\_2, stranica: 2; retci: 51-53)

“To je razvio bolnički informatičar, jedan divni inženjer elektrotehnike koji je prema mojih zahtjevima napravio software koji mi omogućava da imam i svoju virtualnu ambulantu i svoj virtualni odjel. Dakle, naša bolnica, tu ima ukupno 43 krova, 1200 kreveta. Imam software, na ekranu imam pobrojane sve moje pacijente koji su ovog časa u bolnici, imam njihove dijagnoze, posljednje otpusno pismo, kategoriju pacijenta, koje je težine i kategoriju boli. I njegove rehospitalizacije u zadanom periodu, bilo 3, 6 (op. mjeseci), koliko si iskalibriram svoju alatku. To vam je jedna veličanstvena platforma koja vam omogućava da krenemo i sa uključivanjem nastave u palijativnoj skrbi. Jer ne možete držati nastavu palijativne u hospiciju ili stacionaru gdje svako novo lice izaziva kod pacijenta alarm, gdje je pacijent u hospiciju sam ili ih je dvoje u sobi i u pravilu ljudi znaju zašto su došli u hospicij, da su došli umrijeti. A kod naših pacijenata gdje se non-stop vrte bijele ili plave kute, i ružičaste i sive, još dva mantila ne znače ništa. Mi točno znamo po našem software-u koji pacijent je kadar primiti studente i na koliko vremena.” (IP10\_2 stranica 8, retci: 302-313)

„I: Da li u svom radu koristite neke posebne ICT aplikacije, programe? IP11\_2: Da, za procjenu preostalog životnog vijeka. To su aplikacije PIPS- A i – B. Sad smo u fazi da bi naši informatičari napravili kratki program gdje bi mi, temeljem pregleda zdravstvenog stanja s obzirom na učinjenu dijagnostiku, mogli brzo procijeniti koji su nam pacijenti ležeći da ne čekamo prijavu sa odjela.” (IP11\_2, stranica 8, retci: 95-99)

„Jedino što nam je olakšalo da je Centar za koordinaciju napravio bazu podataka pacijenata pa mi onda unosimo i svoje posjete u njihovu bazu podataka pacijenata.” (IP15\_2, stranica 5, retci 192-193)

„I: Možete li pretpostaviti da li bi, znači, korištenje aplikacija zapravo u konačnici skrb za pacijente koji imaju više kroničnih stanja učinilo učinkovitijom i kvalitetnijom? IP19\_2: Dapače. Puno učinkovitijem i druga stvar, sve bi se bilježilo i bilo bi transparentno, dostupno svima. Svi bi mogli iz tih analiza učiti i pogledati kako se može bolje, još bolje pružiti skrb nego... S tim da u svakom slučaju tu bi trebalo koristiti i mobilno zdravlje i puno drugih saznanja koje mi imamo i mogućnosti koje imamo u Hrvatskoj i povezati u jednu cjelinu.” (IP19\_2, stranica: 3; retci: 96-101)

„...jedino šta imamo, to je mobilno zdravlje. Znači, gdje si pacijent sam može mjeriti tlak, šećer, spirometar imati, otkucaje srca, i onda se to bilježi i to se sprema u centralni zdravstveni karton. Kako mislimo da bi negdje u 9-tom mjesecu bio centralni zdravstveni karton, znači sve to što se bilježilo za palijativu, ako on završi u bolnici ili na hitnoj, oni će to moći vidjeti.” IP19\_2 (Stranica: 3; Reticis: 108-111)

“Znači, nama bi u 9-tom mjesecu trebao krenuti portal za pacijente, gdje bi pacijent mogao dohvaćati svoje nalaze, i tako dalje, a vjerojatno u budućnosti upisivati neka svoja mjerenja ili će to raditi preko aplikacije za mobilno zdravlje, a to je sve povezano s E-građaninom, i autentifikacijom preko NIAZ-a i tako dalje.” (IP19\_2, stranica: 4; retci: 132-136)

“I: Spomenuli ste prepreke koje stoje pred uvođenjem aplikacije za pacijente, što bi rekli koje su prepreke za uvođenje aplikacije za znači ostale korisnike u tom programu, od medicinskih sestara, liječnika pa do...IP19\_2: Novci. „ (IP19\_2, stranica: 4; retci: 137-140)

„Znači, svakog pacijenta vodi njegov izabrani liječnik opće obiteljske medicine. Sve podatke koje ima liječnik šalje u centralni zdravstveni sustav. Mi smo rekli da ćemo za palijativu staviti NKB Z.51 ili 55, ovako to sam... uglavnom, Z dijagnozu tako da bi on u sustavu svagdje bio prepoznat da je palijativni. Ako takav pacijent odlazi u bolnicu, njemu se tamo pruži neka skrb, eemmm... bolnički liječnik jednako tako može i eemmm... svaki nalaz, odnosno svoje otpusno pismo se isto stavlja na CEZIH, gdje ga dohvaća liječnik primarac, odnosno onaj liječnik koji treba. Tako isto, znači do 9.-og mjeseca bi tako isto trebala raditi hitna medicina. Znači, sve što se radi sa pacijentom, a tiče se zdravstva, i, ali ugovornog zdravstva, znači ne ono što su privatne klinike, poliklinike i tako dalje, bilježi se u centralni zdravstveni sustav. Po meni je to negdje 90% podataka koji se bilježe. Tako da mi već sada sve imamo zabilježeno u Centralnom zdravstvenom sustavu.” (IP19\_2, stranica: 4-5; retci: 146-155).

„Budući da smo mi bolnički zavod, naša dokumentacija vodi se kroz integrirani bolnički informatički sustav. I moj i sestrin nalaz je jedan od nalaza u medicinskoj dokumentaciji kao što je jedan od nalaza i nalaz socijalnog radnika. Pored toga vodimo i registar palijativnih pacijenata gdje bilježimo stvari koje se ne mogu jednostavno pratiti u bolničkom informatičkom sustavu npr. pacijentovo željeno mjesto smrti i stvarno mjesto smrti. Za sada, kako mi imamo pacijente privremeno, samo jedan dio skrbi ili u neakvim intervalima, kod svake iduće hospitalizacije, ne možemo sustavno pratiti njihovu kvalitetu tako da za sada jedini indikator kojega pratimo je željeno i stvarno mjesto smrti. I to opet ne stignemo kod svih pacijenata zato što vrlo često ne znamo da nam je pacijent umro a nitko osim nas, dobro, mrtvozornik dokumentira, ali se to u našem informatičkom sustavu kojega mi dobijemo od CEZIHA ne prikazuje. Tako da ne znamo je li naš pacijent umro u domu, u nekoj privatnoj socijalnoj skrbi, kod kuće ili hospiciju. Možemo samo znati da li je umro u bolnici ili nije umro u bolnici.” (IP10\_2, stranica 11, retci: 398-409)

„Vodimo registar svojih pacijenata koji su uključeni u palijativnu skrb od datuma uključivanja. Pokušavamo preko Centra za palijativnu skrb grada Zagreba dobiti povratne informacije kad nam pacijenti odlaze iz bolnice tako da znamo što s događa. Uglavnom, probamo ih pratiti cijelo vrijeme. Iako je to još dosta teško, ne znam koji termin bih upotrijebila, zbog još neuspostavljene sveobuhvatne suradnje s primarnom zdravstvenom zaštitom.” (IP11\_2 (stranica 5, retci: 148-152)

„I: Kako se i da li se uopće procjenjuju i vrednuju Vaši rezultati, da li postoji sustav monitoringa i praćenja kvalitete?

IP13\_2: Pa, mislim da, da on nije puno razvijen. Mi smo pilot, pilot projekt koji još uvijek plaća, financira grad Zagreb. Znači, mi djelujemo u sklopu Ustanove za zdravstvenu njegu koja je službena institucija, koja podnosi izvještaje HZZO-u i gradu Zagrebu. Međutim, kako smo mi pilot projekt kojeg plaća grad Zagreb, onda su naši izvještaji usmjereni prema, prema Uredu za zdravstvo grada Zagreba. Znači, mi probamo sumirati te naše, naše rezultate, ali velim, pošto smo mi pilot projekt, to je jedini način...” (IP13\_2, stranica 6, retci: 235-242)

“Procjenu učinaka na zdravstveni sustav gdje je pokazano da troškovi na primarnoj razini umjesto bolničke osim što donose bližu zdravstvenu skrb, donose i financijsku uštedu iako to nije primarno, u prvoj liniji postupanja prema palijativnom pacijentu ali evidentne su bile uštede u nalaizma... Izvršena je evaluacija 10 pilot projekata HZZO koji se financiraju kroz posebne programe jer smo htjeli vidjeti da li je to model koji ćemo moći preslikati dalje.” (IPO4\_2, stranica 9, retci 320-322; 324-325)

“Mi neke elemente samoevaluacije radimo neprekidno i pokušavamo dobiti što više podataka o tome i dobivamo ih; što se događa; što smo napravili; da li je to što smo napravili puno, da li je to malo, da li je to dovoljno, a to su vam elementi praćenja statističkog jer imamo jedan informatički program u kojem se zapisuje sve što god se radi i onda mi možemo recimo saznati koja je dužina trajanja palijativne skrbi što bi bio jedan od najvažnijih podataka; broj pacijenata; broj obitelji; broj poziva; broj telefonskih poziva; broj komunikacija obiteljskih liječnika; u kojem postotku obiteljski liječnici nas zovu, a u kojem postotku obitelj nas zove... ; ...kakav je broj intervencija hitne medicine kod palijativnih bolesnika; gledamo da li se smanjuje broj intervencija hitne medicine ; ... Zatim, jedan od indikatora, to isto pratimo, broj prijema u bolnicu... Ali to su sve elemente evaluacije; ...Pratimo koliko je po pojedinim gradovima angažirana palijativna skrb ...”(IPO3\_2, stranica 6-7, retci 214-221; 226; 232; 238)

“...program palijativne skrbi se razlikuje u smislu plaćanja na primarnoj razini, u nekim djelatnostima i na sekundarnoj, odnosno bolničkoj. Znači na primarnoj razini zdravstvene zaštite, kao što znate, u, u timovima primarne zdravstvene zaštite, obiteljske i pedijatrije imamo posebne postupke, koji uključuju skrb o palijativnom pacijentu, zatim imamo u hitnoj medicini, u patронаžnoj zdravstvenoj zaštiti, znači prepoznate postupke koji uključuju skrb o palijativnom pacijentu, potom naravno ugovaramo koordinate na županijskoj razini u skladu s mišljenjem javnozdravstvene službe i mobilne palijativne timove koji imaju definirane, našim aktima, znači koje objavljuje HZZO, definirane iznose za sam tim. Eemm, na bolničkoj zdravstvenoj zaštiti imamo definirane eemmm... isto u mreži javnozdravstvene službe potrebe u smislu broja postelja za palijativnu skrb, koje onda mi ugovorimo i plaćamo osnovom također nekih pravila financiranja, da li bolničkog liječenja palijativnog pacijenta, evo mislim da je to neka osnova.” (IPO8\_2, stranica 1, retci: 24-34)

“HZZO je sudjelovao u Povjerenstvu za palijativnu skrb i u smislu osmišljavanja cijelog programa, a što se tiče same provedbe smo mi zaduženi za taj dio financiranja jer donositelj zdravstvene politike je Ministarstvo koje donosi



recimo te osnovne zakonske odredbe i mrežu javnozdravstvene službe koja definira pružatelje usluga.” (IP08\_2, stranica 2, retci: 59-62)

“Znači, trenutno kako je koncipiran Hrvatski zavod za zdravstveno osiguranje, u smislu obaveznog zdravstvenog osiguranja, pokriva samo zdravstvene usluge. Znači, u tom smislu zasad... Financiranje u tom smislu suradnje nemedicinskih institucija ne bilo u mogućnosti.” (IP08\_2, stranica 5, retci: 163-165)

“Sve što god je učinjeno je u našem programu i na kraju godine imamo godišnje izvješće, šestomjesečno izvješće u kojem je zabilježen broj posjeta, broj zahvata po vrstama, broj kilometara koji je prevaljen, broj pacijenata, s koliko doktora se komuniciralo, koliko je telefonskih poziva bilo, koliko savjeta, koliko iznajmljivanja medicinskih pomagala u posudionici koja već funkcionira, ne tako kao što će funkcionirat, ali i danas se mi bavimo odnoso pomažemo ljudima i posuđujemo te neke; broj kontakata sa socijalnom skrbi, broj izlazaka djelatnika socijalne skrbi u kuće bolesnika. To su sve pokazatelji.” (IPO3\_2, stranica 17, retci 612-619)

“Tek uspostavljamo sustav kontrole kvalitete...” (IPO1\_2, stranica 8, redak 277)

“HZZO je otvoren za uspostavu sustava i tu nema prepreka. Sada financira 10 pilot projekata iz raznih županija na primarnoj razini i ugovorene palijativne postelje. Razrađeni su postupci koji se prate i ne očekujemo probleme po pitanju financiranja, dapače imamo zeleno svjetlo. Kada smo donosili izmjenu mreže javnozdravstvene službe, gdje smo pobrojali sve previđene subjekte, pružatelje usluga, dobrodošla su sredstva iz županija za nadstandard, sve iznad minimalnih uvjeta.” (IPO1\_2, stranica 7, retci 225-230)

“Naime, budući da ne postoji zakonska osnova za ugovaranje palijativne skrbi na primarnoj razini osnovom objavljene mreže te izdatih rješenja o obavljanju djelatnosti, naime, zakon još uvijek nije prepoznao, odnosno regulirao pitanje provođenja onog oblika palijativne skrbi na primarnoj razini koji je utvrdila Strategija, a to je koordinacijski centar i mobilni palijativni timovi. Dakle, dok se ne donesu odgovarajuće izmjene Zakona o zdravstvenoj zaštiti provodi se pilot projekt palijativne skrbi jer je to jedini način kojim smo mogli financirati taj vid pružanja zdravstvene zaštite. Pilot projekti ugovaraju se sa 10 Domova zdravlja. Dakle, u Hrvatskoj je 40 Domova zdravlja, čini mi se, dakle, jedna trećina provodi pilot. Kadrovski normativ tima je doktor opće medicine i jedna medicinska sestra.” (IPO7\_2, stranica 2, retci 49-57)

“Naime, kroz provođenje pilot projekta pokazalo se da ovaj model: doktor, medicinska sestra, doktor opće medicine i medicinska sestra nije dostatan za provođenje tog vida zdravstvene zaštite, već je iz pilota proizašao drugi model, o kojem sam sad govorila, za koji treba postaviti zakonsku osnovu, dakle model, koordinacijske sestre na razini županije i mobilnog specijalističkog palijativnog tima.” (IPO7\_2, stranica 2, retci 60-64)

“Financiranje tima radi se na temelju fiksnih sredstava, to ću također morati zamoliti nekoga od naših ekonomista da mi da točne podatke, ako su vam takvi potrebni. Dakle, timovi se ugovaraju za ugovorno razdoblje, dakle,

ugovorno razdoblje može biti jednogodišnje ili trogodišnje i isplaćuje se mjesečno sredstva, faktički plaća doktora i medicinske sestre i materijalni troškovi. To je sadašnji palijativni tim.” (IPO7\_2, stranica 2-3, retci 72-76)

“Osoba koja provodi intervju: Dakle, ono što sada financirate to su ti timovi preko pilot projekta i oni su rekli ste preko te fiksne plaće? IPO7\_2: Da. I: One specijalističke timove, kao recimo, mobilni tim koji je prisutan u Istri to se ne pokriva? IPO7\_2: To se ne plaća. Ne. I: To je na Županijskoj razini. IPO7\_2: Tako je, financira se iz Županije.” (IPO7\_2, page 8, line 281-287)

“Da, gledajte, ovaj, mi možemo financirati kao Zavod samo zdravstvene djelatnosti kada to utvrđuje Zakon o zdravstvenoj zaštiti. Dakle, ne-medicinski sudionici se financiraju samo kroz zdravstvenu djelatnost, kao suradnici.” (IPO7\_2, stranica 9, retci 308-310)

“Povjerenstvo za palijativnu skrb morat će definirati sve sudionike odnosno tim, tko čini tim, na kojoj razini i onda ćemo i razmatrati plaćanje svih sudionika koji moraju biti, jer ako je nešto palijativna cjelovita skrb onda treba uključiti i naravno socijalne radnike. S tim, da je naravno u tom projektu uključena su i Ministarstva; i Socijalne skrbi, tako da mi surađujemo s Ministarstvom pa ćemo se i dogovoriti i o načinu plaćanja.” (IPO7\_2, stranica 9, retci 318-322)

“... moram reći da je to bilo prije nego što je Nacionalna strategija za palijativnu skrb donešena tako da smo mi i prije toga uspjeli, uz dobru volju i Ravnatelja istarskih Domova zdravlja, cjelokupnu tu aktivnost odnosno institucionalizaciju svih tih aktivnosti staviti u Dom zdravlja, napraviti taj, na početku je to bila djelatnost za palijativnu skrb i kao pilot program u tom trenutku smo uspjeli, negdje 2011 g. dobiti financiranje od HZZO-a jednog tima, znači liječnika i sestre, čija je uloga bila da koordinira cijeli taj rad i da bude dio tog mobilnog palijativnog tima. Istovremeno već se bila razvila cijela ta priča na način da smo mi iz Županije i plaćali ostale članove mobilnog-palijativnog tima gdje su nam ne samo liječnik koji vodi, (on je inače onkolog, radioterapeut), nego su tu i neurologinja, kirurg, fizijatar, psihijatar; da li sam koga zaboravila? ; uglavnom da..psiholog sam rekla...i kasnije se uključila i viša medicinska sestra.” (IPO2\_2, stranica 6, retci 199-208)

“HZZO je sudjelovao u Povjerenstvu za palijativnu skrb i u smislu osmišljavanja cijelog programa, a što se tiče same provedbe smo mi zaduženi za taj dio financiranja jer donositelj zdravstvene politike je Ministarstvo koje donosi recimo te osnovne zakonske odredbe i mrežu javnozdravstvene službe koja definira pružatelje usluga.” (IPO8\_2, stranica 2, retci: 59-62)

“Znači, trenutno kako je koncipiran Hrvatski zavod za zdravstveno osiguranje, u smislu obveznog zdravstvenog osiguranja, pokriva samo zdravstvene usluge. Znači, u tom smislu zasad... Financiranje u tom smislu suradnje nemedicinskih institucija ne bilo u mogućnosti.” (IPO8\_2, stranica 5, retci: 163-165)

“...model financijske simulacije je samo jedan dio priče u cijelom sustavu, tako da treba definitivno stvoriti mnogo drugih preduvjeta da bi financijska stimulacija imala učinka. Ona sigurno da je jedan koristan alat u motivaciji, ali... Ne, ne može biti jedini. A, što smo... Problemi neki s kojima smo bili suočeni, kao što je sad u razvoju, mi financiramo timove ili sve, ali naravno, i ti timovi se trebaju razviti, u smislu znanja i ljudskih resursa i organizacijski, u kojem svakako da sudjeluju i županijske uprave i neki drugi dionici koji su van sustava zdravstva tako da... Sad, osigurana su sredstva, pa sad imamo sustav. Mislim, nažalost, to se ne događa, ali mislim taj dio financijski koji je osiguran je svakako poticaj lokalnim samoupravama da idu u tom smjeru. Mislim, potrebe su prepoznate i nisu upitne, mislim da su svi toga svjesni, ali kažem... to će biti neki problemi jer osiguranje ljudskih resursa nije tako jednostavno.” (IPO8\_2, stranica 4, retci: 128-138)

“Mi u Hrvatskoj u zdravstvenom sustavu nemamo razvijen uopće poticaj, poticajni sustav za same pacijente.” (IPO8\_2, stranica 4, retci: 140-141)

“Dakle, manjak, nedostatak sustava se najviše pokazivao u nedostatku koordinacije i nedostatku informiranosti i međusobne povezanosti dionika u sustavu.” (IPO7\_2, stranica 3, retci 94-96)

“Potencijalna opasnost je nesuradnja Ministarstva. Dakle, ukoliko ne postoji povezanost i koordiniranost opet može doći ili do dupliciranja ili do: ja sam mislio da ti radiš, a ti si mislio da ja to radim i onda nitko ne radi. E to je to, ili se uopće ne radi ili se radi dvostruko. Dakle, to je opasnost, definitivno i to bi se moralo iskoordinirati.” (IPO7\_2, stranica 9, retci 324-327)

“Da, gledajte ovako, prvi i osnovni problem sa učincima je, to nas često pitaju, je, dakle, uvođenje dijagnoze palijativnog bolesnika, to je ona Z 51.5, što je samo po sebi problem.” (IPO7\_2, stranica 4, retci 132-133)

“Pa, jedini problem može biti da...da...da je cijeli prijedlog preglomazan ili netransparentan u smislu izvještavanja, u smislu analize povratnih informacija: što se zapravo radi i koliko se radi i što se zapravo provodi pod tom palijativnom skrbi. To su nam i sada problemi, to je ono što sam vam rekla. Dakle, rad s rezultatima je dosta loš jer nismo uspostavili sustav izvješćivanja.” (IPO7\_2, stranica 6, retci 223-226)

“Međutim mi još nemamo jedinstvenu platformu, trebamo je tek razviti.” (IPO1\_2, stranica 6, retci 211-212)

“... jer sve ove edukacije koje kod nas postoje su više teoretske, od ljudi koji ne rade palijativnu skrb, koji ne razgovaraju svaki dan s palijativnim bolesnicima, koji nisu s njihovim obiteljima, koji ne znaju koje su njihove svakodnevne teškoće, i onda je to ono na jednoj akademskoj razini, vrlo korektno teoretski, ali meni fali ovog treninga, životnog, gdje ću dobiti baš nekakve vještine.” (IP16\_2, stranica 4, retci 141-145)

“A pogotovo treba educirati liječnike obiteljske medicine koji ne znaju uopće na koji način bi mogli pomoći obiteljima koje imaju palijativnog pacijenta.” (IP15\_2, stranica 2, retci 61-62)

“Problemi koji su dalje bili, a to je s jedne strane educirati sve one koje smo željeli i koji bi trebali uč u rad s palijativnom skrbi.” (IPO2\_2, stranica 13, retci 489)

“Jedna od poteškoća je bila u tom stvaranju sustava da se nas, da obiteljska medicina ne doživi tu kao neku konkurenciju...; Ali, neku vrstu da im se neko mješa u posao, to je bio jedan od stvari koje smo morali razriješiti...” (IPO3\_2, stranica 9, retci 301-302; 305-306)

“A to je da je praktički, sam od trenutka kada sam postao Ravnatelj Istarskih Domova zdravlja, a to je siječanj 2011. godine, dakle više od pet godina, praktički od samog početka, se na neki način dao, angažirao na tome da se upravo uspostavi takva djelatnost u Domu zdravlja. Jer je bilo do tada, palijativna skrb je rađena u Istri...se provodila volonterski i uopće na neki način nije bilo ni neke velike...dakle, nije bila...bila su razmišljanja, ali nije bilo neke konkretne inicijative da je neko reko: evo ga, okej, to treba biti u Domu zdravlja. To nije nitko rekao jer to nije bila niti praksa u Hrvatskoj.” (IPO3\_2, stranica 2, retci 41-50)

“Okolnosti su bile takve da smo imali podršku Županije koja je godinama izdvajala značajna sredstva za razvoj palijativne skrbi.; ... a od trenutka 2011. kada je to ušlo u drugi stadij apsolutno su nas financijski podržali.” (IPO3\_2, stranica 2, retci 65-66; 67-68)

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