

Quick scan of Cancer Infrastructures in European countries

Report

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Executive summary

European Research and Innovation Mission on Cancer

As an integral part of the Horizon Europe Framework Programme for Research and Innovation (2021-2027), the European Commission has initiated the European Research and Innovation Mission on Cancer. The goal of this Mission is to save and improve the lives of millions of European citizens exposed to cancer and its risk factors. In designing the Mission, the European Commission appointed a Board of experts to specify the Mission's objectives and to propose a coherent set of actions to achieve the Mission's goal. In September 2020, the Mission Board handed its Mission Outline over to the Commission, including thirteen recommendations that had been developed in consultation with the Mission on Cancer Assembly, citizens, cancer patients and survivors and many other stakeholders in Europe.

European network of Comprehensive Cancer Infrastructures

One of the Mission recommendations concerns setting up a network of Comprehensive Cancer Infrastructures (CCIs) within and across EU Member States to ensure that "each EU citizen or patient has access to, and could benefit from high-quality cancer research and care". The Board defined CCIs as "national or regional infrastructures that provide resources and services to support, improve and integrate cancer care, research, training of care professionals and education for cancer patients, survivors and families/carers." The Board emphasised that for the network of CCIs to be set up, it is important to keep an open view on (comprehensive) cancer infrastructures that may exist in European countries that are not recognised or accredited (yet) as (Comprehensive) Cancer Centres.

Quick scan

To prepare the implementation of the recommendation to set up this network of CCIs, the EUHealthSupport consortium conducted a survey, by which information was collected about 168 cancer infrastructures in 26 EU Member States (and 21 in 11 other European countries) that reported to provide clinical cancer treatment and care as well as to conduct scientific research. In addition, information was provided by the Organisation of European Cancer Institutes (OECI) and a number of contact persons in particular countries.

Main findings

The number of cancer infrastructures reported in the survey varies considerably per country as does their geographic distribution within countries. However, it is important to note that countries may have (many) more cancer infrastructures than reported in the survey (e.g. Austria, the Netherlands).

All cancer infrastructures reported in the survey declare themselves to be accredited or certified according to national or international standards. All reported cancer infrastructures in EU Member States include hospitals; more than half also include primary care centres, centres for community services and/or hospices. Regarding scientific research, almost all reported cancer infrastructures in

Member States conduct clinical trials, involving slightly more often in phase III and IV trials than in early stage (phase I and II) trials. The proportions of patients with a primary diagnosis of cancer that are invited to participate in clinical trials are for most reported infrastructures maximally 25%. Besides clinical trials, most reported cancer infrastructures in the EU also engage in human sciences and epidemiological studies. All reported infrastructures in EU Member States provide education to care professionals; many also offer information and education to patients and citizens.

Based on information provided by the OEI, there are no internationally cancer-accredited (C)CIs in nine EU Member States. These are particularly smaller countries and some countries in Eastern-Europe. Five EU Member States show almost full coverage of accredited (C)CIs. However, in many countries that have one or more accredited (C)CI, the development of networks around these CCI is patchy.

A number of country-contacts reported the existence or development of a national network of (C)CIs.

Conclusion

Equitable access to high-quality treatment and care, based on the most recent and advanced insights from scientific knowledge, for each cancer patient in the EU, can be facilitated by a strong network of collaborating CCI within and across EU Member States. Although the number of internationally recognised, cancer-accredited CCI is currently limited, cancer infrastructures that combine clinical treatment with scientific research have been identified in almost all EU Member States.

Nevertheless, access to clinical trials for patients is not equally spread across the EU. Follow-up efforts in Member States and at EU level are needed to explore whether and how these cancer infrastructures could become part of an EU-wide network of collaborating CCI that would make high-quality cancer treatment, care, research and education accessible to all patients and citizens in the EU.

1 Background

1.1 EU Mission on Cancer

In April 2019 the Council of the European Union and the European Parliament reached a political agreement on the next EU research and innovation programme Horizon Europe (2021 – 2027), on the basis of which the Commission has started preparing Horizon Europe’s implementation. Among the novelties of Horizon Europe are “missions”, which aim to address important societal challenges by giving direction to EU research and innovation activities that can make a real difference in European citizens’ lives and societies. One of the missions is the Mission on Cancer.

In designing the Mission on Cancer, the European Commission invited a Board of European experts – covering cancer research, innovation, policy, healthcare provision and practice –, hereafter Mission Board, to define an ambitious and measurable goal with a substantial impact on and relevance for society and citizens of Europe. The Commission also asked the Board to propose a coherent set of actions to achieve this goal in a set timeframe. These actions will be implemented through Horizon Europe and other instruments of the European Union (EU) and its Member States, and aligned with other initiatives at EU and Member State level.

During the first phase of the Mission, which lasted until September 2020, the Mission Board developed a Mission Outline¹ in consultation with the Assembly and citizens and stakeholders in all EU countries. In this Outline, the goal of the Mission was defined as: “By 2030, more than 3 million lives saved², living longer and better”. To achieve this goal, the Mission Board identified five areas for action: 1. Understanding cancer, 2. Preventing cancer as far as possible, 3. Improving and optimising cancer treatment, 4. Better quality of life and survivorship support, and 5. Equitable access to cancer research, prevention, treatment, care and support. Within these areas thirteen recommendations were made. One of these recommendation is to set up a network of Comprehensive Cancer Infrastructures (CCIs) within and across all EU Member States to increase the quality of research and care.

The Mission Outline was handed over to the European Commission on 22 September 2020, which decides on which recommendations will be adopted and which resources and instruments will be selected to implement the Mission. The Mission Board will advise the Commission on the portfolio of research and innovation actions, but also on the broader spectrum of actions needed to implement the recommendations of the Board in the coming years.

¹ https://ec.europa.eu/info/publications/conquering-cancer-mission-possible_en

² The Mission on Cancer aims to avert more than 3 million additional premature deaths over the period 2021 – 2030, by accelerating progress of cancer prevention and control programmes and creating more equitable access to these programmes. This goal was set based on an analysis of avoidable deaths by the International Agency for Research on Cancer (IARC).

1.2 EU wide network of Comprehensive Cancer Infrastructures

In its Mission Outline, the Mission Board provides a rationale to set up an EU wide network of CCIs within and across all Member States. It notices that in many European countries, comprehensive cancer centres exist that combine high-quality clinical treatment with cancer research, professional training and/or patient education and counselling. As these centres bundle specialised expertise with a high volume of patients and advanced facilities, these centres have shown to perform better in terms of treatment outcomes. However, at the moment not all cancer patients in European countries benefit from the expertise, treatment and research facilities available in such centres, as inequalities exist in access to and availability of these centres. Therefore, the Mission Board recommends the establishment of one or more networks of accredited CCIs (see below for definition) within and across EU Member States, to ensure that “each EU citizen or patient has access to, and could benefit from high-quality cancer research and care”³.

The Board has defined CCIs as “national or regional infrastructures that provide resources and services to support, improve and integrate cancer care, research, training of care professionals and education for cancer patients, survivors and families/carers. Different formats of CCIs are possible, including existing Comprehensive Cancer Centres or Care Networks.”

With this last sentence the Board emphasises that for the network of CCIs to be set up, it is important to use a broad definition of (comprehensive) cancer infrastructures in European countries. Some are not recognised (yet) as (Comprehensive) Cancer Centres by the Organisation of European Cancer Institutes (OECI), as Onkologische Spitzenzentren by the German Cancer Society (DKG) / European Cancer Centre certification system (ECC), as Designated Centres of integrated oncology and palliative care by the European Society of Medical Oncology (ESMO), or as Comprehensive Cancer Care Networks by partners collaborating in the EU Joint Actions CanCon and iPAAC. This is to ensure access to the network for all CCIs in EU Member States and to facilitate collaborations across Europe.

³ https://ec.europa.eu/info/publications/conquering-cancer-mission-possible_en

2 Quick scan

2.1 Aim

To prepare for the implementation of the Board's recommendation to set up a network of CCIs within and across all EU Member States, the European Commission requested the EUHealthSupport consortium to conduct a quick scan to get an overview of existing (networks of) CCIs within and across Member States, their structures, functions and research and care activities/priorities, and information about the quality standards they meet. Such an overview may illustrate which cancer infrastructures already meet the definition of 'comprehensive' as set by the Mission Board, whether there are others that show potential to develop towards a CCI and could become part of an EU wide network of CCIs in the future.

2.2 Methods

The quick scan consisted of a number of steps:

1. deciding on a working definition for the cancer infrastructures (CI) to identify;
2. identifying CIs in European countries that meet the working definition;
3. collecting information about the identified CIs;
4. data synthesis and reporting.

Step 1: Deciding on a working definition of a CI

The recommendation of the Board is to set up a network of Comprehensive Cancer Infrastructures (CCI) within and across all EU Member States, to ensure that all European citizens and patients have equal access to high-quality cancer treatment and research. The Board has defined CCIs as: "national or regional infrastructures that provide resources and services to support, improve and integrate cancer care, research, training of care professionals and education for cancer patients, survivors and families/carers. Different formats of CCIs are possible, including existing Comprehensive Cancer Centres or Care Networks (CCCNs)."

For the implementation of this recommendation it is important that the European Commission not only gets an overview of recognised CCIs in (a limited number of) EU Member States, but also of CIs that currently do not meet the criteria set by the Board for a CCI, but may have potential to develop towards a CCI in the near future. Such CIs may exist in more Member States and are thus important to identify. Therefore, we applied a less far-reaching 'minimum' working definition for this quick scan in consultation with members of the Board of the Mission on Cancer: "a national or regional infrastructure that provides resources and services to support, improve and integrate cancer clinical care and scientific research."

Step 2: Identifying CIs in European countries that meet the working definition

In October 2020, we sent an email to all members of the Cancer Mission Board and Assembly as well as to the partners of the previous Joint Actions CanCon and iPAAC, explaining the purpose of the quick scan: getting a better picture of which CIs (that meet the working definition) exist in all EU Member States. We asked these persons if they were aware of any such CIs in their country (or in other EU countries) and if they could provide some information for each of these CIs by answering a short online questionnaire (see step 3). The email could also be forwarded to the contact person(s) of the identified CIs to fill in the questionnaire. Furthermore, we asked to forward the email to other contacts who may know relevant CIs or to provide us with the contact details of these persons.

Step 3: Collecting information about the identified CIs

We developed a survey questionnaire to get more information on specific functions, facilities, activities and target populations of the identified CIs in consultation with members of the Mission Board. Since the survey was meant to be a quick scan and should not be too burdening for responders, it was decided to limit the number of questions as well as their level of detail.

When developing the questionnaire we checked for relevant questions and criteria set by other organisations that had mapped (C)CIs in the past, such as:

- the definitions and criteria of a Comprehensive Cancer Care Network (CCCN) developed by partners of the Joint Action Cancon⁴, also applied in the survey of the iPAAC Joint Action in 2018 that focused on National Cancer Control Programmes in EU Member States.
- the criteria set by the Organisation of European Cancer Institutes (OECI) for Cancer Centres (CCs) and Comprehensive Cancer Centres (CCCs)⁵.

Two draft versions of the questionnaire were discussed with a subgroup of the Mission Board, resulting in the final questionnaire that was programmed in the EUSurvey tool.

The link to the EUSurvey questionnaire was included in the email (see step 2). This email was sent in the last week of October 2020; a reminder was sent two weeks later.

Step 4: Data analysis and reporting

The survey data were analysed using descriptive statistics. The results are presented in a number of tables in the next chapter (Chapter 3). In addition, we received information from several contacts about (networks of) (C)CIs in countries, via the EUHealthSupport email. This information is summarised in Chapter 4.

⁴ <https://cancercontrol.eu/archived/guide-landing-page.html>

⁵ https://www.oeci.eu/accreditation/Page.aspx?name=DES_TYPES

3 Results of the survey

In this chapter we will first provide an overview of the reported CIs that meet our working definition per country (section 3.1) and present some general characteristics of these CIs (section 3.2). In the next sections some information about the reported CIs will be presented according to the areas for action identified by the Mission Board. This means that we start with information that relate to the area Understanding cancer (section 3.3), followed by Cancer prevention and screening (section 3.4), Cancer treatment (section 3.5), and Quality of life and survivorship support (section 3.6). The fifth area of action (Equitable access) will be addressed in all sections, emphasising the key importance of an EU wide network of CCI to ensure equitable access for all citizens and patients living in the EU to cancer knowledge and research, prevention, treatment, care and support.

Response

With the help of members of the Mission Board and Assembly, the OECI and CanCon/iPAAC Partners, we received information about 208 CIs by the survey. For the overview in this chapter we excluded 15 reported CIs that did not meet the working definition and another four that did not provide resources or services in Europe. As such, the results in this chapter are based on a total of 168 CIs in (26) EU countries and 21 CIs in (11) other European countries.

Please note that the results presented in this chapter are based on the CIs identified by respondents to the survey. As we do not know how many CIs (that meet the working definition) exist in each country nor how many of these were reached by our invitation, we can only provide information about the reported CIs per country in this report. This is emphasised in the titles of all tables presented in this chapter.

3.1 Overview of reported cancer infrastructures

Table 3.1 and Figure 3.1 provide an overview of the number of reported CIs per country. Table 3.1 shows that we received information about CIs that meet the working definition from all EU countries, except Cyprus.

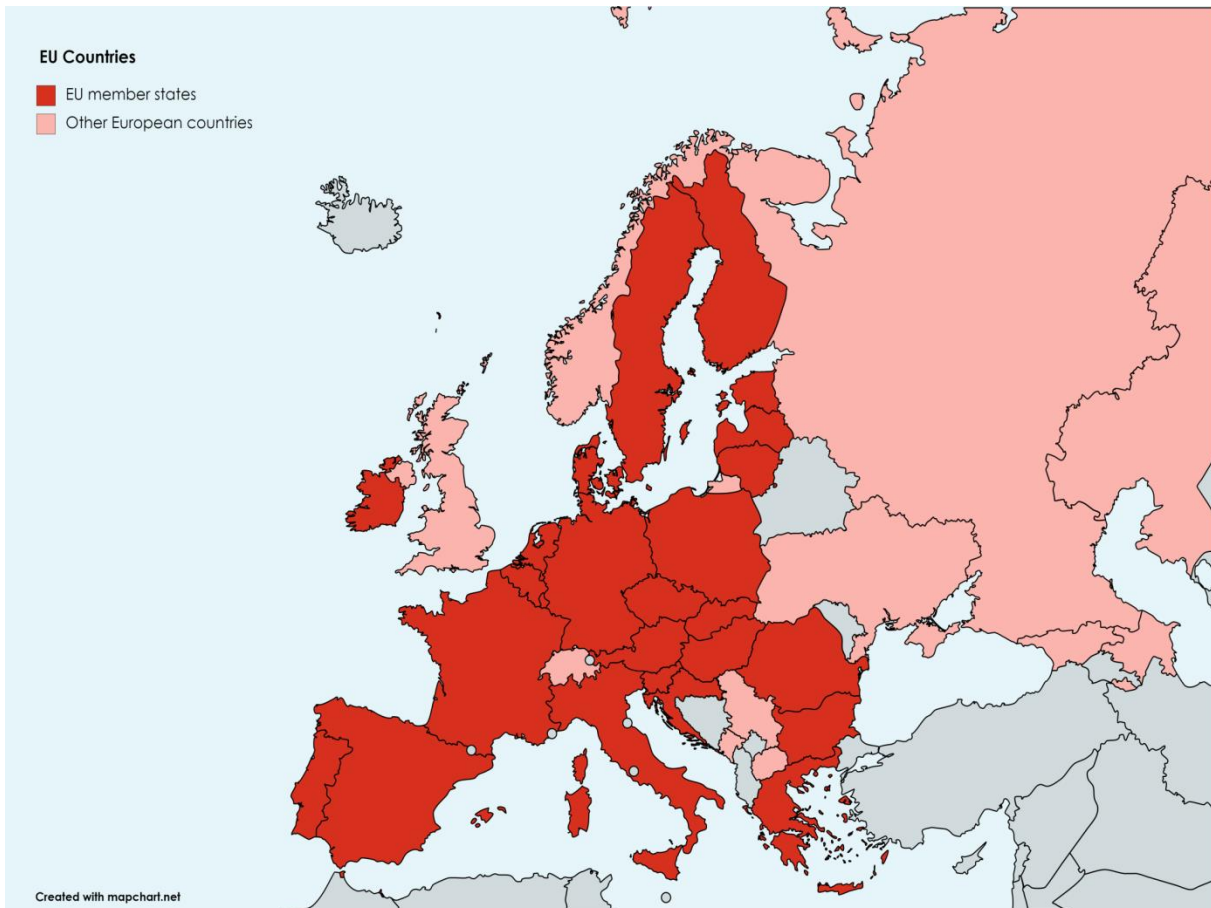
Table 3.1 Overview of reported cancer infrastructures in European countries that meet the working definition, per country

EU countries	N=168 reported CIs	Other European countries	N=21 reported CIs
Austria	3	Azerbaijan	1
Belgium	3	Georgia	2
Bulgaria	2	Kazakhstan	1
Croatia	3	Montenegro	1
Czech Republic	4	North Macedonia	1
Denmark	2	Norway	1
Estonia	1	Russia	2
Finland	3	Serbia	1
France	18	Switzerland	6
Germany	63	United Kingdom	1
Greece	2	Ukraine	4
Hungary	4		
Ireland	3		
Italy	17		
Latvia	1		
Lithuania	4		
Luxembourg	1		
Malta	2		
Netherlands	2		
Poland	11		
Portugal	5		
Romania	5		
Slovakia	1		
Slovenia	1		
Spain	6		
Sweden	1		

Figure 3.1 (next page) shows that in almost all EU countries at least one CI was reported. The number of reported infrastructures per country varies substantially, as is the case regarding their number per

1,000,000 inhabitants and geographical spread over the countries. However, for the purpose of setting up an EU-wide network of CCIs, the reported CIs may provide starting points for EU-wide, or European wide, collaboration.

Figure 3.1 Overview of reported cancer infrastructures in European countries that meet the working definition, per country



3.2 Characteristics of reported cancer infrastructures

In this section we present some characteristics of the reported CIs: their certification/accreditation status, the populations they serve and the institutes or facilities that constitute the infrastructure. Although the tables also include the reported CIs in non-Member States; the text refers to the reported CIs in EU Members States only.

3.2.1 Certification/accreditation status

Table 3.2 presents the certification/accreditation status of the reported infrastructures. It shows that most reported infrastructures in the EU countries are accredited, either by national or international standards.

Table 3.2 Certification/accreditation status of reported cancer infrastructures* in European countries that meet the working definition, per country

	N	Natio- nal stan- dard	OECI member, not in A&D ¹ process	OECI member, in A&D ¹ process	OECI CC ²	OECI CCC ³	EACS ⁴	CCC/ DKG/ ECC ⁵	ESMO ⁶	Other ⁷
EU-27	168	n	n	n	n	n	n	n	n	n
Austria	3	1						1	1	3
Belgium	3	3								2
Bulgaria	2	2								
Croatia	3	2								1
Czech Republic	4	3	1		1	1			1	1
Denmark	2	2								
Estonia	1	1	1		1				1	1
Finland	3				2	1				1
France	18	16	1	2	1	5			4	10
Germany	63	30		1	6	2		44	5	17
Greece	2		1							1
Hungary	4	3				1				1
Ireland	3	2			1					
Italy	17	12	2	3	5	5			6	9
Latvia	1	1								1
Lithuania	4	3			1					3
Luxem- bourg	1							1		
Malta	2		1							
Nether- lands	2	1		2	1				1	1
Poland	11	8	2						1	5
Portugal	5	2	1		2	2			1	5
Romania	5	3			2				1	3
Slovakia	1	1								1

	N	Natio- nal stan- dard	OECI member, not in A&D ¹ process	OECI member, in A&D ¹ process	OECI CC ²	OECI CCC ³	EACS ⁴	CCC/ DKG/ ECC ⁵	ESMO ⁶	Other ⁷
Slovenia	1								1	
Spain	6	4			1					3
Sweden	1									1
Other	21	n	n	n	n	n	n	n	n	N
Azer- baijan	1									
Georgia	2	1							1	1
Kazakh- stan	1	1								
Monte- negro	1									
North Mace- donia	1	1								
Norway	1					1				1
Russia	2									
Serbia	1									1
Switzer- land	6	4						6		3
Ukraine	4	3								2
United Kingdom	1				1		1			

¹ A&D = Accreditation & Designation

² CC = Accredited OECI Cancer Centre

³ CCC = Accredited OECI Comprehensive Cancer Centre

⁴ EACS = Designation of Research Excellence

⁵ Accredited Onkologische Spitzenzentren (CCC) or Deutsche Krebsgesellschaft (DKG) /ECC

⁶ ESMO = European Society for Medical Oncology designated Centres of Integrated Oncology and Palliative Care

⁷ Other = This category often included reference to ISO certification or the name of the national standard.

** Note that this table does not include all cancer infrastructures that are members of the OECI or all centres accredited or designated by the international organisations mentioned above; it includes the cancer infrastructures reported in the survey.*

3.2.2 Population served

Table 3.3 presents which population is served by the reported cancer infrastructures, according to both the type of cancer and geographical coverage. It shows that about 90% of the reported EU cancer infrastructures treat all types of cancer or most types, except the very rare. Care is mostly provided to a regional population, but many infrastructures also serve a national population.

Table 3.3 Types of cancer and population served by reported cancer infrastructures in European countries that meet the working definition, per country

Population served	N	All types of cancer	Most types, except rare	Specific types of cancer	Regional population	National population	Other population*
EU-27	168	n	n	n	n	n	N
Austria	3	3			3	1	
Belgium	3	2		1			
Bulgaria	2			2		2	
Croatia	3	2	1		1	2	
Czech Republic	4	3		1	3	4	1
Denmark	2	2				2	
Estonia	1	1		1	1	1	1
Finland	3	3			3	1	
France	18	15	1	6	15	11	8
Germany	63	35	23	8	55	21	9
Greece	2	1	1		1	1	
Hungary	4	3		1		4	
Ireland	3	2	1	1	2	1	
Italy	17	14	2	1	13	11	7
Latvia	1	1				1	
Lithuania	4	3		1	2	4	1
Luxembourg	1			1	1	1	
Malta	2	2				2	
Netherlands	2	2			2	1	1
Poland	11	9	2		8	7	1

Population served	N	All types of cancer	Most types, except rare	Specific types of cancer	Regional population	National population	Other population*
Portugal	5	4	1		5		
Romania	5	2	2	2	5	1	1
Slovakia	1	1				1	
Slovenia	1	1				1	
Spain	6	5	1		5	2	2
Sweden	1				1	1	1
Other	21	n	n	n	n	n	n
Azerbaijan	1	1			1	1	
Georgia	2		2			2	1
Kazakhstan	1	1				1	
Montenegro	1	1				1	
North Macedonia	1	1			1		
Norway	1	1			1		
Russia	2	1			1		1
Serbia	1			1	1		
Switzerland	6	1	5		5	2	1
Ukraine	4		4		4	1	
United Kingdom	1		1		1		

* multiple answers allowed; 'other' was mostly selected to indicate that the infrastructure also served patients from abroad

3.2.3 Institutes or units that constitute the infrastructures

In the survey we also asked respondents to report on the institutes or units that are part of the infrastructure or with which there is a formal collaboration agreement. The results are presented in the table 3.4 (Part I: diagnostics and registries), 3.5 (Part II: treatment and support) and 3.7 (Part III: research and innovation; see section 3.3.2 Involvement in scientific research).

Table 3.4 shows that almost all infrastructures include diagnostic and laboratory services. Screening and mortality registry are the least mentioned units as part of the infrastructure.

Table 3.4 Institutes or units that constitute the reported cancer infrastructures in European countries that meet the working definition, per country (Part I: diagnostics and registries)

	N	Diagnostic service	Laboratory	Biobank	Screening registry	Cancer registry	Mortality registry
EU-27	168	n	n	n	n	n	n
Austria	3	3	3	2	1	3	3
Belgium	3	3	3	3	1	2	2
Bulgaria	2	1	1			2	1
Croatia	3	3	3	2	1	1	1
Czech Republic	4	4	4	3	1	2	1
Denmark	2	2	2	2			
Estonia	1	1	1	1			
Finland	3	2	2	2		1	1
France	18	16	16	17	9	13	9
Germany	63	63	63	35	30	59	41
Greece	2	1	1	1		1	
Hungary	4	4	4	3	2	4	3
Ireland	3	2	2	2	2	2	2
Italy	17	17	17	14	11	15	11
Latvia	1	1	1	1			
Lithuania	4	4	4	4	3	3	3
Luxembourg	1	1	1				
Malta	2	2	2		1	1	1
Netherlands	2	2	2	2		2	1
Poland	11	11	11	10	10	11	9
Portugal	5	5	5	4	5	5	5
Romania	5	5	5	2	2	3	2
Slovakia	1	1	1	1			
Slovenia	1	1	1	1	1	1	
Spain	6	6	6	6	3	2	3
Sweden	1	1	1	1	1	1	

	N	Diagnostic service	Laboratory	Biobank	Screening registry	Cancer registry	Mortality registry
Other	21	n	n	n	n	n	n
Azerbaijan	1	1	1		1	1	1
Georgia	2	2	2		1	1	1
Kazakhstan	1	1	1		1	1	1
Montenegro	1	1	1	1	1	1	1
North Macedonia	1		1			1	
Norway	1	1	1	1	1	1	1
Russia	2	1	1	1	1	1	1
Serbia	1	1	1	1	1	1	1
Switzerland	6	6	6	4	3	5	4
Ukraine	4	4	4		1	4	3
United Kingdom	1	1	1	1	1	1	1

Table 3.5 shows that general hospitals and specialised hospital department are a formal part in almost all cancer infrastructures. Primary care centres, social community services and hospices are less frequently mentioned, but still by more than half of the responding infrastructures.

Table 3.5 Institutes or units that constitute the reported cancer infrastructures in European countries that meet the working definition, per country (Part II: treatment and support)

	N	General hospital	Univer- sity hospital	Specia- lised cancer hospital	Specia- lised hospital depart- ment	Rehabili- tation centre	Primary care service	Social / commu- nity service	Hos- pice
EU-27	168	n	n	n	n	n	n	n	n
Austria	3	3	1	1	2	3	2	3	2
Belgium	3	3	3	2	3	3	2	2	1
Bulgaria	2	1	1	1					1
Croatia	3		1		2	1			

	N	General hospital	University hospital	Specialised cancer hospital	Specialised hospital department	Rehabilitation centre	Primary care service	Social / community service	Hospice
Czech Republic	4	4	4	3	3	3	1		1
Denmark	2	1	2	2	2				
Estonia	1	1	1	1	1	1	1	1	1
Finland	3	2	2	1	2	2	2	2	1
France	18	14	17	14	14	13	9	11	5
Germany	63	57	50	41	55	39	47	51	57
Greece	2	1	2	1	1				1
Hungary	4	3	3	3	4	3	3	3	3
Ireland	3	3	3	2	3	2	2	1	1
Italy	17	15	15	15	15	15	11	13	13
Latvia	1	1	1		1	1		1	
Lithuania	4	2	3	3	3	4	2	1	
Luxembourg	1	1			1		1	1	
Malta	2	2	2	2	2	2	1	2	
Netherlands	2	2	2		2	1			
Poland	11	9	10	10	9	12	6	7	10
Portugal	5	5	4	5	5	4	2	3	
Romania	5	5	5	5	4	4	5	5	2
Slovakia	1			1			1		1
Slovenia	1	1	1	1	1	1	1	1	1
Spain	6	5	6	3	4	3	1	1	
Sweden	1		1	1	1	1			
Other	21	n	n	n	n	n	n	n	n
Azerbaijan	1	1	1	1	1	1	1	1	
Georgia	2	1	2	1	1		1	1	1

	N	General hospital	University hospital	Specialised cancer hospital	Specialised hospital department	Rehabilitation centre	Primary care service	Social / community service	Hospice
Kazakhstan	1		1	1	1			1	
Montenegro	1	1	1	1	1	1	1	1	
North Macedonia	1		1						
Norway	1	1	1	1	1	1	1	1	
Russia	2	1	1	1	1	1	1	1	1
Serbia	1	1	1	1	1	1	1	1	1
Switzerland	6	6	4	4	6	3	5	5	3
Ukraine	4	1	1	4	3	1	1	1	
United Kingdom	1		1				1		

3.3 Understanding cancer

Understanding cancer is a prerequisite for designing and implementing effective actions to improve cancer prevention, screening, treatment, care and support. For this purpose it is important that CCI in countries collect, store and share data in regional or (inter-)national databases, that they engage in scientific research and that they train care professionals and educate citizens and patients with evidence-based and up-to-date information. Access to cancer knowledge and research is not equally distributed within and across EU Member States. The proposed network of CCIs aims to reduce inequalities in access to cancer knowledge and research.

In this section we present a number of tables that show to what extent the reported CCIs contribute to regional or (inter-)national databases; to what extent they are involved in scientific research and to what extent they provide training to care professionals and education to citizens/patients to increase their knowledge and understanding of cancer.

3.3.1 Storage of patient data

Table 3.6 presents to what extent the reported cancer infrastructures store patient data in regional, national or international databases that provide opportunities for clinical research and/or treatment.

The table shows that cancer data of the reported CIs in EU Member States are not very often stored in international databases, but rather in national databases or, to a less extent, regional databases.

Table 3.6 Storage of patient data in databases by reported cancer infrastructures in European countries that meet the working definition, per country

	N	Regional database	National database	International database
EU-27	168	n	n	n
Austria	3	3	3	1
Belgium	3	3		
Bulgaria	2	2		
Croatia	3	3		
Czech Republic	4	2	2	1
Denmark	2	1	1	
Estonia	1	1	1	
Finland	3	3	2	
France	18	8	11	2
Germany	63	53	28	10
Greece	2			
Hungary	4		4	
Ireland	3	1	2	
Italy	17	9	8	5
Latvia	1	1		1
Lithuania	4	1	4	2
Luxembourg	1		1	
Malta	2		2	
Netherlands	2	1	2	
Poland	11	7	9	1
Portugal	5	1	1	
Romania	5	3		1
Slovakia	1		1	
Slovenia	1		1	
Spain	6	3	4	

	N	Regional database	National database	International database
Sweden	1	1		
Other	21	n	n	n
Azerbaijan	1	1	1	
Georgia	2		1	
Kazakhstan	1		1	1
Montenegro	1		1	
North Macedonia	1		1	
Norway	1		1	
Russia	2	1	1	
Serbia	1			1
Switzerland	6	4	4	2
Ukraine	4	2	2	
United Kingdom	1	1		

3.3.2 Involvement in scientific research

The survey included several questions on whether the cancer infrastructure conducts scientific research. Focusing on institutes that explicitly aim to conduct scientific research, table 3.7 shows that universities are most often mentioned as formal part of the reported CIs in EU Member States, followed by other research institutes and innovation departments. The latter is the least often mentioned, although still in more than half of the reported CIs in Member States.

Table 3.7 Institutes or units that constitute the reported cancer infrastructures in European countries that meet the working definition, per country (Part III: research and innovation)

	N	University	Other research department/ institute	Innovation development facility
EU-27	168	n	n	n
Austria	3	1	1	2
Belgium	3	3	3	3
Bulgaria	2	2	1	
Croatia	3	3	1	
Czech Republic	4	3	3	2
Denmark	2	1	2	1

	N	University	Other research department/ institute	Innovation development facility
Estonia	1	1	1	1
Finland	3	2		
France	18	17	17	15
Germany	63	47	40	28
Greece	2	1		
Hungary	4	3	3	3
Ireland	3	3	3	2
Italy	17	14	14	13
Latvia	1	1		
Lithuania	4	4	4	4
Luxembourg	1			
Malta	2	1		
Netherlands	2	2	2	1
Poland	11	10	8	9
Portugal	5	4	2	1
Romania	5	5	5	4
Slovakia	1	1	1	1
Slovenia	1	1	1	1
Spain	6	6	4	5
Sweden	1	1	1	1
Other	21	n	n	n
Azerbaijan	1	1	1	1
Georgia	2	1	1	1
Kazakhstan	1	1		1
Montenegro	1	1	1	1
North Macedonia	1			
Norway	1	1	1	1
Russia	2	1	1	1
Serbia	1	1		

	N	University	Other research department/ institute	Innovation development facility
Switzerland	6	4	4	3
United Kingdom	1		1	1
Ukraine	4	3		1

Table 3.8 presents to what extent the reported infrastructures perform clinical trials and how many patients participate in these trials. It shows that almost all reported CIs in EU Member States are involved in Phase III and IV clinical trials, and the majority also in early stage (Phase I/II) trials. In less than half of the reported CIs, 10-25% of the patients is offered participation in clinical studies and in about a quarter of the reported CIs this is less than 10%.

Table 3.8 Extent to which reported cancer infrastructures in European countries that meet the working definition offer participation in clinical trials to cancer patients, per country

Participation in clinical trials	N	Phase I or II Clinical trials	Phase III or IV Clinical trials	% of patients with primary diagnosis of cancer offered participation in clinical studies			
				< 10%	10-25%	25-50%	> 50 %
EU-27	168	n	n	n	n	n	n
Austria	3	3	3	2	1		
Belgium	3	2	3			1	2
Bulgaria	2	1	2	1	1		
Croatia	3	2	3	2			
Czech Republic	4	3	3		3		
Denmark	2	2	1		1		1
Estonia	1	1	1	1			
Finland	3	2	3	2			1
France	18	15	16	1	10	3	4
Germany	63	48	63	9	38	10	5
Greece	2	2	2	1	1		
Hungary	4	4	4		1		2
Ireland	3	3	3	3			
Italy	17	15	17	3	7	1	4

Participation in clinical trials	N	Phase I or II Clinical trials	Phase III or IV Clinical trials	% of patients with primary diagnosis of cancer offered participation in clinical studies			
Latvia	1						
Lithuania	4	3	4	1	3		
Luxembourg	1				1		
Malta	2						
Netherlands	2	2	2			1	
Poland	11	10	11	6	4	1	
Portugal	5	2	5	4	1		
Romania	5	2	5	4	1		
Slovakia	1	1	1	1			
Slovenia	1	1	1	1			
Spain	6	6	6		2	1	2
Sweden	1	1	1		1		
Other	21	n	n	n	n	n	n
Azerbaijan	1						
Georgia	2	1	2	1	1		
Kazakhstan	1		1	1			
Montenegro	1		1	1			
North Macedonia	1	1	1	1			
Norway	1	1	1		1		
Russia	2	2	2	1			
Serbia	1	1	1			1	
Switzerland	6	6	6	1	5		
Ukraine	4	4	4		1		1
United Kingdom	1	1	1			1	

Apart from involvement in clinical trials, cancer infrastructures may be involved in other types of scientific research, such as fundamental research, epidemiological studies or human sciences studies (e.g. quality of life studies). Table 3.9 shows that the reported CIs in EU Member States are involved in all types of research. These CIs most frequently mention the involvement in translational and

human science studies, and somewhat less in epidemiological and fundamental research, although these research areas were mentioned by about 80% of the reported CIs in EU Member States.

Table 3.9 Involvement in other scientific studies by reported cancer infrastructures in European countries that meet the working definition, per country

Type of research	N	Fundamental	Translational	Human sciences	Epidemiological
EU-27	168	n	n	n	n
Austria	3	1	2	3	2
Belgium	3	3	3	3	3
Bulgaria	2	1		1	2
Croatia	3	1	2	2	1
Czech Republic	4	4	2	4	3
Denmark	2		2	1	1
Estonia	1	1	1	1	1
Finland	3	3	3	3	3
France	18	15	17	17	13
Germany	63	28	38	52	56
Greece	2		1		1
Hungary	4	3	4	3	4
Ireland	3	2	3	3	3
Italy	17	15	17	16	13
Latvia	1	1		1	
Lithuania	4	4	3	3	4
Luxembourg	1			1	1
Malta	2			2	2
Netherlands	2	2	2	2	2
Poland	11	10	11	11	10
Portugal	5	4	5	4	4
Romania	5	4	4	4	3
Slovakia	1	1	1		
Slovenia	1	1	1	1	1

Type of research	N	Fundamental	Translational	Human sciences	Epidemiological
Spain	6	4	5	3	4
Sweden	1	1	1	1	1
Other	21	n	n	n	n
Azerbaijan	1	1	1	1	1
Georgia	2	1	1	1	2
Kazakhstan	1			1	1
Montenegro	1		1	1	1
North Macedonia	1				
Norway	1	1	1	1	1
Russia	2	2	2	2	2
Serbia	1		1	1	1
Switzerland	6	2	4	6	4
Ukraine	4	2	1	1	1
United Kingdom	1	1	1	1	1

3.3.3 Educating and informing care professionals, patients and citizens

In this section results are presented on training and education of care professionals and patients or citizens. Table 3.10 shows that professional training and education is provided by all reported CIs in EU Member States except one. Services to inform and educate patients and citizens are also frequently reported. This is less the case for facilities to offer case management or a navigation guide to patients and their families.

Table 3.10 Training and education provided by reported cancer infrastructures in European countries that meet the working definition, per country

	N	Education and training of professionals	Information and education for patients and citizens	Case management or navigation guide for patients
EU-27	168	n	n	n
Austria	3	3	3	1
Belgium	3	3	2	2

	N	Education and training of professionals	Information and education for patients and citizens	Case management or navigation guide for patients
Bulgaria	2	2	2	1
Croatia	3	3	3	2 (1)*
Czech Republic	4	4	4	4
Denmark	2	2	1	1
Estonia	1	1	1	1
Finland	3	3	3	2 (1)
France	18	18	16 (1)	12 (2)
Germany	63	63	63	55 (5)
Greece	2	1	1	1
Hungary	4	4	3	3 (1)
Ireland	3	3	3	2 (1)
Italy	17	17	16	13 (2)
Latvia	1	1	1	
Lithuania	4	4	4	3 (1)
Luxembourg	1	1	1	1
Malta	2	2	2	2
Netherlands	2	2	2	2
Poland	11	11	11	5
Portugal	5	5	5	4 (1)
Romania	5	5	5	5
Slovakia	1	1		1
Slovenia	1	1	1	1
Spain	6	6	5	2 (2)
Sweden	1	1	1	1
Other	21	n	n	n
Azerbaijan	1	1	1	1
Georgia	2	2	2	(2)
Kazakhstan	1	1	1	
Montenegro	1	1	1	1

	N	Education and training of professionals	Information and education for patients and citizens	Case management or navigation guide for patients
North Macedonia	1	1		
Norway	1	1	1	1
Russia	2	1	1	1
Serbia	1	1	1	1
Switzerland	6	6	6	6
Ukraine	4	4	4	4
United Kingdom	1	1	1	1

*(..) = concrete plans to offer this in the near future

3.4 Cancer prevention and screening

Many lives may be saved and the quality of life of patients and survivors improved, when cancer is diagnosed at an early stage. Many types of cancer may be detected earlier by systematic screening, and screening should be available to all European citizens.

Respondents indicated whether the reported cancer infrastructures provide services for either genetic screening or population-based screening. With genetic screening we refer to both genetic counselling and testing. Genetic testing is designed to identify individuals in a given population who are at higher risk of having or developing a particular disorder, or carrying a gene for a particular disorder.

The aim population-based screening, as opposed to opportunistic screening, is to discover latent disease in the (apparently healthy) population to detect it in its early stages⁶. In population-based screening each person belonging to the target population is invited personally, to give all eligible persons an equal chance of benefiting from screening and, therefore, to reduce health inequalities⁷.

Table 3.11 shows that reported CIs in EU Member States offer genetic screening somewhat more than population-based screening.

⁶ Segnan N., Patnick J., von Karsa L. (2010) European guidelines for quality assurance in colorectal cancer screening and diagnosis. Luxembourg: Publications Office of the European Union.

⁷ Antoni Castells. (2015) Choosing the optimal method in programmatic colorectal cancer screening: current evidence and controversies. *Therap Adv Gastroenterol.* 8(4): 221–233.

Table 3.11 Genetic and population-based screening services provided by reported cancer infrastructures in European countries that meet the working definition, per country

	N	Genetic screening	Population-based screening
EU-27	168	n	n
Austria	3	3	1
Belgium	3	3	3
Bulgaria	2	1	1
Croatia	3	1	3
Czech Republic	4	3	3
Denmark	2	1	
Estonia	1	1	1
Finland	3	3	2
France	18	16	13
Germany	63	53	48
Greece	2	1	2
Hungary	4	3	3
Ireland	3	2	2
Italy	17	16	12
Latvia	1	1	
Lithuania	4	4	4
Luxembourg	1	1	1
Malta	2	2	1
Netherlands	2	2	1
Poland	11	10	11
Portugal	5	5	5
Romania	5	2	5
Slovakia	1	1	1
Slovenia	1	1	1
Spain	6	5	5
Sweden	1	1	1

	N	Genetic screening	Population-based screening
Other	21	n	n
Azerbaijan	1	1	1
Georgia	2	1	2
Kazakhstan	1		1
Montenegro	1		1
North Macedonia	1		
Norway	1	1	1
Russia	2	2	2
Serbia	1		1
Switzerland	6	6	3
Ukraine	4	1	1
United Kingdom	1	1	1

3.5 Cancer treatment

To treat cancer, many (primary) treatment modalities exist. Among these are therapies with a long history, such as surgery, radiotherapy, chemotherapy, hormone therapy and stem cell transplant, which have nevertheless been developing continuously to produce better outcomes (e.g. minimally invasive surgery). Of a more recent date is immunotherapy; most innovative are targeted therapy or precision medicine approaches. Paediatric oncology provides roughly the same treatment modalities, but as children, adolescents and young adults are affected by other types of cancer developing and responding differently to cancer treatment, they should be treated differently.

Table 3.12 shows that the CIs identified in EU Member States report to provide most treatment modalities, both conventional and more innovative. Stem cell transplantation and paediatric oncology are less often provided by these CIs.

Table 3.12 Cancer treatment modalities offered by cancer infrastructures in European countries that meet the working definition, per country

	N	Surgery	Radio-therapy	Chemo-therapy	Immu-no-therapy	Hor-mone therapy	Stem cell trans-plan-tation	Targe-ted therapy	Preci-sion medi-cine	Paedia-tric onco-logy
EU-27	168	n	N	n	n	n	n	n	n	n
Austria	3	3	3	3	3	3	3	3	3	1
Belgium	3	3	3	3	3	3	3	3	3	3
Bulgaria	2	2	2	2	2	2		2	2	
Croatia	3	3	2	3	3	3	2(1)*	3	2	2
Czech Republic	4	3	3	3	3	3	2	2	3	4
Denmark	2		1	2	2	1		1	1	1
Estonia	1	1	1	2	1	1	1	1	1	1
Finland	3	3	3	3	3	3	1(1)	3	3	3
France	18	15	14	16	16	15	9	17	17	12
Germany	63	63	62	62	61	62	41(1)	60(1)	53(3)	29
Greece	2	2	2	2	2	2		2	2	1
Hungary	4	3	3	4	4	3	3	4	4	4
Ireland	3	3	3	3	3	3	2(1)	3	3	1(1)
Italy	17	16	16	17	17	16	14	17	16(1)	5(1)
Latvia	1	1		1						1
Lithuania	4	4	4	4	4	4	3	4	4	3
Luxem-bourg	1	1	1	1		1		1	1	
Malta	2	2	2	2	2	2		2	2	2
Nether-lands	2	2	2	2	2	2	2	2	2	2
Poland	11	11	11	11	11	11	8(2)	11	11	7
Portugal	5	5	5	5	4	5	4	4	5	4
Romania	5	3(2)	5	5	5	5	1(2)	5	3(2)	3(1)
Slovakia	1	1	1	1	1	1		1	1	1

	N	Surgery	Radio-therapy	Chemo-therapy	Immu-no-therapy	Hor-mone therapy	Stem cell trans-plan-tation	Targe-ted therapy	Preci-sion medi-cine	Paedia-tric onco-logy
Slovenia	1	1	1	1	1	1		1	1	1
Spain	6	5	6	6	6	6	5	5(1)	3(2)	4
Sweden	1	1	1	1	1	1	1	1	1	1
Other	21	n	n	n	n	n	n	n	n	n
Azerbaijan	1	1	1	1	1	1	(1)	1	1	1
Georgia	2	2	2	2	2	2	1	2	1	1
Kazakh- stan	1	1	1	1	1	1	1	1	1	1
Monte- negro	1	(1)	1	1	1	1		1	1	
North Mace- donia	1		1	1	1	1		1		
Norway	1	1	1	1	1	1	1	1	1	1
Russia	2	2	2	2	2	2	1(1)	2	2	2
Serbia	1	1	1	1	1		(1)	1	1	
Switzer- land	6	6	6	6	6	6	3	6	5	2
Ukraine	4	4	4	4	4	4		4	1	
United Kingdom	1	1	1	1	1	1	1	1	1	1

*(..) = concrete plans to offer this in the near future

3.6 Quality of life and survivorship support

Increasing incidence and survival rates will result in many more EU citizens in the near future who will need to find a way to live a good life with or after cancer. Therefore, an important part of the Mission's goal is to achieve the best possible quality of life for everyone in the EU who is exposed to cancer. Supporting the quality of life of people exposed to cancer requires a thorough understanding of their cancer related problems. For patients and survivors these may be (late) side-effects of cancer treatment, symptoms, comorbidities and functional disability, mental health problems and difficulties in returning to work. Therefore, not only the treatment of cancer itself is important, but also addressing these cancer-related problems.

Table 3.13 shows that almost all reported CIs in EU Member States offer care to maintain or improve the quality of life of cancer patients and survivorship support. Rehabilitation is offered by more than 80% of the reported CIs in Member States.

Table 3.13 Quality of life and survivorship support offered by cancer infrastructures in European countries that meet the working definition, per country

	N	Reconstruc- tive surgery	Rehabilitation	Palliative care	Psycholo- gical counselling	Social care
EU-27	168	n	n	n	n	n
Austria	3	3	3	3	3	3
Belgium	3	3	3	3	3	3
Bulgaria	2	2	1	1	2	1
Croatia	3	3	3	3	3	2
Czech Republic	4	4	4	3	3	3
Denmark	2					
Estonia	1	1	1	1	1	1
Finland	3	3	3	3	3	3
France	18	16	14	16	16	15
Germany	63	56	45	62	63	62
Greece	2			2	1	2
Hungary	4	3	3	3	3	3
Ireland	3	2	3	2	2	2
Italy	17	16	14	17	17	14
Latvia	1	1	1	1	1	1
Lithuania	4	4	4	4	4	4
Luxembourg	1	1	1	1	1	1
Malta	2	2	2	2	2	2
Netherlands	2	2	2	2	2	2
Poland	11	11	11	11	11	9
Portugal	5	5	5	5	5	5
Romania	5	3	4	5	5	5
Slovakia	1		1	1	1	1

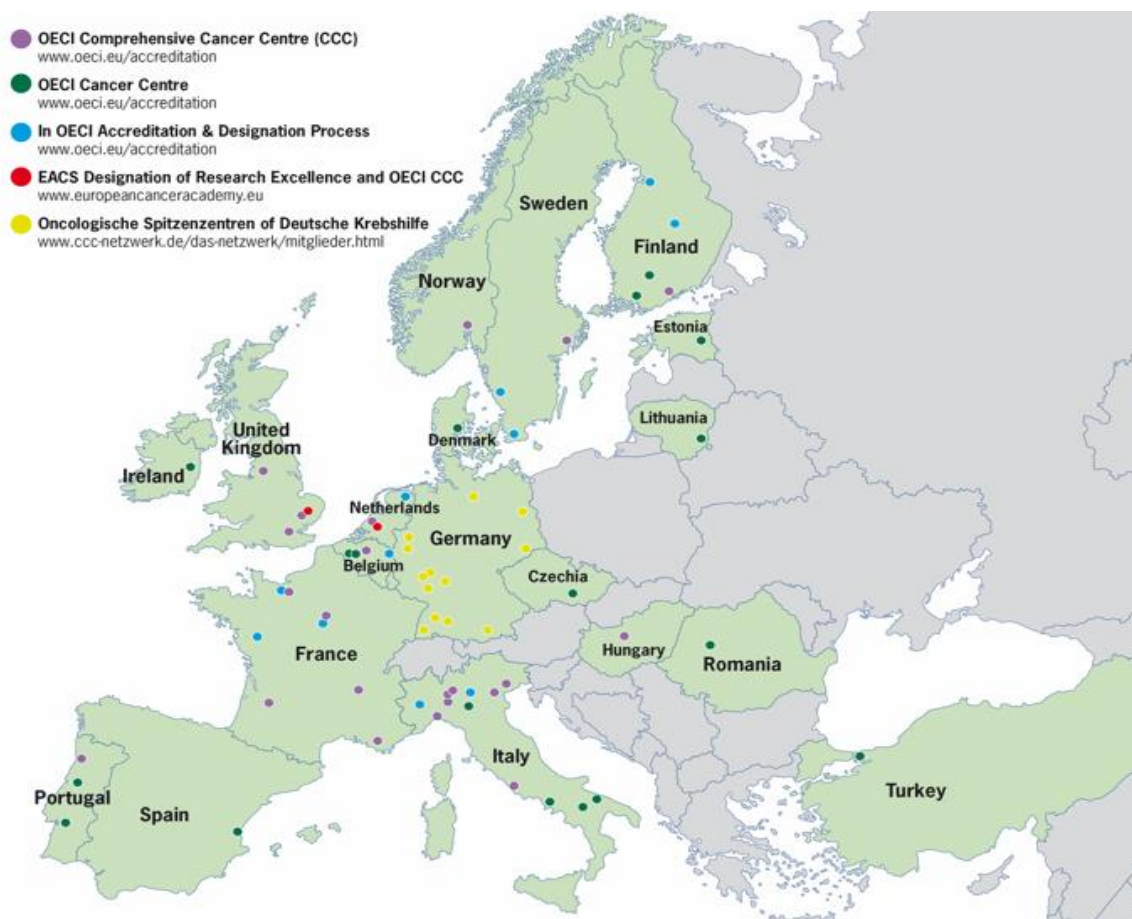
	N	Reconstruc- tive surgery	Rehabilitation	Palliative care	Psycholo- gical counselling	Social care
Slovenia	1	1		1	1	1
Spain	6	4	5	5	6	4
Sweden	1	1	1	1	1	1
Other	21	n	n	n	n	n
Azerbaijan	1	1		1	1	1
Georgia	2	2	1	2	1	1
Kazakhstan	1	1		1	1	1
Montenegro	1			1	1	1
North Macedonia	1					
Norway	1	1	1	1	1	1
Russia	2	2	1	1	1	1
Serbia	1	1	1	1	1	1
Switzerland	6	6	6	6	6	6
Ukraine	4	4	2	4	1	1
United Kingdom	1	1	1	1	1	1

4 Other results

In addition to the survey, we received relevant information about existing (networks of) (comprehensive) cancer centres in EU Member States from the OECI and other contacts. Below we summarise this information.

4.1 Information received from OECI

The Organisation of European Cancer Institutes (OECI) provided a draft overview of cancer centres and networks that integrate cancer care and research, which was based on a mapping exercise conducted in 2018 through its contacts in all EU Member States. Figure 2 was drafted by the OECI and shows the identified (C)CIs that are accredited or in the process of accreditation and designation. This overview was also presented by Professor Thierry Philip at the European Cancer Summit 2020 (18-19 November 2020).



Source: Berns A, Ringborg U, Celis JE, et al. Towards a cancer mission in Horizon Europe: recommendations. *Mol Oncol* 2020, 14: 1589-1615. <https://doi.org/10.1002/1878-0261.12763>

As summarised by the OECl: Nine⁸ EU Member States do not have accredited centres yet: Bulgaria, Croatia, Cyprus, Greece, Latvia (interested), Malta, Poland (applying), Slovakia and Slovenia (in progress). There are five EU Member States with almost full coverage of accredited centres: Finland, France, Germany, Italy and Portugal.

The development of networks around most of the accredited centres in EU Member States is patchy; and largely depends on their health systems. Equitable access for all EU citizens to high-quality cancer treatment, care and research remains a huge challenge. This also relates to the issue of “centralisation” of cancer services. Where this applies (e.g. France, Italy, Finland), patients generally travel to a specialist centre. In more decentralised systems (e.g. Poland, Spain, Germany) the need for strong clinical networks, with research driven from a central CCI, may be even more important.

From the OECl we also received the contact details of persons who had given permission to be contacted by us, to receive more information about the existence of (networks of) (C)CIs in their country. Information provided by these persons is summarised in the next section, together with information we received from other sources.

4.2 Country-specific information

4.2.1 Czech Republic

Information received from Prof. Marek Svoboda, Director of the Masaryk Memorial Cancer Institute (accredited member of the OECl):

In the Czech Republic, there are 15 accredited Comprehensive Cancer Centres, the status of which is granted by the Ministry of Health. Of these 15 centres that are dedicated to the care of patients with solid tumours, six also take care of haemato-oncological patients and two of patients with paediatric tumours. Each centre consists of its own centre (usually a large university or regional hospital) and a regional network of smaller cancer centres/units (outpatient and/or inpatient clinics). The Masaryk Memorial Cancer Institute provides care to all of the above mentioned types of patients, including patients with rare tumours.

4.2.2 Denmark

Information received from Prof. Kjeld Schmiegelow, Dept of Paediatrics and Adolescent Medicine, Rigshospitalet University Hospital, Copenhagen (Denmark):

In 2017 the national Danish Comprehensive Cancer Center (DCCC) for cancer research and treatment was established as part of the National Cancer Action Plan IV (launched in 2016). The DCCC integrates management, leadership and professional expertise in the field of cancer and healthcare

⁸ Luxembourg has an organ-specific accreditation; see the DKG website <https://www.oncomap.de/centers?selectedCounty=Luxemburg>

in Denmark in a national structure for cancer research, diagnostics, treatment and follow-up. Building on the existing infrastructure, the aim of DCCC is to contribute to optimise cancer treatment in Denmark by promoting collaboration and coordination in cancer research and clinical care and by increasing access to funding and international partnerships. Moreover, the DCCC contributes to spread new knowledge and treatment faster and more systematically across the country to shorten the path from research to clinical practice.

The DCCC is organised with a Governance Board, a Steering Committee and a Scientific Council. The Governance Board consists of the health chief executives from the five Danish Regions and the Executive Vice President from the Danish Regions. The Governance Board is authorised to make national decisions in the area of health in Denmark and is the top decision-making authority of the DCCC. The Steering Committee consists of hospital and university managers from the five Regions, and directors from national organisations such as the Danish Health Authority and the Danish Regions. The role of the Steering Committee is to: identify important strategic fields of development in research, education, recruitment, diagnosis, treatment, etc.; create and develop new knowledge environments and networks across hospitals and universities; facilitate national dissemination and execution of clinical trials which are not yet standardised; make national decisions on evidence based, national guidelines; develop and coordinate local research competencies and environments to strengthen national coherence in the field of cancer; appoint centres and organisations to the DCCC. The Scientific Council is a committee with professionals from the various cancer groups – both clinicians and researchers with a broad geographical representation.

Since 2016, 11 national research centres have been established focusing on immune therapy, radiotherapy, survivorship and late adverse effects, precision medicine, blood cancer, equity in cancer, lung cancer, circulating tumour DNA guided treatment, childhood cancer and brain tumours. The research centres are organised across hospitals and specialist functions to benefit all patients with cancer in Denmark. The centres include researchers and clinicians from hospitals and universities throughout the country. Together they develop and apply the latest knowledge and facilitate collaboration with colleagues to ensure that patients with cancer across Denmark are invited to participate in research and have access to the best treatment. The national research centres are formally part of the DCCC, which implies that: (i) the research conducted has national aims and is embedded nationwide; (ii) the centres work as platforms for (inter-)national collaboration and share knowledge and new research achievements; (iii) the management of the centres are represented in the Scientific Council of the DCCC.

For more information see: <https://www.dccc.dk/english/>

4.2.3 Hungary

Information received from Dr. Agnes Czibalmos:

In Hungary, the National Institute of Cancer (NIC) is responsible for the management of the National Cancer Registry; the service providers of cancer care send data to this institute. There is another

registry that collects data of paediatric cancer patients; this registry is under the responsibility of the Paediatrics Clinic II of the Semmelweis University, Budapest. A third registry comprises the data of patients with haematological diseases, including the data of patients with malignant haematological diseases. This relatively new registry is developed and managed by the National Institute of Haematological Diseases. The NIC has a close working relationship with the two other registering institutes; all Hungarian cancer data are available in the NIC's registry.

4.2.4 Ireland

Information received from Kay Duggan-Walls (<https://www.hse.ie>):

The National Cancer Control Programme (NCCP) is responsible for overseeing national services for the treatment of cancer. These treatments include surgery, radiotherapy and systemic anti-cancer therapy (SACT). An early priority for the NCCP was the establishment of designated cancer centres for cancer surgery. The majority of all cancer surgery now takes place in the designated cancer centres. Nine hospitals were designated as cancer centres (with a satellite unit in Letterkenny General Hospital). In 2013 the Department of Health announced the formation of six Hospital Groups. There are now seven Hospital Groups, including the Children's Hospital Group. Each of the Hospital Groups has at least one designated cancer centre. The NCCP has also progressed various initiatives to develop radiotherapy and SACT services across Ireland.

There are nine designated cancer centres. The services provided in the designated cancer centres are summarised in the table at the next page. A further 17 public hospitals provide systemic anti-cancer therapy (chemotherapy, immunotherapy etc.). An additional two centres provide radiotherapy services. Ireland's nine Designated Cancer Centres are aligned with the Hospital Group structure.

The NCCP works to ensure that designated cancer centres for individual tumour types have adequate case volumes, expertise and concentration of specialist skills, working in multidisciplinary teams to ensure the best outcome for patients.

● Designated centre
○ Contracted Service

NCCP Designated Cancer Centres

		St. James's	Mater	St. Vincent's	Beaumont	Cork	Galway	Limerick	Waterford	SLRON*	Other†
Lung	Rapid Access Clinic	●	●	●	●	●	●	●	●		
	Surgery	●	●			●	●				
Breast	Symptomatic Breast Disease	●	●	●	●	●	●	●	●		Letter-kenny
	Surgery	●	●	●	●	●	●	●	●		Letter-kenny (Galway satellite)
Prostate	Rapid Access Clinic	●	●	●	●	●	●	●	●		
	Surgery	●	●	●	●	●	●				
Upper GI	Surgery	●		●	●	●					
Pancreas	Surgery			●		●					
Rectal	Surgery	●	●	●	●	●	●	●	●		Letter-kenny (Clinical with Galway)
Neuro-oncology					●	●					
Radiation Oncology						●	●	○ Mater Private Limerick	○ Waterford	●	

*SLRON: St. Luke's Radiation Oncology Network, which has locations at St. Luke's Hospital, Rathgar, and on the campuses of St. James's Hospital and Beaumont Hospital.
†Letterkenny Hospital is a designated satellite of Galway University Hospital.

Source: <https://www.hse.ie/eng/services/list/5/cancer/about/services/>

4.2.5 The Netherlands

Information gathered from (Dutch language) websites⁹:

In 2014, the Taskforce Oncology was established by the Dutch Association of Hospitals (NVZ), the Dutch Federation of University Medical Centers (NFU), the Oncological Cooperation Foundation, the Living With Cancer patient movement, the Netherlands Integral Cancer Center (IKNL) and the Dutch Association of General Practitioners (NHG). The Taskforce formulated the ambition that oncological patient care in the Netherlands should be among the best internationally by 2020 and that the Netherlands would then be a leader in research and innovation in the field of care for patients with cancer. To achieve this, a vision was developed with the formation of regional Comprehensive Cancer Networks (CCN) at its core. Comprehensive refers to care that is holistic, coherent and multidisciplinary, and that is strongly related to scientific research (both fundamental, translational and clinical) and care innovation. The agreements within a CCN must guarantee that there is an adequate volume and a range of oncology care available in the region.

The development of CCNs in the Netherlands is a 'bottom-up approach', which aims to do justice to the regional diversity. It is conceivable that a national guideline of quality requirements will be issued, on the basis of which a network can acquire the designation CCN. The Ministry of Health, Welfare and Sport makes a financial contribution to the development of the CCNs.

⁹ <https://www.oncologienetwerken.nl/nieuws/artikel/regios-kaart-gebracht>; <https://www.zonmw.nl/nl/onderzoek-resultaten/kwaliteit-van-zorg/programmas/project-detail/citrienfonds/programmaplan-naar-regionale-oncologienetwerken-2019-2022/>

4.2.6 Spain

Information received from Leonor Norton, PhD, International Projects Fundació Sant Joan de Déu:

Hospital Sant Joan de Déu will launch in 2022 the Paediatric Cancer Centre Barcelona (PCCB). It may become one of Europe's largest paediatric oncology centres. The Cancer Centre is a 60 million EUR project and its construction started in 2019. The facilities will cover a 5,137 square-metre areas, four-story building that will be able to attend 400 new patients a year. The centre will have eight suites for haematopoietic stem cell transplantation and will be equipped with the latest state-of-the-art technological advances. In a second phase, the centre will incorporate an innovative radiotherapy treatment with protons that is not currently available in Spain.

5 Discussion

Main findings

Based on a survey completed by contact persons in European countries, we identified 168 cancer infrastructures (CIs) in EU Member States and 21 CIs in other European countries that met our working definition, i.e. they combine clinical care with scientific research. The number of reported CIs per country varies considerably with regard to the number per 1,000,000 inhabitants and the geographic distribution across countries. However, for the purpose of setting up an EU-wide network of CCI, the reported CIs may provide starting points, as in all Member States except Cyprus one or more CIs that meet the working definition were reported.

Based on information provided by the OECI, there are no accredited (C)CIs in nine EU Member States. These are particularly smaller countries and some countries in Eastern-Europe. Five EU Member States show almost full coverage of accredited (C)CIs. However, in many countries that have one or more accredited (C)CI, the development of networks around these CCI is patchy. A number of countries report the existence or development of a national network of (C)CIs.

All CIs reported in the survey declare themselves to be accredited according to national or international standards. Many offer screening options, with genetic screening more often mentioned than population-based screening. General hospitals and specialised hospital units are almost always included in the CIs, and most of the reported CIs treat all types of cancer. In addition to hospitals, half of the CIs include primary care centres, centres for community services and/or hospices. Regarding their involvement in scientific research, almost all reported CIs conduct clinical trials, though the proportion of patients with primary tumours invited to participate in these trials are mostly maximally 25%. Besides, most reported CIs also conduct human sciences and epidemiological studies. All reported CIs in EU Member States provide education to professionals, and many also offer information and education to patients and citizens. Almost all also report to offer care and support that focus on quality of life and survivorship, such as psychological counselling and social care.

Considerations

It is important to note that the majority of the results presented in this report rely on information collected by a survey. We distributed the survey questionnaire through various channels (Mission on Cancer Board and Assembly, iPAAC/CanCon partners, OECI and their contacts in countries) and send reminders, to get as many responses as possible. Nevertheless, the reported CIs should certainly not be considered all CIs that exist in a country and combine clinical treatment with scientific research.

Furthermore, it should be noted that the information received through the survey was reported by contact persons of the CIs or persons who were - more or less - familiar with these CIs. Given the limited time available for this quick scan, the survey information was not verified with other sources.

Conclusions

Equitable access to high-quality treatment and care, based on the most recent and advanced insights from scientific knowledge, for each cancer patient in the EU can be facilitated by a strong network of

collaborating CCIs within and across EU Member States. Although the number of internationally recognised, accredited CCIs is currently limited, CIs that combine clinical treatment with scientific research were identified in almost all EU Member States. Nevertheless, access to clinical trials for patients is not equally spread across the EU. Follow-up efforts in Member States and at EU level are needed to explore whether and how these CIs could become part of an EU-wide network of collaborating CCIs that would make high-quality cancer treatment, care and education accessible to all patients and citizens in the EU.

Appendix I: Recommendation as formulated in the Mission Outline

Recommendation 10: Set up a network of Comprehensive Cancer Infrastructures within and across all EU Member States to increase quality of research and care

The current situation in the EU is characterised by substantial differences in the standards of care, research and education between Member States, and even within a country: patients receiving care from hospitals in more remote areas often do not have access to interventions that are offered only in the context of clinical studies. Uniform quality criteria set by accreditation standards are expected to decrease current inequities.

To ensure that each EU citizen or cancer patient has access to and could benefit from high-quality cancer research and care, it is proposed to support establishing a strong network of Comprehensive Cancer Infrastructures¹⁰ (CCIs) within and across EU Member States. EU citizens or cancer patients should have access to an accredited CCI in their own country (at least one CCI in each Member State), albeit through a national access point to an accredited CCI in another country, if relevant. The network will contribute to sharing experiences and harmonising standards of care and research implementation. Each CCI should take into account the structure, governance, and geographical context – drawing, when possible, on EU-accredited care, teaching and research standards; liaise with the (EU-wide, national or regional) cancer and screening registries and with the European Reference Networks dealing with cancer (EURACAN¹¹, EuroBloodNet¹², Genturis¹³ and PaedCan¹⁴); and integrate data collection to allow quality assurance and data consolidation. CCIs are expected to liaise also with biobanking facilities, and to build strong partnerships with research institutes and universities, as well as with an extensive international network. Newly established infrastructures should preferably align with existing initiatives within countries to ensure sustainability. Twinning arrangements with existing CCIs could facilitate the establishment and performance of new CCIs.

¹⁰ National or regional infrastructures that provide resources and services to support, improve and integrate cancer care, research, training of care professionals and education for cancer patients, survivors and families/carers. Different formats of Comprehensive Cancer Infrastructures are possible, including existing Comprehensive Cancer Centres or Care Networks. (this outline)

¹¹ European Reference Network Rare Adult Solid Cancers (<https://euracan.ern-net.eu/nl/start/>)

¹² European Reference Network Hematological Diseases (<https://www.eurobloodnet.eu/>)

¹³ European Reference Network on Genetic Tumour Risk Syndromes (<https://genturis.eu/l=eng/Home.html>)

¹⁴ European Reference Network for Paediatric Oncology (<https://paedcan.ern-net.eu/>)