

# Origins and effects of the 2014-2016 national strategy for palliative care in Croatia

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Source / Izvornik: **Health Policy, 2018, 122, 808 - 814**

Journal article, Published version

Rad u časopisu, Objavljena verzija rada (izdavačev PDF)

<https://doi.org/10.1016/j.healthpol.2018.07.011>

Permanent link / Trajna poveznica: <https://um.nsk.hr/um:nbn:hr:184:664742>

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Download date / Datum preuzimanja: **2024-07-28**



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## Health Reform Monitor

Origins and effects of the 2014–2016 national strategy for palliative care in Croatia<sup>☆</sup>Karmen Lončarek<sup>a,\*</sup>, Aleksandar Džakula<sup>b</sup>, Renata Mardetko<sup>c</sup>, Anna Sagan<sup>d</sup><sup>a</sup> Department of Palliative Medicine, Rijeka University Hospital Center, Krešimirova 42, 51000 Rijeka, Croatia<sup>b</sup> Department of Social Medicine and Organization of Health Care, Andrija Štampar School of Public Health, University of Zagreb School of Medicine, Rockefellerova 3, 10000 Zagreb, Croatia<sup>c</sup> Centre for Coordination of Palliative Care of the City of Zagreb, Preradovičeva 17/1, 10000 Zagreb, Croatia<sup>d</sup> European Observatory on Health Systems and Policies, LSE Health and Social Care, Sheffield Street, London WC2A 2AE, United Kingdom

## ARTICLE INFO

## Article history:

Received 12 September 2016

Received in revised form 9 June 2018

Accepted 13 July 2018

## Keywords:

Policy development

Palliative care

Health care provision

Health care organization

Health care reform

Croatia

## ABSTRACT

Croatia is among the last countries in Europe to develop organized palliative care at the national level. Real changes in this area started after the parliamentary elections in 2011 and culminated in the 2013 adoption of the Strategic Plan for Palliative Care Development 2014–2016. The National Board for Palliative Care (NBPC), appointed by the Ministry of Health, was in charge of creating a scalable palliative care model and national guidelines. The Board drew on experiences from both neighbouring countries with similar societies and/or health care models (Bosnia and Herzegovina, Poland) and an international leader in palliative care (United Kingdom). It recognised that provision of palliative care in Croatia, thus far based on volunteering and isolated enthusiastic activities, needed to be improved through professionalization, regulation, and organized development. A variety of policy measures was used to implement these changes, including the introduction of professional guidelines and new payment models. The development of new palliative care structures and services significantly increased the number of patients who could access palliative care, from around 1–2% of patients needing such care in 2011 to 20–35% in 2014. It also ensured the provision of more appropriate services at each point of the palliative care pathway. The Strategy was extended for the 2017–2020 period.

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## 1. Background

The Croatian health care system is funded predominantly from public sources, which account for over 80% of total spending on health [1]. The remainder is covered by out-of-pocket payments. The Croatian Health Insurance Fund (CHIF) is the sole insurer in the mandatory health insurance system, and is the main purchaser of health care services [2]. Twenty-one counties manage primary and secondary health care facilities and own the latter. Private practices provide primary care, with the majority of them (over 70%) oper-

ating as ‘concessions’<sup>1</sup> in county owned health centres<sup>2</sup>. Tertiary health care facilities are state-owned.

Although Croatia has recognized the right to palliative care as a legal right since 2003 (in the 2003 amendment of the Health Care Act), not much has been done until 2011 to develop formal palliative care and to assure access to it (Table 1). The provision of end-of-life care largely relied on the few enthusiastic individuals and groups and their volunteering activities [3]. Within the statutory health care system, palliative care was mainly provided at primary care level and was limited to four palliative care support teams (three paid teams in Rijeka and one in Pula) and four (unpaid) volunteer hospice teams in Zagreb [4,5]. According to estimates, annually, between 26,000 and 46,000 patients nearing the end of

<sup>☆</sup> Open Access for this article is made possible by a collaboration between Health Policy and The European Observatory on Health Systems and Policies.

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<sup>1</sup> A ‘concession’ in the context of the Croatian health system is a model of public–private partnership (PPP), whereby county governments organize tenders for the provision of primary health care services for the chosen types of primary care specialties, depending on county-specific needs.

<sup>2</sup> According to the legislation, there must be at least one primary health centre per county and at least three in the city of Zagreb.

**Table 1**  
Key developments in palliative care in Croatia until 2016.

Year	Key developments
1994	The Croatian Society for Hospice/Palliative Care is founded
2000	The Croatian Association on Pain Treatment (Croatian Medical Association) is founded
2002	The Regional Hospice Centre in Zagreb is opened by the Croatian Association of Hospice Friends
	David Oliver from Wisdom Hospice in Rochester, England, is elected as visiting Professor of the Medical Faculty, University of Zagreb
2003	Kathleen Foley from the Open Society Institute, New York, is elected as guest Professor of the Medical Faculty, University of Zagreb
2008	The first mobile palliative care team established in Rijeka
2011	Amendments to the Health Care Act enable provision of palliative care at the secondary level of care
	Adoption of the National Health Care Strategy 2012–2020
2012	The first coordination centre for palliative care established in Zagreb
	Ministry of Health appoints the National Board for Palliative Care (NBPC)
2013	Adoption of the Strategic Plan for Palliative Care Development 2014–2016
	First hospice opened in Rijeka (14 beds)
2014	The Ministry of Health appoints the Board for the Implementation of the National Strategy of Palliative Care
	Palliative wards established in ten hospitals
2015	The first department of palliative medicine established at the University Hospital Rijeka
2016	The Croatian programme of integrated palliative care included into the EU-funded Horizon2020 project SELFIE 2020

Source: Authors based on Centeno et al. [4], Ministry of Health of Republic of Croatia [9], and SELFIE 2020 Work Package 2 Report for Croatia [10].

life require some form of palliative care in Croatia [6]. In 2011, less than 500 patients, or at most 2% of patients needing palliative care had access to such care [7], demonstrating the high level of unmet need in this area.

Limited public funding (the result of the poor economic situation), the inadequate regulation and training in the area of palliative care, and the lack of a strategic plan were all responsible for hampering the development of a formal palliative care program. The lack of a strategic plan could be mostly explained by the instability of the leadership, i.e. the frequent changes in personnel, particularly in the Ministry of Health [8].

Since 2010, growing number of civic initiatives and public awareness activities have drawn media attention to the inadequacy of palliative care [11–13]. Following the parliamentary elections in 2011, the new government appointed the National Board for Palliative Care (NBPC) and officially recognized the need for a national strategy for palliative care [5]. Between 2012 and late 2013, the Strategic Plan for Palliative Care 2014–2016 was developed, putting forward a new model of ‘integrated palliative care’ to be implemented on the national scale. This model incorporated palliative care into all levels of care (from primary to tertiary), and into the wider welfare system.

In this paper, we analyze the policy process that led to the implementation of the Strategic Plan for Palliative Care 2014–2016 (Section 3), as well as its content (Section 4), and offer preliminary insights into its implementation (Section 5). Finally, we offer lessons for other countries (Section 6).

## 2. Health policy processes

It was not until the 2011 parliamentary elections that real developments in the field of palliative care had started. The first step was the adoption of the National Health Care Strategy 2012–2020 [14]. The Strategy recognized the limitations of the existing legal framework for palliative care set out in the 2003 amendment of the Health Care Act. The Act (Art. 83) envisioned the provision of palliative care mostly as a service provided alongside primary care [15]: “A palliative care institution is a health care institution that provides home visits by interdisciplinary teams (doctor, nurse, physiotherapist, and social worker trained in working with dying patients), a pain clinic, and a day care centre.” In accordance with the Act,

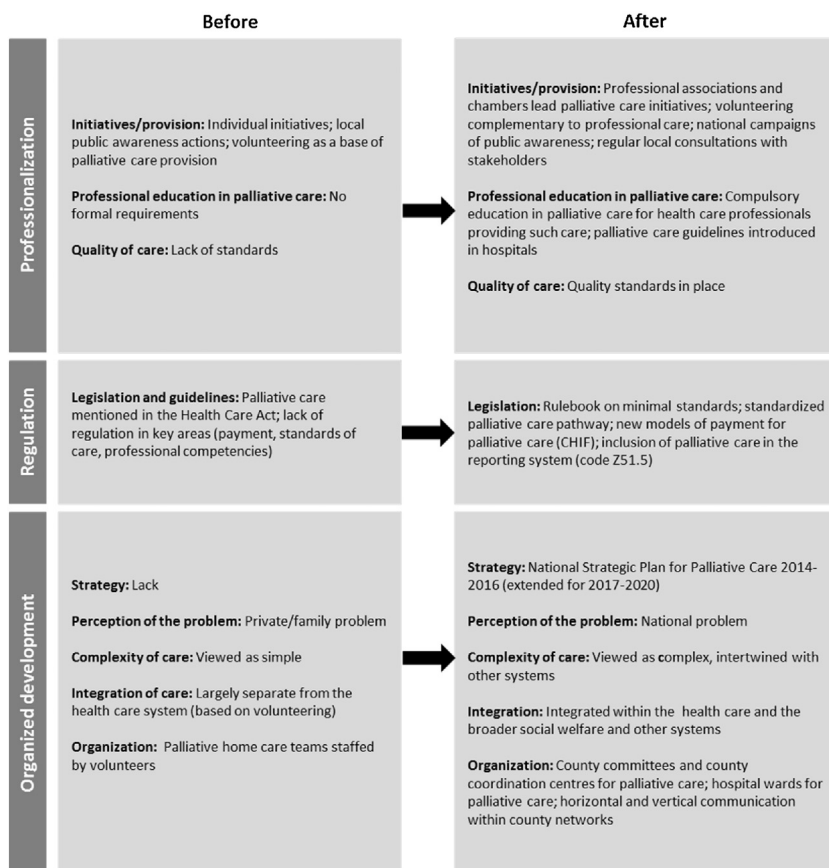
county-owned primary health centers are responsible for organizing the provision of palliative care in their area, if it is not otherwise organized [15].

In 2012, the Ministry of Health asked experts in the field of health care organization from the Zagreb School of Medicine to review existing models of palliative care organization and delivery in Croatia. The purpose was the development of a national palliative health care strategy, and a care model that could be scaled nationally. The White Paper on the Standards and Norms for Hospice and Palliative Care in Europe, written by the European Association for Palliative Care (EAPC) [16,17], and the Recommendation REC(2003)24 of the Committee of Ministers of the Council of Europe to the member states on the organization of palliative care [18], served as a framework for the new model. In January 2012, experts started a series of workshops to agree on the recommended way forward. This was the beginning of a comprehensive public consultation process that lasted two years, and culminated in the adoption of the Strategic Plan for Palliative Care 2014–2016 in December of 2013.

The key findings of this exercise, summarized in the guidelines for the Strategic Plan were as follows: there is great need for the development of palliative care; some models of good practice can already be found in Croatia, but they need further improvement; there are resources in the health care and social welfare sectors that could be used for the provision of palliative care, but they are insufficient, or inappropriately utilized. The recommendations to the Ministry of Health were the following: first, palliative care should be included among the priorities for the health care system; and, second, palliative care should be developed as an integral part of the existing health care model, rather than as a parallel system based on volunteering and other informal activities.

In February 2012, the Ministry of Health appointed the NBPC. The Board consisted of twelve experts in palliative care, public health, social welfare, health insurance, and medical education. Its tasks were to analyze the existing organization and provision of palliative care; identify barriers to achieving international standards in palliative care; create guidelines for a new model of palliative care provision; and, finally, to systematize all the above in a strategic plan [12].

The Board drew on experiences from two neighbouring countries with similar societies and/or health care models (Bosnia and



**Fig. 1.** Key changes to the organization and provision of palliative care in Croatia: before and after the implementation of the National Strategic Plan for Palliative Care. *Source:* Authors based on the Strategic Plan for Palliative Care Development in Croatia 2014–2016 [28]. *Notes:* BINSPC = Board for the Implementation of the National Strategic Plan for Palliative Care; ICD = International Classification of Diseases; Z51.5 = encounter for palliative care. \* Living and Dying Well Short Life Working Group 5. Recommendations on Palliative Care in Acute Hospitals. September 2010 [30].

Herzegovina, Poland) and an international leader in palliative care (United Kingdom). Bosnia and Herzegovina, which has a similar health care model to Croatia, started developing palliative care in 2003 with the establishment of a high standard palliative care unit in Tuzla. Provision was focused on the clinical aspects of palliative care. This has essentially meant a rejection of a comprehensive approach (e.g. inclusion of home care, volunteers) and confined provision of palliative care to hospital settings [19–21]. Poland, which is similar to Croatia socioeconomically and culturally (transitional economy, strong influence of the Catholic Church, among others) and which has, like Croatia, a long history of a humanitarian approach in the development of palliative care, has opted for an integrated model of palliative care and involvement of stakeholders outside the health care system (including the Catholic Church). However, although the development of palliative care in Poland started in 1980s, it is still not entirely integrated into the health system, or the broader social care system, and both the funding and the workforce are still heavily reliant on private donations and volunteering [22,23]. The United Kingdom is renowned for its high standards of palliative care nationwide. This was achieved through a system and society wide approach to palliative care, although the initial approach to palliative care was largely uncoordinated [24]. Like the Polish model, residential palliative care in the United Kingdom is mostly provided in hospices in the private sector (the NHS owns only 20% of hospice beds). Experiences from these three models indicated the importance of financial and organizational integration from the outset of the implementation of the new model. They also highlighted the importance of good coordination of care across various sectors and settings within them.

Between 2012 and 2013, the NBPC organized six workshops to evaluate existing initiatives and programmes in palliative care in four counties: Istria, Primorje-Gorski Kotar, Osijek-Baranja, and the City of Zagreb. During this period, palliative care wards were piloted in three general hospitals (Rijeka, Zagreb, Ogulin) and in two special hospitals (Duga Resa, Novi Marof) [25]. In addition, provision of palliative home care (including support for family members and caregivers) was piloted by a volunteering organization in Zagreb. The results of initiatives and programs that were deemed to be sustainable and transferrable were incorporated into the Strategic Plan [26].

In September 2013, the NBPC proposed the National Strategic Plan for Palliative Care (see Section 3). The key stakeholders reacted in different ways to these proposals. Health care professionals were skeptical towards the new model as it required a shift from the classical curative approach to medicine (in which their role ended once it was established that cure was not possible) to the one focusing on reducing symptoms and enhancing the quality of life of patients who could not be cured – a model that they were not familiar with and that required a new skill set. The managers of health care institutions were skeptical because the new model required strong intersectoral cooperation, which had not been practiced before. They also feared that the implementation of the Strategic Plan would require significant human and capital resources. NGOs were concerned with the shift away from an approach based on volunteering towards an organized system of integrated services provided within the public health care sector. During the final consultations with the Ministry of Health, all con-

**Box 1: Journey of a palliative care patient.**

The journey typically starts at the hospital where the palliative care need is identified\* and coded (ICD-10 code Z51.5). Patient will no longer be discharged as it would have normally been the case before the introduction of the Strategic Plan but instead will be directed to a special county coordination centre for palliative care which will coordinate his/her further care across the three health care sectors (general home care, domiciliary palliative care teams and hospital care). The centre's responsibility is to assure vertical and horizontal cooperation and collaboration at the county and national levels. The centres also liaise with informal (voluntary) caregivers as well as providers of medical aids rentals. The centres will in the future provide relevant socio-medical data to the registry of palliative care patients which are currently being tested).

\* This can also be done by the primary health care physician.

cerns and proposals were discussed until consensus between the key stakeholders was reached [12,26,27].

Three months later, in December 2013, the Croatian Government accepted the Strategic Plan [28]. Its key principles are described in the next Section.

### 3. Content of reform

The National Strategic Plan acknowledged the broad consensus that palliative care was a basic human right in a civilized society, and that palliative care needs of Croatian patients were largely not met. The concept of palliative care as an enthusiastic and humanitarian issue was recognized as ineffective in meeting these needs on the national scale, and the need for a paradigm shift was identified. The changes in the organization and provision of palliative care set out in the Strategic Plan can be grouped into three themes: professionalization; regulation; and organized development (Fig. 1) [28]. Together, they constitute a fundamental change (a paradigm shift) in the approach to palliative care in Croatia:

- (1) **Professionalization:**
- (2) Increasing professional competencies of palliative care personnel through education (establishment of Palliative Care Education Centre at the Zagreb School of Medicine, introduction of a system of continuous professional education in palliative care and education toolkits for health professionals and volunteers), peer support (e.g. new professional societies, support from professional medical chambers), managerial support;
- (3) Introduction of palliative care guidelines and catalogues of competencies;
- (4) Voluntary activities to be complementary to professional care.
- (5) **Regulation:**
- (6) Introduction of a standardized palliative care pathway (see Fig. 2 and Box 1), including ICD-10 code Z51.5 for palliative care;
- (7) Introduction of new procedures within the standardized palliative care pathway (e.g. accelerated management of palliative care patients in general hospitals, also known as 'fast lanes') and work standards (e.g. evidence based check lists and recommendations);
- (8) Key aspects of palliative care provision (e.g. standards of care) to be regulated;
- (9) Allocation of financial resources to palliative care (CHIF) and introduction of payment models for palliative care.
- (10) **Organized development:**
- (11) Palliative care to be organized on three levels: (1) home care (provided by family medicine physicians, community (dis-

trict) nurses and home care – the latter delivered by mobile palliative home care teams and/or by NGOs); (2) extended and non-medical palliative care (provided by social services, NGOs and religious communities); and (3) hospital care [1];

- (12) Counties to meet minimum requirements for palliative care resources set in the Strategic Plan (see Table 2); additional palliative care services to be developed if the existing resources fail to achieve the required capacity;
- (13) Other sectors, e.g. the education sector and civil society to be formally included in the development and provision of palliative care (e.g. through the introduction of new courses in palliative care in medical schools);
- (14) Vertical and horizontal collaboration within the health care sector, e.g., cooperation with the emergency care system, nursing homes, and teaching hospitals to be improved (see Fig. 2) to assure rational and efficient use of existing resources;
- (15) Introduction of a national system of continuous informing and engaging of the public and the stakeholders in the promotion and development of the palliative care system (e.g. through a dedicated Internet portal [www.palijativna-skrb.hr](http://www.palijativna-skrb.hr)) [29].

The National Strategic Plan for Palliative Care envisages that palliative care needs and resources are assessed twice a year, but no formal mechanisms have been established yet. Monitoring and evaluation of quality are to be conducted regularly by the Board for the Implementation of the National Strategic Plan for Palliative Care (see Section 4).

### 4. Implementation of the strategic plan: preliminary outcomes

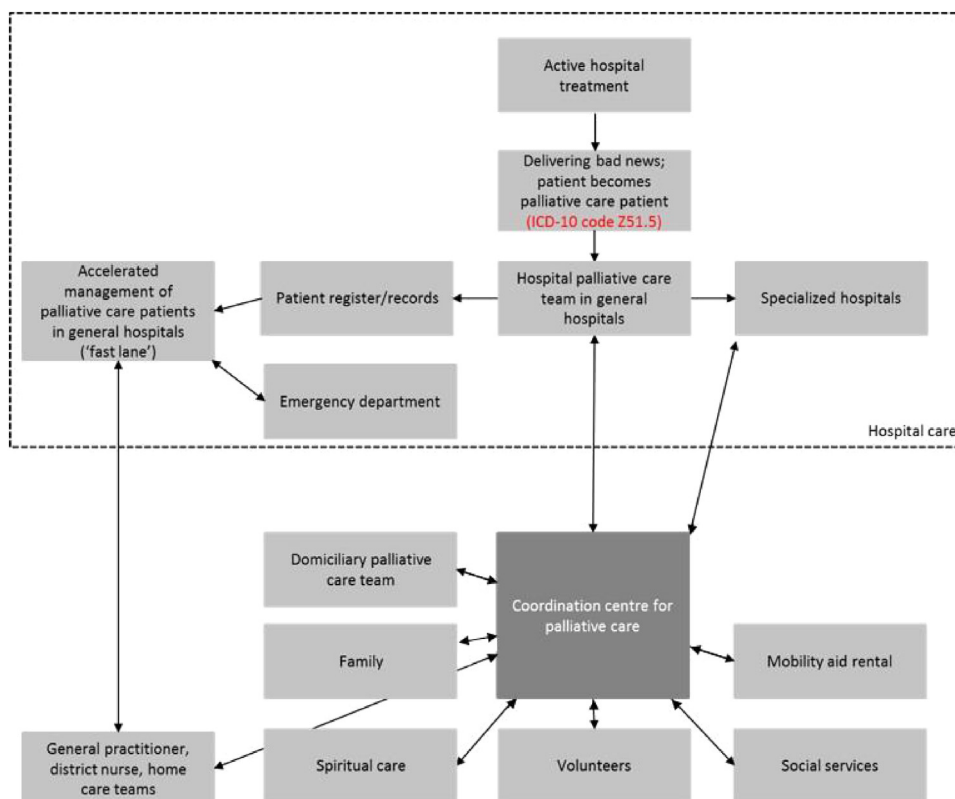
After the Government adopted the Strategic Plan in December 2013, the Ministry of Health appointed the Board for the Implementation of the National Strategic Plan for Palliative Care (BINSPC). Much effort was invested in convincing the key stakeholders that developing palliative care was not an admission of the ineffectiveness of classical medicine and that better organized palliative care and cooperation with other parts of the health care system would not require more resources but merely a different configuration of the existing resources [31,32]. The Board also focused on working with the civil society to encourage the creation of new groups of volunteers that would be, from the outset, closely associated with health or social care institutions and would establish cooperation with the county coordination centres.

The Board organized a series of meetings and workshops with local stakeholders across the country during 2014 and 2015. During these meetings and workshops, the Strategic Plan and the palliative care pathway were presented to the local stakeholders to gain their acceptance and thereby improve the chances of their successful implementation. The focus was also on identifying existing local resources, encouraging training in palliative care based on local educational resources, promotion of the Strategic Plan in the media, and raising public awareness about palliative care through a wide spectrum of outlets - local and regional conferences, Internet portals and television.

By the end of 2016, the following changes in palliative care organizational structures, facilities and services had been achieved (see Table 2):

- (1) **New organizational structures:** Seven counties established *county committees for palliative care* tasked with building inter-sectoral cooperation and ensuring that the specific local palliative care needs are met; five counties established *county coordination centers for palliative care* tasked with coordinating the existing health care, welfare, and educational system





**Fig. 2.** National palliative care pathway in Croatia: Journey of a palliative patient. *Notes:* ICD = International Classification of Diseases; Z51.5 = encounter for palliative care. The arrows stand for coordination and communication of providers. *Source:* Authors based on the Strategic Plan for Palliative Care Development in Croatia 2014–2016 [28].

**Table 2**  
Palliative care organizational structures, facilities and services available in Croatia at the county/national level, 2005–2016 (selected years).

Palliative care resources*	2005 <sup>a</sup>	2012 <sup>b</sup>	2016 <sup>c,d,e,f</sup>
One county coordination centre	0	0	5/21
One county committee for palliative care	0	0	7/21
One palliative care mobile home team per county	0	4	10/21
One mobility aid rental per county	0	4	21/21 (47 in total*)
One hospital palliative care team in each acute care hospital	0	0	16/31
80 palliative care beds per 1 million people	0	3 per 1 million	48 per 1 million
One hospital based palliative pain clinic per county	0	0	19/21 (31 in total*)

*Sources:* \* According to minimum requirements set by the National Strategic Plan for Palliative Care. <sup>a</sup>EAPC Task Force on the development of Palliative Care in Europe, 2006 [34]; <sup>b</sup>Centeno et al., 2013 [4]; <sup>c</sup>Ministry of Health of the Republic of Croatia, 2014 [8]; <sup>d</sup>Ministry of Health of the Republic of Croatia, 2015 [5]; <sup>e</sup>Ministry of Health of Republic of Croatia, April 2016 [33]; <sup>f</sup>Ministry of Health of Republic of Croatia, May 2017 [25,33].

*Note:* Completely new organizational structures and facilities/services are shaded in grey. The hospice in Rijeka (opened in 2013) has organized as specific service with 14 beds before the National strategy 2014–2017 was issued, and still is the only institution operating as independent institution.

resources, as well as NGOs to provide the best possible palliative care and promote public awareness.

(2) **New facilities and services:** Provision of inpatient palliative care became mandatory for all hospitals, with one per cent of hospital beds in every general hospital designated for palliative care. The number of palliative care beds increased from 3 per million inhabitants in 2012, to 48 in 2016 (206 beds in total across the country), which is 60% of the target. There must be at least one hospital palliative care support team per hospital (51% of hospitals met this target in 2016); and one hospital based palliative care clinic per country (this target was exceeded). The number of voluntary hospice services (organized by the NGOs in cooperation with local authorities or health care institutions) increased from 3 in 2005 to 19 in 2016 [25,33].

“New facilities and services” also include existing hospital resources that have been reorganized according to the new “inte-

grated care” model and better equipped and officially formed teams (now also known as special PC task force).

(3) The number of certain **existing facilities and services** was increased. For example, the number of palliative care mobile home teams increased to ten and the number of mobility aid rentals to 47 (exceeding the target of one per county).

Because of these changes, the number of patients receiving palliative care grew substantially: from 447 patients in 2005 to 7290 patients in 2014 for palliative home care (a 16-fold increase), and from 8 patients in 2005 to 1821 patients in 2014 for hospital palliative care (over 200-fold increase) [25,33]. This means that between 20% and 35% of patients needing palliative care received it in 2014, compared to 1–2% before the introduction of the Strategic Plan (see Section 1).

Based on the above, the Ministry of Health decided to continue the implementation of this model during the 2017–2020 period

(the National Plan for Palliative Care Development 2017–2020 draft was subject to public consultations in May–June 2017 [32]) and listed the development of palliative care as one of its twelve goals for the health care sector in two documents drafted in June and July 2017: the Health Care Act [35] and the Operational Plan of the Ministry of Health for 2018–2020 [36]. The former postulates amending the existing legal framework to allow for the provision of palliative care at the level of tertiary care, which is foreseen in the Strategic Plan for Palliative Care Development in Croatia 2014–2016 but is currently not possible (palliative care can only be provided within primary and secondary care settings). This would allow for clinical institutions to be included in the network of hospitals that provide specialist treatment for certain groups of palliative care patients and for the provision of the most complex services to end-of-life patients.

## 5. Discussion

Palliative care services (inpatient, outpatient, and community) have repeatedly been found to improve patient and family satisfaction with care, to improve symptom control and quality of life, and to reduce health care utilization in the last months of life. These benefits are seen in patients with cancer, neurological disease, multimorbidity and frailty, and organ failure [37,38].

In Croatia as well as elsewhere in Europe palliative care developed largely outside clinical medicine. The lack of integration of palliative care with medical care has become particularly noticeable with the rapid development of oncology therapies [37]. In spite of progress in the development of palliative care over the last ten years, gaps in research, workforce deficits, and deficiencies in public and professional knowledge, have become increasingly visible [39] and resulted in efforts to develop organized palliative care at the national levels.

Croatia is among the last European countries to have done so [4]. Before 2012, when the process for new Strategic Plan of palliative care in Croatia started, there was no sense of responsibility over palliative care: health care professionals treated palliative care as a social issue; social care professionals treated it as a health care issue; and the Ministry of Health and the CHIF steered away from it out of fears of potential cost implications.

The key strategic decision was to adopt, from the outset, a comprehensive approach to palliative care development and to recognize palliative care as an ecosystem of care, not as a set of specific services. This decision was based on international evidence as well as on Croatia's own experiences in the area. Integration and professionalization were recognized as key for all future activities. Professionalization of care and transition from isolated initiatives towards an organized system of integrated activities spanning across various levels of care and encompassing health care, social welfare and other systems can be seen as the essence of the 'paradigm shift' that took place in the area of palliative care in Croatia.

## 6. Conclusions

Professionalization of care lends itself to achieving better utilization of specific resources and better monitoring and evaluation of provided care. While it may be more difficult to implement compared to a non-professional model, since it requires a formal introduction of new roles and professional competencies, it may be easier to sustain in the long term compared to a model based on non-professional provision and volunteering [24,40].

An integrated system offers a larger pool of resources which can be tapped into. It also results in an earlier recognition on palliative care needs, improved continuity of care as well as improved oppor-

tunities to better meet patients' needs [41]. Use of existing health care resources may be more cost effective and may result in greater availability of resources for palliative care. Inclusion of palliative care in the regular health budget provides stable and continuous funding.

However, achieving this paradigm shift demanded a much higher level of acceptance from the key stakeholders and this has not yet been achieved. Although the Strategic Plan was extended for the 2017–2020 period, health care professionals still do not fully accepting the new concept of palliative medicine and some of them see it as the defeat and a professional failure of classical medicine (though this is not unique to Croatia; [42]).

## Conflict of interest statement

The authors declare that they have no conflict of interests.

## Funding

No funding was received in the context of this paper.

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