

*Report on the basis of the literature review
and terminological assessment of the terms
„Governance/Stewardship in/of Cancer Care“*

WP 10 – Governance of Integrated and Comprehensive Cancer Care

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Abbreviations

CANCON JA - Cancer Control Join Action

EPAAC JA - European Partnership for Action Against Cancer Joint Action

EU – Europe

iPAAC JA - Innovative Partnership for Action Against Cancer Joint Action

MeSH – Medical Subject Headings

MS - Member State

MSs - Member States

NCCP - National Cancer Control Programme

NCCPs - National Cancer Control Programmes

OECD - The Organisation for Economic Co-operation and Development

WHO – World Health Organization

WP - Work Package

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Executive summary

In the scientific literature in the field of cancer care, especially cancer programmes, the terms governance and stewardship in/of cancer care are used in many different contexts. The terms are usually not explained or defined.

Therefore, we planned a literature search in order to:

- find the definitions of the terms governance and stewardship in/of cancer care or
- create new definitions of the mentioned terms in case of unsuccessful finds.

A literature search using Pub Med, Google and MeSH as well as an opportunistic search for extra articles and chapters from books was performed.

The selection criterion for articles to be included in the review was that they were published in the last 10 /15 years. We decided to analyse also articles older than 15 years.

Most of the analysed articles do not give exact explanation of the terms governance/stewardship in/of cancer care or they cite older articles (published before the year 2000) where the terms are used mostly in the field of clinical governance or in completely other fields, mostly banking, economy, religion or spirituality (stewardship).

It was decided to create two new definitions as described below:

Definition of Governance in/of cancer care

„Governance in/of cancer care is a continuous process of management at macro level through which Health Care Systems can provide/assure, develop and improve quality, capacity and outcomes in cancer care.“

Definition of Stewardship in cancer control

„Stewardship in cancer control represents the State's highest level of responsibility in the field of cancer with the aim of reaching the national health policy objectives.,,

The definitions will be useful for the further work on the project as well as in the field of national cancer control programmes and will facilitate the understanding of the leadership tasks in the area of cancer care and cancer control.

1 Introduction

The World Health Organization's seminal annual report introduced the concept of stewardship to the health sector, identifying it as one of the four major functions of health systems worldwide (1). It distinguished stewardship from governance, defining it as the "careful and responsible management of the well-being of the population." Subsequently, a series of reports and articles further expanded upon the concept and defined its conceptual framework. Travis et al. framework for stewardship is arguably the most referenced and comprehensive of these in the health system literature (2).

Following these efforts, most notably, in June of 2008, stewardship was included in the Tallinn Charter, which was adopted at the WHO European Ministerial Conference on Health Systems and endorsed by all 53 Member States in the WHO European Region (3, 4). As such, these States committed themselves to catalyzing the implementation of health system stewardship by pledging the following: "While each Member State has its own way of governing its health system, ministries of health set the vision for health system development and have the mandate and responsibility for legislation, regulation and enforcement of health policies, as well as for gathering intelligence on health and its social, economic and environmental determinants. Health Ministries should promote inclusion of health considerations in all policies and advocate their effective implementation across sectors to maximize health gains. Monitoring and evaluation of health system performance and balanced cooperation with stakeholders at all levels of governance are essential to promote transparency and accountability."

As one of the four major functions of health systems, stewardship needs to play an important role on the health agenda of countries worldwide and - in particular - of those involved in the devolution of powers, as is the case of Italy, Germany, Spain, the UK and others. There is, however, little empirical evidence to support or guide its implementation. Moreover, they lack relevant data and information for its proper measurement. The reason for this is two-fold:

- (i) stewardship is a fairly new concept to health systems, and
- (ii) its theory has not reached an operational level.

For example, take Travis et al. stewardship framework; when applied empirically, it leaves substantial room for interpretation by the author(s) (5). This makes it less robust for cross-country analysis and more difficult to understand the effects of the implementation of stewardship. Helping to bridge the Italian experience could be a possible contribution. We

placed specific attention to cancer screening programs due to their particular value as public health interventions and given their complexity as an interdisciplinary disease management aimed at serving large population and involving so many actors and stakeholders (6). Such a “case” showed that we can clarify Travis et al. sub-functions into certain activities on an operational platform. It illustrated what the theory could mean in terms of everyday tools and practices at the level of the MoH. The importance of such an approach has been recently confirmed at the European level in the European Guide on Quality Improvement in Comprehensive Cancer Control issued by the Joint Action CANCON, which recognises that “Governance and decision-making processes are at the core of well-functioning cancer screening. Governance is here to be understood in the conceptual framework of stewardship as elaborated by WHO (7, 8)”.

According to Stoker, governance is concerned with creating the conditions for ordered rule and collective action; the outputs of governance are not therefore different from those of government. Governance refers to a set of institutions and actors that are drawn from but also beyond government, it identifies the blurring of boundaries and responsibilities for tackling social and economic issues, it identifies the power dependence involved in the relationship between institutions involved in collective action. Governance is about autonomous self-governing networks of actors and it recognizes the capacity to get things done which does not rest on the power of government to command or use its authority (9).

However, the terms “governance and stewardship in/of cancer care” are frequently used in the scientific field of cancer, but there is a lack of definition of the mentioned terms in the field of cancer care. They often appear in use as being of general knowledge even though a systematic search fails to identify any development of the respective definitions.

The aim of this work was to find the literature that defines the terms governance and stewardship in/of cancer care/control or create definitions in case of unsuccessful literature search.

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2 Methodology

In order to define the terms governance in/of cancer care and stewardship in/of cancer care a descriptive research methodology was used to perform a review of the literature. A systematic literature review made it possible to obtain data from various sources and thus ensure a comprehensive understanding of the research field. In our work, we used the databases PubMed, Google and MeSH in accordance with the Priority Reports for Systematic Examinations and Meta-Analysis (PRISMA-P) 2015 (1). We used different combinations of keywords in English. When selecting the literature, we were searching for the articles published in the last 10, 15, 20 years and older than 20 years. Members of the working group prepared a keyword proposal from which the keywords used to search the literature were then selected. As part of the literature review, articles on the use of the terms governance and stewardship in/of cancer care and cancer control were then identified, reviewed and analysed on the basis of keywords. These articles were published in the professional literature as well as in some relevant international documents and research studies. Gray literature identified and proposed by the working group were also included and reviewed. We searched for the documents opportunistically, meaning a focused or focused search based on information found by each partner of the working group in their own country. Among the gray literature, we reviewed unpublished documents or those that are otherwise difficult to find, including various reports. Letters, information from editorials, various interviews as well as posters and articles without access to the full text were not included in the study.

At the beginning of the research it was agreed that in case of unsuccessful literature search new draft definitions would be created by the members of the working group using the terms found in the definitions from related fields, and discussed and adopted at the work package meeting with European experts on cancer from different institutions, Ministries of Health, academia, representatives of cancer organisations, cancer institutes as well as cancer patients.

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<https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/2046-4053-4-1>

3 Results

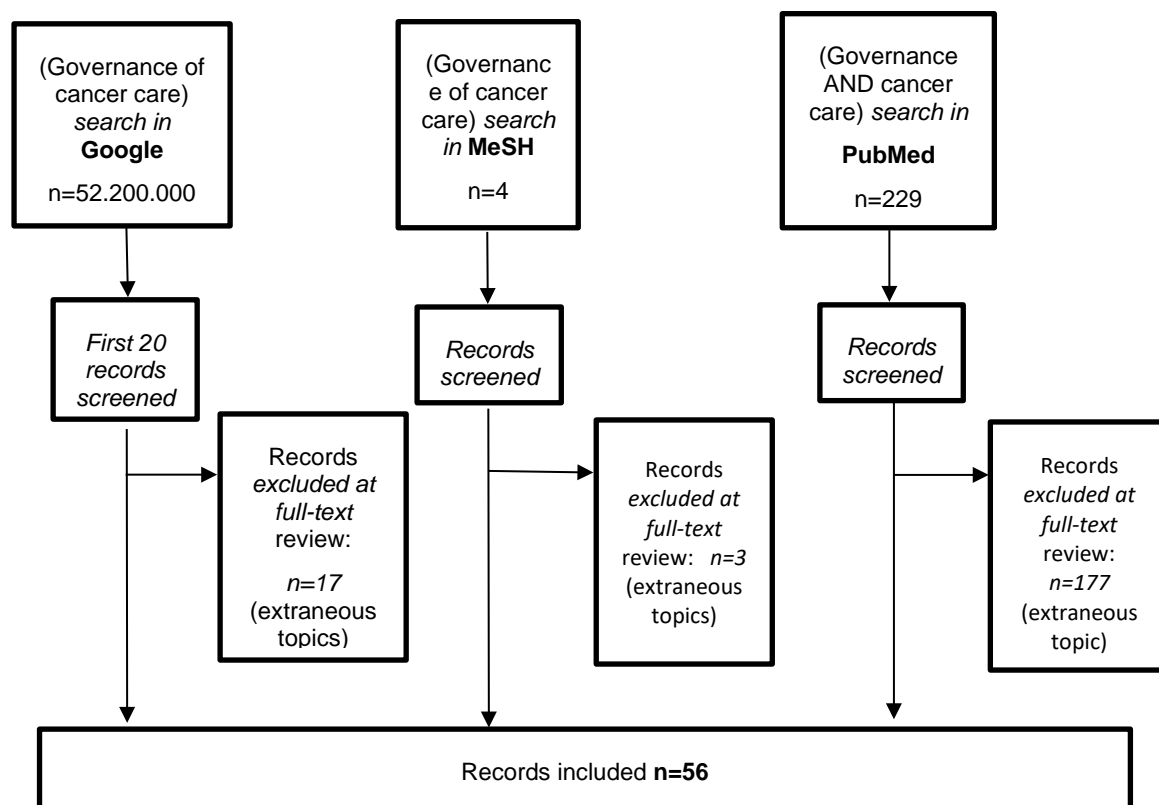
Governance in/of cancer care

The initial search in PubMed resulted in total 229 records, of which 52 remained after full text review. The initial search in Google resulted in a total of 52.200.000 records. We screened full text of first 20 records and excluded 17 records. The initial search in MeSH resulted in total of 4 records, of which 1 remained after full text review.

We ended up with 56 eligible studies.

The flowchart of the study identification process for the term governance in/of cancer care is displayed in Figure 1.

Figure 1. Flowchart of the study selection process for the term governance in/of cancer care.



Stewardship in/of cancer care

Far less articles are available in the field of stewardship in/of cancer care. The search in PubMed resulted in total of 105 records. After full text review we excluded 101 articles and 4 articles remained for the review. The initial search in Google resulted in a total of 8 records. We screened full text articles and excluded 2 records. We added some articles found by opportunistic search and we ended up with 24 studies.

We analysed all the above mentioned articles searching for the definitions of governance and stewardship in/of cancer care.

Most articles do not give any explanation of the terms or they cite the articles where the terms are used in other fields, mostly banking, economy, religion or spirituality (stewardship). The definition created by OECD (6) in 2013 was perhaps the most useful definition: „Governance refers to how system of care is steered and managed at macro level, particularly with respect to improving its quality and outcomes. Governance seeks continuous improvement in what a system delivers and how it delivers.“

The search results for the terms governance/stewardship of/in cancer care are presented in Table 1.

Search item	Results Title/ Abstract (10 years)	Results Title/ Abstract (15 years)	Results Title/ Abstract (20 years)	Results Title/ Abstract (all years)	Results All Fields (10 years)	Results All Fields (15 years)	Results All Fields (20 years)	Results All Fields (all years)
Governance	7627	9022	10230	11128	9375	10925	12236	13148
Cancer Care	7652	8996	81514	91627	13200	15667	208280	260901
Governance in Cancer Care	0	0	100	101	191	214	226	229
Governance of Cancer Care	81	95	100	101	196	220	226	229
Stewardship	4887	5162	5532	5660	5309	5611	6020	6156
Stewardship in Cancer Care	0	0	43	43	100	103	105	105
Stewardship of Cancer Care	43	43	43	43	100	103	105	105

Table 1. The search results for the terms governance/stewardship of/in cancer care.

The most important search results for the terms »governance of cancer care« in »google« are presented in Table 2.

Author	Title of the article	Terms governance of cancer care
OECD (1)	"GOVERNANCE of cancer care systems" in Cancer Care: Assuring Quality to Improve Survival.	<p>OECD Publishing, Paris: https://doi.org/10.1787/9789264181052-7-en.</p> <p>Over recent decades, countries have strengthened the GOVERNANCE of cancer care systems by introducing national cancer control programmes, and developing monitoring and quality assurance mechanisms. This chapter addresses the cross-country variation and trends related to GOVERNANCE surrounding cancer care.</p>
<p>-----</p> <p>Governance refers to how a system of care is steered and managed at a macro level, particularly with respect to improving its quality and outcomes. Governance seeks continuous improvement in what a system delivers and in how it delivers. Over recent decades, countries have strengthened the governance of cancer care systems by introducing national cancer control programmes with specific targets and clinical guidelines, which often involves identifying a lead person or organisation that is held accountable for delivering the outcomes. Some countries instead address cancer control through region-specific policies, within broader national health policies or through policies targeting specific aspects of cancer control, such as screening and establishing a registry.</p> <p>National policies are often set out to steer cancer control efforts</p> <p>National cancer control plans (NCCP) set out a country's broad ambitions in the face of cancer: they seek to reduce the number of cancer cases and cancer deaths and to improve the quality of life of cancer patients by systematically and equitably applying best practice in key areas such as cancer prevention, early detection, diagnosis, treatment and palliative care. The terms used by individual countries to refer to their national plans inevitably differ, but wherever a national plan or strategy adheres to the general features above, we refer to it as an NCCP.</p> <p>In recent years, based on the responses collected through the OECD HCQI Questionnaire on Systems of Cancer Care, NCCPs have become increasingly prominent across countries, and they have now matured with clear lines of responsibility and dedicated funds. Some countries, however, have not introduced NCCPs and instead address cancer control through region-specific policies, within broader national health policies or through policies targeting specific aspects of cancer control, such as screening and establishing registries.</p>		
Brawley OW. (2)	The role of government and regulation in cancer prevention	Government, be it local, state, provincial, national, or even a union of nations, has clear roles in the control of cancer. It is widely appreciated that much of the research that has

		defined the causes and treatment of cancer was, and is, government funded. Less appreciated, the body of work about how to control cancer shows the importance of an environment that encourages individuals to adopt healthy behaviours, and government has a vitally important role. Through regulation, education, and support programmes, governments can create an environment in which tobacco use is reduced and citizens maintain good levels of physical activity, healthy bodyweight, and good nutrition. Cancer prevention and the creation of a culture of health is an essential mission of government, beyond that of the traditional health-focused departments such as health ministries; it is in the domain of governmental agencies involved in environmental protection, occupational safety, and transportation .
Gorod A (3)	Toward Systemic GOVERNANCE of Cancer Treatment as a System of Systems	<p>This paper presents a system of systems view of cancer patient treatment and how GOVERNANCE can be improved by this approach.</p> <p>Literature indicates that governance is the preferred approach in the management of system of systems due to their complex nature.</p> <p>Thus, treatment governance is the result of consolidating information collected through data and management strategies from feedback and acting upon it, given existing positive and negative constraints from state and national levels. These include: national requirements for practicing professionals; accreditation and safety standards of health care facilities and environs; techniques/ treatment schedules/clinical trials; evidenced based best practice standards (including wait times/ advanced care); and the appropriate and timely utilization of therapeutic goods and equipment (e.g. chemotherapy drugs, Linear Accelerators, Computerized Topography Units).</p>
Bhaidkar A (4)	GOVERNANCE and Cancer Care in India: A Drive for Quality Improvement.	Governance plays a critical role in regulation and delivery of quality healthcare.

Table 2: The search results for the terms »governance of cancer care« in »google«.

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4 Bhaidkar A. Governance and Cancer Care in India: A Drive for Quality Improvement. *IJMEI* 2018; Vol 04, 7: 1815-21.

The search results for the terms »governance of cancer care« in Mesh are presented in Table 3.

Author	Title of the article	Definition and understanding of terms governance
Scally (1)	Clinical GOVERNANCE and the drive for quality improvement in the new NHS in England Clinical GOVERNANCE	A framework through which the United Kingdom's National Health Service organizations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish. Clinical governance is a system through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.
Anthony (2)	Shared GOVERNANCE, Nursing	Model of nursing practice with shared decision processes designed to integrate core values and beliefs that professional practice embraces, as a means of achieving quality care.
Anon (3)	Clinical Audit	A detailed review and evaluation of selected clinical records by qualified professional personnel to improve the quality of patient care and outcomes. The clinical audit was formally introduced in 1993 into the United Kingdom's National Health Service.

Rhodes (4)	<p>Understanding GOVERNANCE: Ten Years On, 1997</p> <p>https://www.researchgate.net/publication/233870082_Understanding_GOVERNANCE_Policy_Networks_GOVERNANCE_Reflexivity_and_Accountability</p>	<p>The term network GOVERNANCE has two faces. First, it describes public sector change whether it is the increased fragmentation caused by the reforms of the 1980s or the joined-up GOVERNANCE of the 1990s, which sought to improve coordination between government departments and the multifarious other organizations. Second, it interprets British government; it says the hierarchical Westminster model of responsible government is no longer acceptable.</p>
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Table 3. The search results for the terms »governance of cancer care« in Mesh

References

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The search results for the terms »governance of cancer care« in PubMed are not presented in a table because the document is too large.

Key finds from the literature using opportunistic search for the composition of the definition of »governance/stewardship in/of cancer care« are presented in Table 4.

Author	Title of the article	Definition and understanding of terms governance/stewardship
Marks L (1)	<p>Public health governance: views of key stakeholders</p> <p>Public Health</p>	<p>'Governance' is a notoriously slippery term. It may be associated with a set of principles, the exercise of legitimate authority through law and regulation, or processes for ensuring accountability and managing risk within organizations. It may also apply to the</p>

		<p>systematic application of procedures. There are complex relationships within and across local, national and global levels of governance,¹ as well as between regulatory, community/participatory and multi-agency approaches. Tensions may arise through the co-existence of different ‘modes’ of governance, commonly characterized as markets, hierarchies or networks,² or as a result of ‘newer’ forms of governance being layered on to existing arrangements.</p> <p>While stewardship of the health of the population was considered a key principle of governance, participants described how notions of stewardship were changing from a top-down, collective approach to one based on choice.</p> <p>..., the complexity of governance arrangements relevant to improving health and to public health practice was a common thread; concentrating on certain aspects of governance could lead to the neglect of others.</p>
<p>Albrecht T, Federici A (2)</p>	<p>Governance and financing. From European Guide for Quality National Cancer Control Programmes</p>	<p>Governance is a political process that involves balancing competing influences and demands’. These include:</p> <ul style="list-style-type: none"> -Maintaining the strategic direction of policy development and implementation; -Detecting and correcting undesirable trends and distortions; -Articulating the case for health in national development; -Regulating the behaviour of a wide range of actors - from healthcare financiers to healthcare providers; -Establishing transparent and effective accountability mechanisms. <p>It is important to stress that governance in health does not imply only the management of resources within healthcare, but includes collaboration with other departments and agencies in the government and also with</p>

		<p>other sectors, such as the private sector and civil society, to promote and maintain population health in a participatory and inclusive manner. In countries that receive significant amounts of external development assistance, governance should also be concerned with managing these resources in ways that promote national leadership, contribute to the achievement of agreed policy goals, and strengthen national health systems. While the scope for exercising governance functions is greatest at the national level, it also covers the steering role of regional and local authorities (81). This in particular applies to those countries where state administrative and political functions are strongly devolved and transferred to regional and local authorities.</p> <p>Governance in cancer management</p> <p>Cancer management is one of the most complex disease management segments of healthcare. Given the broad scope and the multiple elements involving a great number of actors, governance in cancer is important for at least the following key reasons:</p> <ul style="list-style-type: none"> • Management and planning of all resources needed in healthcare for cancer management; • Coordinate, nationally manage and sustainably finance comprehensive cancer services, including: screening, diagnosis, treatment and rehabilitation; • Secure adequate level of knowledge about cancer for the population; • Ensure stability of organisational support and financing of services supporting cancer patients beyond treatment and immediate oncological care.
Albrecht T (3)	From 'on paper' to 'into action': development of National Cancer	The WHO template for health systems, with its four main framework functions, provided an important guide for us, serving to standardise the approach to setting up and

	<p>control programmes in the EU</p> <p>From: Boosting Innovation and Cooperation in European Cancer Control. Key findings from the European Partnership for Action Against Cancer</p>	<p>consequently evaluating NCCPs in the EU. This template covers governance/stewardship, resource generation, financing and service provision, linking related activities to overall health system goals: better population health, responsiveness and fair financial contribution. For cancer control, stewardship challenges are marked by the complexity of the disease, characterised by different aetiologies and a number of important determinants.</p> <p>The problems are added on to deeper issues, having to do with the strength and quality of health systems, governance mechanisms, decisionmaking processes, payment systems and other aspects crucial to adequate health service provision.</p>
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Table 4. Key finds from the literature using opportunistic search for the composition of the definition of »governance of cancer care«.

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4 Discussion and conclusion

In the scientific literature in the field of cancer, especially cancer programmes, the terms governance and stewardship in/of cancer care are frequently used in different contexts. The terms are usually not explained or defined.

In order to find the definitions of the terms governance and stewardship in/of cancer care a literature search was carried out.

We analysed the above mentioned articles searching for the definitions of governance and stewardship in cancer care. Only few articles were useful. Most of the articles do not give any explanation of the terms or they cite the articles where the terms are used in other fields, mostly banking, economy, spirituality (stewardship).

Some explanations of the terms stewardship and governance from different fields that were helpful for final definitions:

Governance in general

According to the general definition of governance that The World Bank prepared in 1991, governance is the exercise of authority, control, management, power of government. It is the manner in which power is exercised in the management of a country's economic and social resources for its development (1).

Governance in health care

According to WHO governance in health care is a wide range of steering and rule-making related functions carried out by governments/decision-makers as they seek to achieve national health policy objectives that are conducive to universal health coverage (2).

Governance in cancer

Governance in cancer is important for at least the following key reasons:

- Management and planning of all resources needed in healthcare for cancer management;
- Coordinate, nationally manage and sustainably finance comprehensive cancer services, including: screening, diagnosis, treatment and rehabilitation;
- Secure adequate level of knowledge about cancer for the population;

- Ensure stability of organisational support and financing of services supporting cancer patients beyond treatment and immediate oncological care.

It is important to stress that governance in health does not imply only the management of resources within healthcare, but includes collaboration with other departments and agencies in the government and also with other sectors, such as the private sector and civil society, to promote and maintain population health in a participatory and inclusive manner (3, 4).

Stewardship in health

Stewardship has recently been defined as a “function of a government responsible for the welfare of the population, and concerned about the trust and legitimacy with which its activities are viewed by the citizenry”. It requires vision, intelligence and influence, primarily by the health ministry, which must oversee and guide the working and development of the nation’s health actions on the government’s behalf (2).

Stewardship in health policy

Stewardship encompasses the tasks of defining the vision and direction of health policy, exerting influence through regulation and advocacy, and collecting and using information. At the international level, stewardship means mobilizing the collective action of countries to generate global public goods such as research, while fostering a shared vision towards more equitable development across and within countries. It also means providing an evidence base to assist countries’ efforts to improve the performance of their health systems (2).

Stewardship in health sector

The capacity of stewardship to galvanize socially as well as economically responsible dimensions of the state can be particularly appropriate in the health sector. A stewardship approach based in developing the collective health commons fits well with the sense of mission that has traditionally been the central motivation of health care providers. For physicians, this mission-oriented framework lies at the core of the Hippocratic oath. The notion of stewardship, if properly developed, is also consistent with an evidence-based health policy framework. Given its dual grounding in ethical as well as economic criteria, a national health strategy based on stewardship can marshal the available evidence about what works well to support population-based measures that can improve overall health status (5).

One of the useful definitions is the definition created by OECD (6) in 2013:

„Governance refers to how system of care is steered and managed at macro level, particularly with respect to improving its quality and outcomes. Governance seeks continuous improvement in what a system delivers and how it delivers.“

Due to the lack of articles with exact definitions of the terms stewardship and governance in/of cancer care it was decided to create new definitions in the frame of the WP 10 of the iPAAC JA project using the terms found in the literature, even if not directly linked to cancer care. Task leader proposed the first version of both definitions, that were created using the words and meaning from the analysed definitions used in related fields. The proposed definitions were discussed during the meeting of the work package on Governance of integrated and comprehensive cancer care (WP 10) at the Hungarian National Institute of Oncology in Budapest in September 2019. European experts from the partner organisations, Ministries of Health, National Institutes of Public Health and Institutes of Oncology, Universities as well as members of *Organisation of European Cancer Institutes (OECI)*, *European Cancer Organisation (ECCO)*, *Digestive Cancers Europe*, representatives of cancer patients and others, participated professionally in the formulation of definitions. Regarding the definition of stewardship it was agreed at the meeting to use the term in connection with cancer control (stewardship in cancer control) because of the broader content meaning of the term stewardship in comparison with governance.

The final agreed versions of definitions are:

Definition of Governance in/of cancer care

„Governance in/of cancer care is a continuous process of management at macro level through which Health Care Systems can provide/assure, develop and improve quality, capacity and outcomes in cancer care.“

Definition of Stewardship in cancer control

„Stewardship in cancer control represents the State's highest level of responsibility in the field of cancer with the aim of reaching the national health policy objectives.,,

The definitions will be useful for the further work on the project as well as in the field of national cancer control programmes and will facilitate the understanding of the leadership tasks in the area of cancer care and cancer control.

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