



# european pancreatic cancer index

Health Consumer Powerhouse

# Euro Pancreatic Cancer Index 2014

Report

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# A silent killer, which should be brought into the light

Pancreatic cancer is a nasty disease – in every way. It is hard to detect. And if not detected early, the chances of survival diminishes further. They are already low; among the best performing countries in the 2014 Euro Pancreatic Cancer Index no more than around 6 out of 100 patients survive five years after diagnose. And as the forecast is this bad, it can be suspected that cancer care often surrenders early in the process. It looks like a mortal irony that the best developed part of pancreatic cancer care generally is palliative care. And without any doubt, offering as good as possible terminal care to the sufferers is essential.

Against this somber background, is there much to do? Yes, is the answer given by the EPCI!

It should be a fight along a few main directions:

**Raising awareness** – pancreatic cancer is labeled a "rare disease" because ~10 in 100 000 people get it. This may give the false impression that the consequences of the disease are minor. This is utterly false. Presently there are more than 100 000 Europeans diagnosed. Almost the same number die every year. This means that this "rare" illness if one of the most lethal cancers, every year killing roughly as many people as breast cancer. Pancreatic cancer is no "rare" killer, instead a major health threat, hitting – as it seems – at random. This makes awareness even more crucial.

Because what we know, and the EPCI shows, is that *early detection* is the maybe most critical component to improve survival. When the cancer is detected early, first line doctors can quickly send patients to a specialist who receives them without delay and starts the specialized treatment process. Then the poor survival rate could improve. That requires patients-to-be and GPs to be alert to signs of cancer and the whole treatment chain to be on top. Alarmingly, the Index reveals that in most countries there is no agreed best practice and the outcomes documentation is poor or even non-existent. It is a well-known fact that if data is not collected, monitored and published, health care organizations are kept in the dark. Such a state literally kills patients.

Most likely the lack of awareness affects *resources for research a*nd systems improvement. If the critical components just mentioned are dealt with, survival will improve. Mankind has experienced how stronger focus has contributed to advancement of research and treatment in breast and prostate cancers, a break-through regarded unlikely 20 years ago. It gives hope for progress also in pancreatic cancer. The EPCI provides a unique documentation of what should be done, and where.

The 2014 EPCI has received an unrestricted research grant from Celgene. Without that support, most of this information would not have been brought together and presented to lay-persons and experts.

Brussels March 18, 2014

Johan Hjertqvist Founder & President HCP Ltd.

# 1. Summary

The Euro Pancreatic Cancer Index 2014 is the first Index of its kind. It reflects pancreatic cancer healthcare provision in 30 countries (28 EU member states, Norway and Switzerland) and provides a quick orientation into the matter. The approach taken: how do countries take care of pancreatic cancer patients? What do pancreatic cancer patients receive in terms of healthcare provision? This Index provides an evaluation of the situation in 6 main sub-disciplines important for pancreatic cancer patients and also carers. It looks into Patient rights, information and accessibility issues for pancreatic cancer patients, Prevention, Outcomes, Diagnostics, Treatment and pharmaceuticals and Palliative care by benchmarking countries.

This Index provides 900 scores to 30 indicators x 30 countries. The sub-disciplines and indicators were carefully identified with the valuable expertise of pancreatic cancer specialists. Needless to say, more needs to be done in all areas and most countries can look up to the Netherlands (the winner of the EPCI 2014), closely followed by Denmark, France, Ireland and the UK. The most critical observation is the Outcomes sub-discipline where much of the information hardly exists in the public domain.

On the basis of the information obtained, pancreatic cancer is the only major cancer where survival rates are not improving and action needs to reverse this trend. Improvement will not happen spontaneously, but it can happen. Twenty years ago, most believed HIV/AIDS would remain a death sentence. This Index shows that governments need to invest to make a difference in data collection and provide information to the public and even more so, support patients with pancreatic cancer and improve integrated care and ensure a speedy pathway of treatment: from diagnosis to treatment to outcomes. There may be a need to establish centres of excellence given the incidence rate and combine efforts throughout the EU, Norway and Switzerland for an improved and earlier detection of diagnosis and treatment. Pancreatic cancer patients should not be immediately considered as palliative patients. Speed of care is vital for survival!

### 1.1 Main conclusions:

- Pancreatic cancer, although being fairly rare, has today overtaken stomach cancer to become the fourth largest cancer cause of death in the EU, with currently close to 100 000 deaths per year.
- The low survival rate seems to have created a sense of hopelessness, even among medical professionals. The way forward must be to build on the relative differences of >100 % in national survival rates (from less than 3 % to 7 8 %).
- Pancreatic cancer patients are in a particularly vulnerable situation, as the nature of the disease makes it very difficult to form patient organisations/support groups, particularly in countries with less than ~40 million people (= all of the 30 countries except 6).
- It would seem that the low survival rates of pancreatic cancer largely due to late diagnosis of the disease have de-motivated registry holders from monitoring progress of pancreatic cancer care.
- There might be a risk for complacency as a result of palliative care being well established, thus blurring the focus on curative treatment.

# 1.2 What to do

- Early detection: educate primary care physicians to recognize and act on the *combination* of vague symptoms of Pancreatic Cancer.
- Because of the relative rarity of pancreatic cancer, surgery for the disease should be concentrated to specialist centres, information about and *rapid* access to such centres should be a high priority.
- Collect and report pancreatic cancer data to national cancer registries and make this information layman-friendly and readily available.
- Better manage survival rates by taking actions in narrowing the gaps in pancreatic cancer care provision.
- Measure pancreatic care provision in the same way as any other more common cancer.
- Encourage governments to invest in pancreatic cancer research especially in the field of early diagnostics.
- Improve integrated care for pancreatic cancer patients by ensuring rapid referral for specialist treatment as speed is vital for survival.

# 2. Some interesting facts

### 2.1 Pancreatic cancer incidence and survival

One main problem with pancreatic cancer is that the disease has weak and vague symptoms in its early stages. For this reason, it is often detected late, when the cancer has frequently spread to other parts of the body.

The most recent "official" 5-year survival data, which is still widely quoted, is from EUROCARE<sup>1</sup>4, and shows 5-year survival for patients diagnosed between 1995 and 1999. Even if treatment results for pancreatic cancer have improved to a lesser degree over the last 15 years than for many other cancer forms, this is clearly unsatisfactory.

Ferlay *et al.* (2013) of the WHO International Agency for Research on Cancer (IARC) have tried to remedy this by publishing, bi-annually since 2006, carefully scrutinized incidence and survival data for many cancer forms at country level for essentially all European countries.

Such data is found on IARC's website<sup>2</sup> and is illustrated in the figure below. An intriguing feature of that graph is that several countries show a higher rate of mortality from pancreatic cancer than the rate of incidence. This is not an effect of random variation in a single year – the effect remains for many countries also if data is added up for 5 - 7 years.

There are at least two plausible explanations for this discrepancy:

- a) Inadequate diagnostics, and/or
- b) Cancer first detected after spreading to other organs, but then found (in autopsy?) to have originated in the pancreas.

The composition of the group of countries showing higher mortality than incidence is quite original, and consists of countries rarely found clustered on any healthcare quality parameter (see the Euro Health Consumer Index 2006-2013<sup>3</sup>, hereafter referred to as EHCI). It is highly likely that the main explanation behind higher mortality than incidence for the Netherlands, Belgium and Sweden is different from the explanation for Montenegro, Russia, Albania and Bosnia & Herzegovina.

For this reason, it has proved impossible to give a high weight to the key indicator "5-year survival for pancreatic cancer", as would have been the basic approach in a HCP Index.

<sup>&</sup>lt;sup>1</sup><u>www.eurocare.it</u>

<sup>&</sup>lt;sup>2</sup><u>http://eco.iarc.fr/eucan/Cancer.aspx?Cancer=15</u> <sup>3</sup><u>www.healthpowerhouse.com</u>



Figure 1: Pancreatic cancer incidence and mortality in European countries (source: IARC<sup>4</sup>)

<sup>&</sup>lt;sup>4</sup><u>http://eco.iarc.fr/eucan/Cancer.aspx?Cancer=15</u>



### 2.2 A possible proxy for pancreatic cancer incidence?

According to the EUCAN data, the incidence rates of pancreatic cancer in all European countries fall in the range  $10\pm4$  per 100 000 population. Considering the uncertainties in these numbers, which is illustrated by the graph above, it could be of interest to match the incidence data with the main known risk factor, tobacco smoking.

In the graph below, the blue bars denote the EUCAN 2012 reported incidence. The red bars have been calculated as 10/100 000 multiplied by "cigarette consumption *per capita*"<sup>5</sup>, indexed so that the EU *per capita* consumption was set to 1.00.



**Figure 2:** Pancreatic cancer incidence (per 100 000) (source: EUCAN, cigarette consumption from CECCM (cigarettes sold per capita, corrected for Roll-Your-Own and non-duty paid).

Perhaps the most remarkable feature of Figure 2 above is the low reported pancreatic cancer incidence of high smoking rate countries such as Greece, Bulgaria and Cyprus. If the hypothesis of tobacco smoking being a main risk factor is considered true, the figure more or less proves that there are serious weaknesses in the reported incidence.

<sup>&</sup>lt;sup>5</sup>Data from the tobacco industry association, CECCM, adjusted for Roll-Your-Own, duty-free and illicit sales. These numbers have a significantly higher accuracy than numbers based on surveys on "people regarding themselves as daily smokers", where numbers vary greatly between studies and also with calendar time due to the "New Year's Resolution" effect.

# 3. Some interesting facts and countries

Two countries excel in the EPCI 2014 – The Netherlands and Denmark.

The Netherlands is the only country which has consistently been among the top three in the total ranking of any EHCI edition that the HCP has published since 2005; and is oftentimes followed by Denmark. The Dutch healthcare system does not seem to have any really weak spots in the other sub-disciplines, except possibly some scope for improvement regarding the waiting times situation, where some central European states excel.

With regards to the ranking of the Netherlands: it tops all HCP Indexes and creates a strong temptation to claim that the Dutch maintain "the best healthcare system in Europe". There should be a lot to learn from looking deeply into the Dutch progress! Similarly could be claimed about pancreatic cancer healthcare provision.

In southern Europe, Italy (10<sup>th</sup>) and Spain (13<sup>th</sup>) provide healthcare services where medical excellence can be found in many places. Real excellence in southern European healthcare seems to be a bit too much dependent on the consumers' ability to afford private healthcare as a supplement to public healthcare. Also, both Spain and Italy show large regional variation, which tends to result in a lot of Amber scores for the countries.

# 3.1 Some facts on (pancreatic) cancer:

- According to Malvezzi *et al.* (2013) cancer mortality confirms a favourable trend in overall cancer mortality in the EU, as wells as in several major cancer sites, with the notable exceptions of pancreatic cancer in both sexes, and lung cancer in women.
- The 2013 predicted number of cancer deaths in the EU was 1.314.296 (Malvezzi *et al.*, 2013). Malvezzi *et al.* (2013) predicted that all cancers would fall by 6% in men and by 4% in women --- but exception with pancreatic cancer. Pancreatic cancer also had unfavourable mortality rates (8/100 000 men and 5.5/100 000 women) for 2013; these are higher than those of 2009 (7.9/100 000 men and 5.3/100 000 women) even though by a very small margin (Malvezzi *et al.*, 2013).
- According to Bosetti *et al.*, 2012, cigarette smoking, the best recognized risk factor, cannot account for recent trends in men, given that lung cancer was declining. It seems that increases in obesity prevalence may play a role in the recent trends.
- The pancreas is presently the fourth cancer mortality site in the EU for both sexes, having recently overtaken stomach cancer rates and uterine cancer rates (Ferlay *et al.*, 2013<sup>6</sup>).
- According to Ferlay *et al.* (2013) there was an estimated 3.45 million new cases of cancer and 1.75 million deaths from cancer in Europe in 2012.
- The important role of cancer registries and disease surveillance and in planning and evaluating national cancer plans is becoming increasingly recognized, but needs to be further advocated (Ferlay *et al.*, 2013).
- According to Boyle *et al.* (2013), "not only have the incidence and the mortality both increased, but with more and more patients alive within five years of diagnosis, the prevalence has been growing at an even quicker rate." This is of substantial importance

<sup>&</sup>lt;sup>6</sup> http://www.iarc.fr/en/media-centre/iarcnews/pdf/Ferlay%20J\_EJC\_2013.pdf



for health service provision and its costs, since the five-year period after diagnosis is the time when many cancer patients are receiving active treatment and intense follow-up."

- In 1943, Nathanson reviewed published rates about the curability and survival from cancer. Much he wrote is applicable today: cancer frequently considered a death sentence by the general population, despair at the late presentation of disease, optimism of the oncological community and hope for the development for future therapies. The reported five-year curability rates in common types of malignant neoplasms do not include cancer of the pancreas (Boyle *et al.*, 2013).
- Throughout the second half of the 20<sup>th</sup> century until modern times, there has been a remarkable improvement in many aspects of oncology from understanding the causes, both lifestyle and biological, and enormous progress in developing more effective treatment for many forms of cancer (Boyle *et al.*, 2013). However these improvements have not been available for all patients with cancer.
- For pancreatic cancer it is essential to alter the balance of palliation over cure that exists at present. It seems that with a lack of cure and proper diagnosis, palliation is the only treatment available.
- Cancer costs the European Union EUR 126 billion annually, with cancer care costs accounting for EUR 51 billion (40%) (Boyle *et al.*, 2013). The papers by Boyle *et al.* (2013) and Luengo-Fernandez *et al.* (2014) point out that lung cancer accounted for 15% (EUR 19 million) of overall cancer costs, followed by breast cancer (12%, EUR 15 billion), colorectal cancer (10%, EUR 13 million) and prostate cancer (7%, EUR 8 billion). There is no mention of pancreatic cancer, as the reason may lie in the fact that no one is keeping track on the European level of the costs incurred.
- As Boyle *et al.* (2013) put it, allow the development of a new paradigm of cancer management consistent with 21<sup>st</sup> century demands; aim to gain better understanding of cancers benchmarked internationally which will further improve clinical outcomes.
- Boyle *et al.* (2013) state that "steps must be taken to prevent those cancers which have been determined to be preventable and prevention should be considered as a single, unified action" The authors claim that "silo mentality of cancer prevention, diabetes prevention, and CVD prevention is an old and failed model."
- •

# 4. Background

The Health Consumer Powerhouse (HCP) has become a centre for visions and action promoting consumer-related healthcare in Europe. "Tomorrow's health consumer will not accept any traditional borders" was declared in the 2012 EHCI Report, and this is already becoming a reality today.

As stated by the European Commission (2014) "meeting patients' expectations of the highest quality healthcare, which are even higher when they seek treatment away from home" (European Commission<sup>7</sup>, 2014).

The Directive 2011/24/EU on patients' rights in cross-border healthcare clarifies the rules on access to healthcare in another EU country. All EU countries passed their own laws implementing the Directive on 25 October 2013.

<sup>&</sup>lt;sup>7</sup> <u>http://ec.europa.eu/health/cross\_border\_care/policy/index\_en.htm</u>

In order to become a powerful actor and empowered participant, building the necessary reform pressure from below, the consumer needs access to knowledge to compare health policies, consumer services and quality outcomes.

The Euro Indexes are efforts to provide healthcare consumers with such tools and so is the first ever Euro Pancreatic Cancer Index 2014 (hereafter, EPCI 2014). There are no studies or initiatives that generate comparative analyses of pancreatic cancer care provision within European countries or contexts as to what to compare. The EPCI 2014 is the first such initiative.

The HCP team worked in collaboration with a number of international experts who formed the so-called Expert panel (more under Section10).

The aim of the EPCI 2014 is to provide an overview on the state of pancreatic cancer care provision, as reliably as possible and comprehensive analyses of the development of pancreatic cancer care in each EU country, Norway and Switzerland.

This overview of pancreatic cancer care provision provides governments and policy-makers with the means to promote pancreatic cancer care. This will, in turn, have a positive impact upon providers of pancreatic cancer services in a practical and direct way and especially on the user/the patient and his/her carers. The EPCI 2014 can be considered as a tool to help improve the practice and future service design for pancreatic cancer.

The EPCI 2014 has four objectives:

- 1. To provide an overview of the development of pancreatic cancer care in the EU, Norway and Switzerland in a manner that is relevant to the user/patient, to the providers themselves and to national governments
- 2. To explore the current organisation of pancreatic cancer care and issues related to the availability of information in the EU, Norway and Switzerland
- 3. To facilitate access to information and communication to the user/patient
- 4. To aid the identification of the needed key information to be set in the public domain for pancreatic cancer patients, their carers and authorities, forming a potential best practice for pancreatic care in Europe.

# 5. Results: the EPCI 2014 Matrix

# **Euro Pancreatic Cancer Index 2014**

Sub-		ъ	φ.	p	0	0	R	De	ш	п	-	Ge	0	Ŧ	_	
discipline	Indicator	lustri	elgiur	ılgari	roati	ypru	Czecl	nmar	stoni	inlan	ranc	rman	Greec	Ingan	relan	Ital
	1.1 Oncology facilities p.m.p.	<u> </u>	3	a P	a	s P	ر ، ا	× P	a P	<b>₽</b>	• ()	× @P	°	A A	<u>م</u>	V
	1.2 Clinical guidelines	\$	\$	<b>(</b> ]	\$	\$	æ	ß	\$	\$	\$	\$	ϡ	\$	\$	\$
	1.3 Pancreatic cancer society	( <sup>¶</sup> )	æ	v (†	æ	( <sup>†</sup> )	æ	\$	æ	æ	\$	\$	\$	\$	\$	\$
	1.4 Direct cancer research spending	v P	æ	ر ا	n.a.	, (†	æ	P	<b>(</b> ]	æ	\$	\$	<b>(</b> ]	æ	æ	\$
	1.5 Pancreatic cancer registry	\$	\$	\$	\$	\$	\$	\$	A	s	P	æ	\$	\$	\$	æ
1. Patient rights	1.6 Pancreatic cancer patient org:s	9	9	9	9	9	9	9	9	Ŧ	Ð	s	9	æ	æ	9
and information, accessibility	1.7 Multidisciplinary teams	æ	<pre></pre>	9	æ	æ	æ	\$	P	S	S	æ	æ	Ŧ	S	æ
	1.8 Specialist dieticians p.m.p.	æ	n.a.	n.a.	n.a.	æ	n.a.	S	n.a.	<b>(</b> ]	æ	S	P	Ŧ	n.a.	9
	1.9 Waiting time for CT or MRI exam	æ	\$	9	9	9	æ	P	9	æ	S	æ	P	<b>(</b> ]	<b>(</b> ]	<b></b>
	1.10 # of certified HPB surgeons p.m.p.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
	1.11 Waiting time for treatment		ß	P	œ	Ð	9	\$	œ	<b>P</b>	\$	<b>₽</b>	9	9	9	œ
	Subdiscipline weighted score	209	209	136	182	182	182	236	173	218	245	245	182	209	209	200
	2.1 Smoking per capita	P	œ	9	n.a.	œ	P	œ	P	\$	\$	\$	9	9	P	<b>B</b>
	2.2 Alcohol intake	9	æ	æ	æ	\$	9	Ŧ	9	æ	9	æ	\$	æ	æ	\$
2. Prevention	2.3 BMI	\$	ß	P	Ŧ	9	9	Ŧ	\$	ß	\$	P	\$	9	9	\$
	2.4 Screening of high-risk groups	n.a.	s	<b>P</b>	n.a.	æ	<b>₽</b>	s	n.a.	n.a.	Ð	s	Ŧ	P	\$	Ð
	Subdiscipline weighted score	88	125	88	75	100	88	113	88	113	125	125	113	75	100	125
	3.1 5-year survival rate	S	S	n.a.	n.a.	n.a.	n.a.	S	P	P	P	S	n.a.	n.a.	S	\$
	3.2 Median survival - curative	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	S	n.a.	n.a.	Ð	n.a.	n.a.	n.a.	P	n.a.
	3.3 Inhospital mortality after surgery	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	S	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	æ	n.a.
3. Outcomes	3.4 Survival - palliative chemotherapy	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	\$	n.a.	n.a.	Ð	n.a.	n.a.	n.a.	s	n.a.
	3.5 Median survival - supportive care	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	\$	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	\$	n.a.
	Subdiscipline weighted score	93	93	67	67	67	67	200	80	80	133	93	67	67	173	93
	4.1 Endosonography (+/- FNA)	\$	\$	æ	ß		\$	\$			₽	æ	s	æ		\$
4. Diagnostics	4.2 Diagnostic laparoscopy	æ	æ	æ	Ŧ	\$	æ	ß	Ŧ	Ŧ	₽	P	Ŧ	P		\$
Diugnoolieo	Subdiscipline weighted score	104	104	83	104	125	104	125	104	104	125	83	104	83	125	125
	5.1 Evidence-based chemotherapy	Ð	Ð	n.a.	<b>P</b>	Ð	Ð	S	Ð	Ð	Ð	Ð	Ð	Ð	Ð	
	5.2 % of intended curative surgery	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	S	Ŧ	n.a.	Ð	n.a.	n.a.	n.a.	Ð	n.a.
5. Treatment / Pharmaceuticals	5.3 Monoclonal antibodies	S	S	9	9	æ	Ŧ	P	9	Ð	Ð	Ð	9	9	S	P
	5.4 Adjuvant chemotherapy	Ð	Ð	Ð	S	Ð	Ð	S	Ð	Ð	Ð	Ð	Ð	S	Ð	S
	Subdiscipline weighted score	104	104	63	73	94	94	115	94	104	125	104	83	83	125	94
	6.1 Palliative care beds p.m.p.	9	Ð	9	9	9	¢	Ŧ	9	9	<b>6</b>	Ð	9	9	9	S
	6.2 Availability of homecare delivery	Ţ	æ	Ţ	9	æ	Ţ	\$	P		9	P	9	P	Ŧ	œ
6. Paillative	6.3 Palliative care pathways	₽		P	9	9	P	\$	9	P	♪	P	9	9		9
cure	6.4 Access to palliative care	P	ß	9	9	9	9	æ	P	9	9	9	9	œ	₽	9
	Subdiscipline weighted score	58	83	33	33	42	42	83	50	58	58	67	33	50	75	58
	Total score	657	719	470	534	609	576	872	588	677	812	718	582	567	807	695
	Rank	14	8	30	28	20	23	2	21	12	3	9	22	26	4	10

Figure 3a: The EPCI 2014 matrix.

# **Euro Pancreatic Cancer Index 2014**

		1		_												
			5	Luxe		Neth				স	6	~			Swit	x
Sub-	lu dia sés a	Lat	ithua	mbou	M	erlar	Norw	Pola	ortu	loma	Slova	Slove	sp	Swec	zerla	Unit
aiscipline	11 Oncology facilities p.m.p.	via	nia	gır	alta	spi	/ay	ind	gal	nia	kia	nia	ain	len	bu	ted om
	1.1 Oncology lacinies p.m.p.	<b>P</b>	GP		CP ·		GP I		œ	CP-	<b>P</b>	<b>\$</b>	GP		<b>P</b>	9
		A	P	P	Ð	Ð	A		Ð	Ð	Ð	Ð	Ð	Ð	Ð	Solution
	1.3 Pancreatic cancer society	<b>B</b>	æ	n.ap.	n.ap.	Ð	æ	Ð	9	Ð	9	9	P	<b>P</b>	9	Ð
	1.4 Direct cancer research spending	9	Ţ	9	9	s	P	Ŧ	P	9	P	P	Ŧ	Ð	n.a.	Ð
	1.5 Pancreatic cancer registry	Ð	Ð	\$	Ð	\$	Ð	Ŧ	Ð	Ē	Ð	Ð	æ	Ð	P	P
1. Patient rights	1.6 Pancreatic cancer patient org:s	Ð	9	n.ap.	n.ap.	Ð	9	9	P	9	P	P	P	9	9	s
accessibility	1.7 Multidisciplinary teams	P	æ		\$	æ	æ	æ	æ	P	æ	P	Ŧ	æ	Ð	<b>₽</b>
	1.8 Specialist dieticians p.m.p.	P	9	Ŧ	n.a.	\$	\$	n.a.	n.a.	n.a.	n.a.	5	9	Ŧ	<b>P</b>	P
	1.9 Waiting time for CT or MRI exam	9	9	æ	9	æ	9	9			æ	1	<b>(P</b>	<b>P</b>	Ð	æ
	1.10 # of certified HPB surgeons p.m.p.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
	1.11 Waiting time for treatment	<b>(</b> ])	æ	ß	\$	ß	<b>(</b> ]	(1)	æ	<b>(</b> ]	\$	<b>(</b> ]	æ	(1)	A	P
		N 400	-				N	100	400	V			400			
	2.1 Smoking per capita	182	164	218	200	264	191	182	182	164	200	164	182	200	200	227
	2.2 Alcohol intake	V A	<b>1</b>	V A	A A	A A	A A	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~	- 	<b>1</b>		- 	~~	A	- 	ها مح
2. Prevention	2.3 BMI	۲°	7	7	<b>1</b>	<u>ر</u> ه ۲	<u>ر</u> ها ا	4	Se	ک <sup>ر</sup> ۱	<b>A</b>	<b>B</b>	SE	1 1 1 1	49 (	4
	2.4 Screening of high-risk groups		5	5	5			5			1	5	5	<u>م</u>	<b>()</b> )	5
		<b>(</b> )	n.a.	n.a.	n.a.	CPP	(P	n.a.	n.a.	n.a.	n.a.	(P	<u>و</u>	<b>(</b> )	n.a.	(
	Subdiscipline weighted score	88	63	50	100	138	138	75	88	88	75	88	100	150	100	113
	3.1 5-year survival rate	Ð	æ	n.a.	n.a.	Ð	Ð	Ð	n.a.	n.a.	Ð	Ð	Ð	Ð	æ	æ
	3.2 Median survival - curative	n.a.	n.a.	n.a.	n.a.	Ð	n.a.	n.a.	n.a.	n.a.	Ð	n.a.	n.a.	n.a.	n.a.	Ð
3 Outcomes	3.3 Inhospital mortality after surgery	P	æ	n.a.	n.a.	æ	n.a.	n.a.	n.a.	n.a.	Ð	n.a.	n.a.	n.a.	n.a.	n.a.
5. Outcomes	3.4 Survival - palliative chemotherapy	n.a.	n.a.	n.a.	n.a.	Ð	n.a.	n.a.	n.a.	n.a.	Ð	n.a.	n.a.	n.a.	n.a.	
	3.5 Median survival - supportive care	n.a.	n.a.	n.a.	n.a.	s	n.a.	n.a.	n.a.	n.a.	Ð	n.a.	n.a.	n.a.	n.a.	<b>₽</b>
	Subdiscipline weighted score	107	93	67	67	187	93	93	67	67	200	93	93	93	80	160
	4.1 Endosonography (+/- FNA)	s	s	S	n.a.	S	s	S	S	S	S	S	S	S	S	
4. Diagnostics	4.2 Diagnostic laparoscopy	æ	æ	\$	n.a.	æ	\$		æ		æ	æ	\$	æ	æ	æ
Diagnostics	Subdiscipline weighted score	104	104	125	42	104	125	125	104	125	104	104	125	104	104	104
	5.1 Evidence-based chemotherapy	GP-		\$	n.a.			\$		\$			\$			\$
	5.2 % of intended curative surgery	A	n.a.	n.a.	n.a.	\$	n.a.	n.a.	n.a.	n.a.	æ	\$	n.a.	n.a.	n.a.	\$
5. Treatment /	5.3 Monoclonal antibodies	(B)	(1)	A	n.a.	(1)	æ		æ	(1)	æ	æ	æ	æ	2	(1)
Pharmaceuticals	5.4 Adjuvant chemotherapy	۷ م	۷ چ	\$ {}	na	N A	<del>م</del>	N A	<mark>ک</mark>	N N	<mark>م</mark>	<mark>م</mark>	<mark>م</mark>	<mark>ک</mark>	A.	<u>م</u>
		871		8.J	π.α.			<b>3</b> -1				<b>B</b> 7		<b>1</b>	<b>a</b> 7	<b>1</b>
	Subdiscipline weighted score 6.1 Palliative care beds p.m.p.	94	83	104	42	104	94	83	94	83	104	115	94	94	104	104
	6 2 Availability of homecare delivery	5	7	8	5		1	(1)	۶°		\? \	\} \	<u>م</u> ک ۲		5	(1)
6. Palliative	6.3 Palliative care pathwave	¢P	CP A	P		CP A	P	æ	8	5	<u>ل</u>				S.	GP A
care	6.4 Assess to polliptive care	<b>P</b>		œ			9	9	ϡ	P	9	Ð		<b>P</b>	9	
	0.4 Access to pamative care	9	9	A	P		P	P	9	9	9	P	P		9	A
	Subdiscipline weighted score	50	58	67	75	83	50	67	42	50	50	75	83	83	33	92
	Total score	624	565	631	525	879	690	625	576	576	733	638	677	725	622	800
	Rank	18	27	16	29	1	11	17	23	23	6	15	12	7	19	5

Figure 3b: The EPCI 2014 matrix (continued).

# 5.1 Summary of results of the EPCI 2014

Normally, the HCP takes care to state that the Euro Health Consumer Index (EHCI) is limited to measuring "consumer friendliness" of healthcare systems, *i.e.* does not claim to measure which European state has the *best* healthcare system across the board.

The scoring for EPCI and every other HCP Index has intentionally been done in such a way that the likelihood that two states should end up sharing a position in the ranking is almost zero. It must be noted that great efforts should not be spent on in-depth analysis of why one country is in the 13<sup>th</sup> place, and another in 16<sup>th</sup>. Very subtle changes in single scores can modify the internal order of countries, particularly in the middle of the ranking list. It is worth noting also the fact that many countries did not have available data which, as already mentioned earlier, does not necessarily mean that the quality of care is inferior. It only means that data for some of the sought after indicators is not collected or presented in the public domain. Data and information had to be compiled from several disparate sources for several indicators where CUTS<sup>8</sup> could not be identified.

The EPCI 2014 total ranking of pancreatic cancer healthcare provision, as indicated in Figure 4, shows a narrow victory for The Netherlands, scoring 879 points out of 1000, 7 points ahead of runner-up Denmark at 872 points.

Availability of Outcomes (survival) data became very decisive for the ranking in the EPCI. Only 6 out of the 30 countries could report data on at least 3 of the 5 Outcomes indicators, which greatly affected the total scores, with these 6 countries all doing well.

After the top two countries excelling in pancreatic cancer provision, there is a 60-point gap down to two countries: France taking the 3<sup>rd</sup> position (with 812 points) followed by Ireland (4<sup>th</sup>) with 807 points; these countries are then followed by the next larger gap of more than 70 points, where the UK settles in 5<sup>th</sup> position with 800 points. After the UK, the scores fall more all less at an even rate with Bulgaria (with 470 points) ranking last.

<sup>&</sup>lt;sup>8</sup> CUTS are explained under Section 8.



Figure 4: Total scores in the EPCI 2013

Some eastern European EU member systems are doing surprisingly well in the EPCI, particularly Slovakia and Slovenia, considering their much smaller healthcare spend in Purchasing Power adjusted dollars per capita. However, readjusting from politically planned to consumer-driven economies does take time.

Just as noted in the EHCI's over the years, European healthcare continues to improve but medical outcomes statistics is still appallingly poor in many countries although one can note improvements in healthcare provision and available information for the user/consumer.

With the cross-border directive and especially if the administrative barriers are lowered, it can be speculated that pancreatic cancer patients will be inclined to move for healthcare provision to those countries where there are centres of excellence or where information on the healthcare provision for pancreatic patients proves more transparent.

If healthcare officials and politicians took to looking across borders, and to "stealing" improvement ideas from their European colleagues, there would be a good chance for a national system to come much closer to the theoretical top score of 1000. As a prominent example; if Sweden could achieve a Belgian waiting list situation, that alone would suffice to lift Sweden to compete with The Netherlands at ~880 points!

In all, the first sub-discipline "Patient rights, information and accessibility" on pancreatic cancer care the scores indicate that it is possible to obtain information and access to healthcare providers. This sub-discipline is the largest containing 11 indicators to stress how important it is for a patient with pancreatic cancer to be able to access and get the needed healthcare provision, and also how well the healthcare system functions towards providing proper care for patients affected with pancreatic cancer (*e.g.* Are there pancreatic cancer guidelines in place? What is the number of HPB surgeons (meaning what)? What is the access time between the decisions to treat to the actual treatment? and so on) to give an estimate of how good is the entry stage to healthcare delivery is for pancreatic cancer patients.

The highest score on sub-discipline 1 was achieved by the Netherlands; followed by France, Germany, and Denmark, meaning the coverage of oncology facilities with radiation and medical treatment p.m.p. is high enough to provide cancer care; also it seems there is good understanding or use of clinical guidelines for pancreatic cancer (could be nationally developed or ESMO<sup>9</sup> guidelines); there are professional societies to review the development of pancreatic cancer care provision. Pancreatic cancer is registered in most cancer registries but, as described below, (sub-discipline: Outcomes) not all cancer registries provide the crucial information for pancreatic cancer patients.

It was rather difficult to find the exact amount of money spent for pancreatic cancer research. What can be readily found are overall figures of cancer research spending for 2006, more recent data is not readily and publicly available. Access to information in this domain can in many ways reflect the importance that is dedicated to a certain cancer field. Outdated and sparse data reveal that this cancer is given low priority. Pancreatic cancer patients seem to be left to deal with the disease on their own as there are few pancreatic cancer patient organisations which in turn mean that the voice of pancreatic cancer patients is not heard well enough.

According to the EPCI 2014 Expert panel multi-disciplinary teams (MTD) should include specialist nurses. With their holistic approach towards the patient, these specialized nurses are important contributors to the care of pancreatic cancer patients and are most often easily accessed by patients. Waiting times are important indicators, reflecting the organization and management of pancreatic cancer patients. The most obvious deficiency in terms of access is the availability of the number of HPB<sup>10</sup> surgeons. Pancreatic cancer patients want to know what surgeon they can approach and how fast, and be assured these surgeons have specialist training in pancreatic cancer surgery.

In all and for most countries there seems to be enough foundations for improved pancreatic cancer care.

In terms of "Prevention": nations that smoke and drink less than the average (or very little), with low BMI, and carrying out pancreatic cancer screening of high-risk groups, such as Sweden, Norway, the Netherlands, followed by Belgium, France, Germany and Italy (all scoring Green), seem more likely to have better outcomes. But it is too early to come to any conclusions as a lot of data is not publicly available. Also, it is difficult to draw any conclusion at this stage with regards to the relation between prevention and pancreatic cancer outcomes.

As for "Outcomes", the EPCI reveals a disappointing "black hole": most registries that follow pancreatic cancer in the 30 countries were unable to provide any data! Those who could did so on basis of HCP's request, a process that in some cases took over 3 months. Some information –

<sup>&</sup>lt;sup>9</sup>European Society for Medical Oncology, <u>www.esmo.org</u>

<sup>&</sup>lt;sup>10</sup>HPB stands for hepato-pancreato-biliary



such as 5-year survival rate– was possible to retrieve from Cancer Registry Reports. This astonishing lack of readily available information in the public domain is a sign that very little attention has been paid to pancreatic cancer over the last decade. More efforts on behalf of the providers and policy-makers should be invested in pancreatic cancer as median survival rates, be it curative, palliative chemotherapy or best supportive care, all are crucial pieces of information for pancreatic cancer patients.

Whether EU member states, Norway and Switzerland at the end the end of the day decide to pull efforts together and establish centres of excellence for pancreatic cancer is hard to say at this stage. Such measures are probably necessary to address the abovementioned shortcomings.

In terms of "Diagnostics" it seems most countries are well covered and do carry out the necessary diagnostics procedures. The only question that could not be encompassed by this project is the geographic distribution of these diagnostics procedures.

The results of the "Treatment/pharmaceutical" sub-discipline are more colourful. There is a general lack of information *re.* the percentage of intended curative surgery – another indicator that would normally be collected by the cancer registry and should by all means be publicly available. Otherwise, evidence-based chemotherapy is available in almost all the countries, same goes with adjuvant chemotherapy – meaning that there are good grounds to provide pancreatic cancer care in most countries.

The scores in the sub-discipline "Palliative care" are readily available in most countries and with good coverage – does this mean that many pancreatic cancer patients are doomed to palliative care only?

## 5.2 Results in the EPCI 2014 hexathlon

The EPCI 2014 is made up of six sub-disciplines. As no country excels across all aspects of measuring a healthcare system, it can therefore be of interest to study how the 30 countries rank in each of the six parts of the "hexathlon". The scores within each sub-discipline are summarized in Table 1 below.

As the table indicates, the total top position of the Dutch healthcare system is to a great extent a product of an even performance across the sub-disciplines, very good medical quality and top score on Patient rights, information and accessibility; taking up third positions in any of the other sub-disciplines. Similarly, the runner-up Denmark comes very close to the Netherlands with minimal differences across all the sub-disciplines. Denmark scores higher (all Greens) on the Outcomes sub-discipline (with a difference of 27 points between the two countries), but this is compensated by the Prevention sub-discipline where the Netherlands scores 138 points and Denmark 113 points. Denmark and the Netherlands come even on the Palliative care sub-discipline.

Sub-disciplines	Austria	Belgium	Bulgaria	Croatia	Cyprus	<b>Czech Republic</b>	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom
1. Patient rights, information and accessibility	209	209	136	182	182	182	236	173	218	245	245	182	209	209	200	182	164	218	200	264	191	182	182	164	200	164	182	200	200	227
2. Prevention	88	125	88	75	100	88	113	88	113	125	125	113	75	100	125	88	63	50	100	138	138	75	88	88	75	88	100	150	100	113
3. Outcomes	93	93	67	67	67	67	200	80	80	133	93	67	67	173	93	107	93	67	67	187	93	93	67	67	200	93	93	93	80	160
4. Diagnostics	104	104	83	104	125	104	125	104	104	125	83	104	83	125	125	104	104	125	42	104	125	125	104	125	104	104	125	104	104	104
5. Treatment /Pharmaceuticals	104	104	63	73	94	94	115	94	104	125	104	83	83	125	94	94	83	104	42	104	94	83	94	83	104	115	94	94	104	104
6. Palliative care	58	83	33	33	42	42	83	50	58	58	67	33	50	75	58	50	58	67	75	83	50	67	42	50	50	75	83	83	33	92
Total Score	657	719	470	534	609	576	872	588	677	812	718	582	567	807	695	624	565	<mark>631</mark>	525	879	690	625	576	576	733	638	677	725	622	800
Rank	14	8	30	28	20	23	2	21	12	3	9	22	26	4	10	18	27	16	29	1	11	17	23	23	6	15	12	7	19	5

 Table 1: The EPCI 2014 hexathlon

Sub-discipline	Top countries	Score	Maximum Score
1. Patient rights, information	Netherlands	264	
and accessibility	Germany, France	245	300
	Denmark	236	
2. Prevention	Sweden	150	150
	Netherlands, Norway	138	
3. Outcomes	Denmark, Slovakia	200	200
	Netherlands, Ireland	173	
4. Diagnostics	Cyprus, Denmark, France, Ireland, Italy, Luxembourg, Norway, Poland, Romania, Spain	125	125
5. Treatment /Pharmaceuticals	France, Ireland	125	125
	Denmark, Slovenia	115	
6. Palliative care	UK	92	100
	Belgium, Denmark, Netherlands, Spain, Sweden	83	

**Table 2:** Top scores in the 6 sub-disciplines.

As Table 1indicates, Denmark comes very close to the maximum scores in almost every subdiscipline, followed by the Netherlands. Denmark loses a few points in its total score to the Netherlands in the sub-discipline of Prevention. Also, as it can be depicted from Table 2, not only affluent countries come close to the maximum score but there are Cyprus, Poland and Romania paralleling with Denmark, France, Luxembourg, Norway and Spain in terms of diagnostics – attaining the maximum score for the sub-discipline of Diagnostics.

Sweden's score on prevention is the maximum possible number; Denmark and Slovakia's scores in the Outcomes sub-discipline match the maximum possible score; France and Ireland also reach the maximum score for the Treatment/Pharmaceuticals sub-discipline. Palliative care seems to be optimal in the UK, and is followed by Belgium, Denmark, Netherlands, Spain and Sweden where the tradition of palliative care and homecare has had a long-standing tradition.

# 6. Transparent monitoring of healthcare quality

Generally speaking, the need to monitor healthcare quality is becoming an everyday issue among citizens across Europe. In 2005, Dr. Foster<sup>11</sup> of the UK was the single shining star on the firmament of provider (hospital) listing, where patients could actually see which hospitals had good results in term of actual success rates or survival percentages.

In 2007, there were already a couple more examples, where the Health Consumer Powerhouse believes that the most notable is the Danish platform Sundhedskvalitet<sup>12</sup>, where hospitals are graded from  $\star$  to  $\star \star \star \star \star$  as if they were hotels, with service level indicators as well as actual results, including case fatality rates on certain diagnoses. Perhaps the most impressive part of this system is that it allows the public to click down to a link giving the direct-dial telephone number of clinic managers.

Germany did join the limited ranks of countries scoring Green by the power of the public institute BQS<sup>13</sup>, which also provides results quality information on a great number of German hospitals. Estonia, the Netherlands, Norway, Portugal and Slovakia have joined the ranks of countries providing this information to the public. From a broader perspective, there exist not-so-perfect, but already existing, catalogues with quality ranking in Cyprus, Hungary, FYR Macedonia, Italy (regional; Tuscany *et al.*) and Slovenia!

In France, the HCP team still has not found any other open benchmark than *Le Point* and *Figaro Magazine* annual publishing of "The best clinics of France". As French patient organisations were top of Europe at knowing about this service, France gets a Green score on the strength of this. Ministry sources of FYR Macedonia claim that they will shortly begin publishing lists of "the 100 best doctors". That will be most interesting to follow, not least from a methodology standpoint! Publishing results at individual physician level is also starting in the UK!

## 6.1 Background to the Euro Indexes

Since 2004 the HCP has been publishing a wide range of comparative publications on healthcare in various countries. Such first Index was the Swedish Health Consumer Index<sup>14</sup> in 2004 (also available in English): by ranking the 21 county councils by 12 basic indicators concerning the design of "systems policy", consumer choice, service level and access to information benchmarking was introduced as an element in consumer empowerment. In two years' time this initiative had inspired – or provoked – the Swedish Association of Local Authorities and Regions together with the National Board of Health and Welfare to start a similar ranking, making public comparisons an essential Swedish instrument for change.

For the pan-European indexes or the so-called Euro Indexes developed between 2005 and 2008, HCP aimed to follow the same approach as it did in Sweden, *i.e.* selecting a number of indicators describing to what extent the national healthcare systems are "user-friendly", thus providing a basis for comparing different national systems.

<sup>&</sup>lt;sup>11</sup><u>http://drfosterintelligence.co.uk/</u>

<sup>&</sup>lt;sup>12</sup>www.sundhedskvalitet.dk

<sup>&</sup>lt;sup>13</sup>www.bqs-institut.de

<sup>&</sup>lt;sup>14</sup><u>www.vardkonsumentindex.se</u>

Since 2008 the HCP has enlarged the existing benchmarking program considerably (all the noted Indexes are available on HCP's website):

- In January 2008, the Frontier Centre and HCP released the first **Euro-Canada Health Consumer Index**, which compared the health care systems in Canada and 29 European countries. The 2009 edition was released in May 2009.
- The **Euro Consumer Heart Index**, launched in July 2008, compares 29 European cardiovascular healthcare systems in five categories, covering 28 performance indicators.
- The first edition of **Canada Health Consumer Index** was released in September 2008 in co-operation with Frontier Centre for Public Policy, examining healthcare from the perspective of the consumer at the provincial level, and repeated 2009 and 2010.
- The **Euro Consumer Diabetes Index**, launched in September 2008, provides the first ranking of European diabetes healthcare services across five key areas: Information, Consumer Rights and Choice; Generosity, Prevention; Access to Procedures and Outcomes.
- Other Indexes published include the Euro HIV Index 2009, the Euro Headache Index 2012 and the Euro Hepatitis Index 2012. The 2013 Euro Vision Scorecard represents a more limited, highly targeted comparison.
- The most recent edition of the **Euro Health Consumer Index (2013)** covers 48 healthcare performance indicators for 35 countries.
- This year beside the Euro Pancreatic Cancer Index 2014, a second Euro Consumer Diabetes Index 2014 is also due.

Though still a somewhat controversial standpoint, HCP advocates that quality comparisons within the field of healthcare is a true win-win situation. For instance, it can help answer questions of the consumers: who will have a better platform for informed choice and action?; to governments, authorities and providers, the sharpened focus on consumer satisfaction and quality outcomes will support change; and to the media, where HCP offers ranking of clear-cut facts for consumer journalism with some drama into it.

This goes not only for evidence of shortcomings and method flaws but also illustrates the potential for improvement. With such a view the Euro Indexes are designed to become an important benchmark system supporting interactive assessment and improvement.

At one of the presentations/launches of a Euro Index, one of the Ministers of Health, when seeing his country's preliminary results, claimed: "It's good to have someone still telling you: you could do better."

# 6.2 The scope of Euro Indexes

The aim of the Euro Indexes has been to select a limited number of indicators, within a definite number of evaluation or rather sub-discipline areas, which in combination can present a telling tale of how the healthcare consumer is being served or are the "real" offered or provided services by the respective healthcare systems (this includes both

sectors: the private and the public). The most common that makes up the building blocks of the Indexes are: patient rights and information, access, prevention, diagnosis, pharmaceuticals, treatment and outcomes depending on the subject matter.

# 6.3 Country scores

There are no countries, which excel across the entire range of EHCI indicators. The national scores seem to reflect more of "national and organisational cultures and attitudes", rather than mirroring how large resources a country is spending on healthcare. The cultural streaks have in all likelihood deep historical roots. Turning a large corporation around takes a couple of years – turning a country around can take decades!

## 6.4 How to interpret the results of the Euro Indexes?

The first and most important consideration on how to treat the Euro Indexes results is: with caution, lots of caution, especially with the EPCI 2014!

Just like any of the Euro Indexes, also the EPCI 2014 is an attempt at measuring and ranking the performance of healthcare provision from a consumer viewpoint. The results definitely contain information quality problems. There is a shortage of pan-European, uniform set procedures for data gathering. The European Commission attempts to introduce common, measurable health indicators have made very little impact.

But again, the HCP finds it far better to present the results to the public, and to promote constructive discussion rather than staying with the "only-too-common" opinion: as long as healthcare information is not a hundred percent complete it should be kept in the closet.

It is important to stress that the Euro Indexes, including the Euro Pancreatic Cancer Index 2014, displays consumer information, not medically or individually sensitive data.

While by no means claiming that the EPCI 2014 results are dissertation quality, the findings should not be dismissed as random findings. The Index is built from bottom up – this means those countries that are known to have quite similar healthcare systems should be expected not to end up far apart in the ranking.

Previous experience from the general Euro Indexes reflects that consumer ranking by similar indicators is looked upon as an important tool to display healthcare service quality. The HCP hopes that the EPCI 2014 results can serve as inspiration for how and where European healthcare can be improved, especially for pancreatic cancer patients

## 6.5 Why do citizens not know?

Normally, each year, the results of the survey used towards Euro Indexes is carried out in co-operation with Patient View reveal an interesting fact: in some countries, the patients' organisations and health campaigners (even very respectful ones) do not know about some of the services available in their country. The so-called "Single Country Score Sheets"<sup>15</sup> returned from national bodies (where these sheets are validated)normally share

<sup>&</sup>lt;sup>15</sup> A Single Country Score Sheet (SCSS) is a sheet for a country with its scores on the indicators of the pursued Index.

common views and often point out that certain patient rights or information services indeed do exist in their country.

For example, the research team constantly finds negative or no answers on the existence of doctors' registries, pharmacopoeias, access to medical records etc. Given the experience of HCP researchers, this kind of information can be easily found or tracked even without the knowledge of local language. Oftentimes, national authorities make considerable improvements, but miss out on communicating these to the wide public. As healthcare moves from a top-down experts culture into a communication-driven experience industry, such a situation must be most harmful to users as well as tax-payers and healthcare systems!

In the private industry, it is well known and established knowledge that a product or service, be it ever so well designed and produced, needs skilful marketing to reach many customers. In the public sector in general, the focus is (at best) on planning and production of a service, but there is frequently an almost total lack of focus on the information or marketing of a particular service.

# European healthcare systems need to increase its focus on informing citizens about what services are available!

In terms of carrying out a patient survey in the case of the EPCI 2014 and given the nature of the extremely challenging disease, and overall lack of pancreatic cancer patient organisations or groups throughout the EU, except for France, Germany, Netherlands, Spain and the UK and Ireland, the patient or even carers survey could not be carried out.

# 7. Scope and content of the EPCI 2014

The evolvement of the EPCI 2014 took place between April 2013 and February 2014. It involved all 28 EU member states, Norway and Switzerland.

In the design and selection of indicators, the EPCI 2014 took into consideration the following three criteria as has been the case of all the other Indexes since 2005 when the first Euro Health Consumer Index was developed:

- 1. Relevance
- 2. Scientific soundness
- 3. Feasibility (*i.e.* data can be obtained)

These same three criteria also govern the German quality indicators project at BQS Institut für Qualität und Patientsicherheit<sup>16</sup>.

The international Expert panel (more on the Experts on the Panel and their role is presented under "How the EPCI 2014 was built") for the EPCI 2014 drew up a long list of indicators to result in the Index after intense brainstorming sessions to ensure the important sub-disciplines and their indicators were properly identified to satisfy and respond to the needs of the pancreatic cancer patient or the needs of the carers of pancreatic cancer patients.

<sup>&</sup>lt;sup>16</sup><u>www.bqs-institut.de</u>



After having had to surrender to the "lack of statistics syndrome" and after the scrutiny by the Expert panel, of the initial 47 indicators, 30indicators "survived" and some of the initial indicators had to be redefined.

There are six main sub-disciplines and 30 indicators that form the EPCI 2014. These subdisciplines are presented below. All indicators are discussed in detail under "Content of the EPCI 2014 indicators".

*Sub-discipline* 1 combines **patient rights**, **information and accessibility** for pancreatic cancer patients and their carer(s) which in turn encompass the 11 indicators:

- 1.1 Oncology facilities with radiation/medical treatment p.m.p.<sup>17</sup>;
- 1.2 Clinical guidelines for pancreatic cancer;
- 1.3 Pancreatic cancer professional societies;
- 1.4 Direct cancer research spending;
- 1.5 Pancreatic cancer in national cancer registry;
- 1.6 National pancreatic cancer patient organisations/groups;
- 1.7 Multidisciplinary teams (MDT) for the treatment of pancreatic cancer;
- 1.8 Specialist dietician p.m.p.;
- 1.9 Waiting time for CT or MRI exam;
- 1.10 Number (#) of certified HPB (Hepato-Pancreato-Biliary) surgeons p.m.p.;
- 1.11 Waiting time between decision to treat and start of treatment (chemotherapy/surgery).

*Sub-discipline 2* combines 4 important **prevention** indicators for pancreatic cancer:

- 2.1 Smoking per capita;
- 2.2 Alcohol intake;
- 2.3 Body Mass Index (BMI);
- 2.4 Screening of high-risk groups.

*Sub-discipline 3* combines **outcomes** indicators that are considered very important for the provision of care of pancreatic cancer patients:

- 3.1 5-year survival rate;
- 3.2 Median survival curative;
- 3.3 In hospital mortality after surgery;
- 3.4 Median survival palliative chemotherapy;
- 3.5 Median survival best supportive care.

*Sub-discipline 4* combines the **diagnostics** indicators that are crucial for the early detection of pancreatic cancer:

<sup>&</sup>lt;sup>17</sup> p.m.p. stands for "per million population".



- 4.1 Endosonography (+/- FNA<sup>18</sup>) availability;
- 4.2 Diagnostic laparoscopy.

*Sub-discipline 5* combines the **treatment and pharmaceutical** indicators vital for the quick and efficient treatment of pancreatic cancer patients:

- 5.1 Availability of evidence-based chemotherapy;
- 5.2 Percentage (%) of intended curative surgery;
- 5.3 Monoclonal antibodies deployment p.m.p.;
- 5.4. Adjuvant chemotherapy availability.

*Sub-discipline 6* combines **palliative care** indicators that are inevitable for pancreatic cancer patients:

- 6.1 Palliative care beds p.m.p.;
- 6.2 Availability of homecare delivery;
- 6.3 Palliative care or pain management pathway;
- 6.4 Access to palliative care.

Sub-discipline	Number of indicators
1. Patient rights, information and accessibility	11
2. Prevention	4
3. Outcomes	5
4. Diagnostics	2
5. Treatment /Pharmaceuticals	4
6. Palliative care	4

**Table 3:** Summary table of the EPCI 2014

# 8. Scoring in the EPCI 2014

The performance of the respective national healthcare systems were graded on a threegrade scale for each indicator, where the grades have the rather obvious meaning of Green = good ( $\checkmark$ ), Amber = so-so ( $\checkmark$ ) and red = not-so-good ( $\checkmark$ ).

A green score earns 3 points, an amber score 2 points and a red score (or a "not available", n.a.) earns 1 point.

The EHCI 2009 introduced for certain countries the score "not applicable" or "n.ap." score, which earns 2 points. That score was applied onindicators *1.3* Pancreatic Cancer

<sup>&</sup>lt;sup>18</sup>FNA stands for fine needle aspiration.

Professional Society and *1.6*Pancreatic Cancer Patient Organisation for Luxembourg and Malta given their population size (both countries would have in the order of 50 cases/year, and with the high mortality of the disease, this makes the forming of dedicated organisations very difficult).

The HCP has been using the same methodology since its first Euro Index in 2005. For each of the sub-disciplines, the country score is calculated as a percentage of the maximum possible (*e.g.* for *1. Patient rights and information, accessibility*, the score for a state was calculated as % of the maximum  $3 \times 11 = 33$ ).

Thereafter, the sub-discipline scores were multiplied by the weight coefficients given in the following section and added up to make the final country score. Thus, for the EPCI 2014 these percentages were then rounded to a three digit integer, so that an "All Green" score on the 30 indicators would yield 1000 points. "All Red" gives 333 points.

# 8.1 EPCI 2014 weight coefficients

Explicit weight coefficients for the six sub-disciplines were introduced after a careful consideration of which indicators should be considered for higher weight. The **patient rights and information**, **accessibility** and **outcomes** sub-disciplines were decided as the main candidates for higher weight coefficients based mainly on discussions with the Experts on the Panel.

In the EPCI 2014, the scores for the six sub-disciplines were given the following weights as presented in Table 4.

	Sub-discipline	Relative weight: "All Green"score contribution to totalmaximum score of 1000	Points for a Green score in each sub- discipline
1.	Patient rights, information and accessibility	300	27.27
2.	Prevention	150	37.50
3.	Outcomes	200	40.00
4.	Diagnostics	125	62.50
5.	Treatment /Pharmaceuticals	125	31.25
6.	Palliative care	100	25.00
	TOTAL SUM OF WEIGHTS	1000	

Table 4: The EPCI 2014 six sub-disciplines and their weight coefficients

Consequently, as the percentages of full scores were added and multiplied by (1000/Total sum of weights), the maximum theoretical score attainable for a national healthcare system in the Index is 1000, and the lowest possible score is 333.

It should be noted that, as there are not many examples of countries that excel in one sub-discipline but do very poorly in others.

As a side note, the HCP has been experimenting with the EHCI with other sets of scores for green, amber and red, such as 2, 1 and 0 (which would really punish low performers), and also 4, 2 and 1, (which would reward real excellence). The final ranking is remarkably stable also during these experiments.

# 8.2 Data sources for the EPCI 2014

The HCP looks into various data sources. These can be CUTS, information based on patient surveys, and interviews with national experts.

### 8.2.1 "CUTS" data sources

Whenever possible, research on data for individual indicators has endeavoured to find a "CUTS" (*Comprehensive Uniform Trustworthy Source*). If data on the underlying parameter behind an indicator is available for all or most of the 30 countries from one single and reasonably reliable source, then there is a definitive preference to base the scores on that particular CUTS.

A CUTS would normally be information or data from *e.g.* ECDC data, WHO databases, OECD Health data, Special Eurobarometers<sup>19</sup> or scientific papers using well-defined and established methodology. In the case of the EPCI 2014, CUTS that were also relevant is

<sup>&</sup>lt;sup>19</sup><u>http://ec.europa.eu/public\_opinion/archives/eb\_special\_en.htm</u>



data available from organisations, such as, ESMO, EUREG, UEMS, EHCI 2013, or sources, such as, EAPC Atlas of Palliative Care (2012).

Apart from the sheer effectiveness of the approach, the basic reason for the concentration on CUTS, when available, is that data collection primarily based on information obtained from 30 national sources, even if those sources are official Ministry of Health or national agencies, generally yields a very high noise level.

It is notoriously difficult to obtain precise answers from many sources even when these sources are all answering the same, well-defined question. For example, in an earlier Index project, it was difficult to ask questions about a well-defined indicator such as "SDR of respiratory disease for males >45 years of age". For one country protesting violently against their score, it took three repeats of asking the question in writing before the national representative observed that the indicator was for "males 45+" only, not the SDR for the entire population.

It has to be emphasized that also when a CUTS for an indicator is identified, the data is still reviewed through cross-check procedures, as there have frequently been occasions where national sources or scientific papers were able to supply more recent and/or data with higher precision.

### 8.3 Other sources

For the EPCI 2014 it was challenging to obtain precise answers to crucial questions of most interest to pancreatic cancer patients or carers. Of the 30 indicators, there were 5 to 6 indicators for which information could not be found in the public domain and very precise questions had to be addressed to national/regional cancer registries as the only possible source.

The HCP studied but could not make use of EUCAN that is available online as part of the European Cancer Observatory (ECO) at the International Agency for Research on Cancer (IARC)<sup>20</sup>. What was retrieved from their database was the needed list of national and regional cancer registries that was then used to contact the cancer registries directly.

The IARC through its programmes of collaboration with population-based cancer registries in Europe, members of the European Network of Cancer Registries (ENCR)<sup>21</sup> provides estimates of cancer burden in Europe over the last 25 years. However, this type of information is not of much use for pancreatic patients.

As already mentioned several times in the report, the information on the healthcare provision, outcomes and so on that is available for pancreatic cancer care provision is very limited. The EPCI 2014 aimed at answering questions that go beyond the estimates of incidence and mortality rate – two pieces of information that hardly give any tangible information on pancreatic cancer care.

The conclusion of this part of the EPCI 2014 was that pancreatic cancer is not very well covered in cancer registries, whether national or regional.

<sup>&</sup>lt;sup>20</sup>http://eco.iarc.fr

<sup>&</sup>lt;sup>21</sup><u>http://www.encr.com.fr</u>

### 8.3.1 Additional data gathering – surveys

Normally, in addition to public sources, all HCP Indexes so far make use of a web-based survey to Patient organisations commissioned from PatientView<sup>22</sup> based in the UK. However, as already mentioned in the Introduction, for the EPCI 2014, it was not possible to carry out a patient survey given the nature and challenges of pancreatic cancer as a disease and for the fact that there are hardly any pancreatic cancer patient organisations or Groups in countries, making it impossible to reach out and thus the result of this Index relies on the validation process by national entities.

### 8.3.2 Validation and feedback from National Ministries / Agencies

Preliminary score sheets were sent out to Ministries of Health or national agencies of 30 countries, giving the opportunity to supply more recent data and/or higher quality data than what is available in the public domain.

Throughout the project there were extensive correspondence via e-mail, telephone contacts and some personal visits to national bodies. Feedback responses on the Single Country Score Sheets (SCSS) were provided by official national sources. The SCSS sent out to national agencies contained only the scores for that respective country. Corrections were accepted only if supported by actual data and not by national agencies simply altering a score of an indicator (frequently from Red to something better, but surprisingly often honesty prevailed and scores were revised downwards).

### 8.3.3 Threshold value settings

The performance of national healthcare systems was graded on a three-grade scale for each indicator (see more information in the Section on Scoring). At the HCP, tt has not been the ambition to establish a global, scientifically-based principle for threshold values to score green, amber or red on the different indicators. Threshold levels were set after studying the actual parameter value spreads, in order to avoid having indicators showing "all Green" or "totally Red".

Setting threshold values is typically done by studying a bar graph of country data values on an indicator sorted in ascending order. The usually "S"-shaped curve yielded by that is studied for notches in the curve, which can distinguish clusters of states, and such notches are often taken as starting values for scores. A slight preference is also given to threshold values with even numbers. An illustration of this procedure can be the scoring diagram for the indicator 2.3 BMI.

<sup>&</sup>lt;sup>22</sup><u>http://www.patient-view.com/</u>



Figure 5: Scoring for BMI Adults aged  $20 \ge$  who are obese (%), indicator 2.3. (Source: WHO World Health Statistics 2013)

As illustrated in Figure 5, the scoring for indicator 2.3 BMI illustrates the "notches in the S-curve".

Finally, the HCP is a value-driven organisation. HCP believes in the empowerment of patient/consumer – an approach that places highest importance on quantitative and qualitative healthcare services. HCP also finds it evident that individuals are better fit to make decisions about their health and healthcare than rulings driven by moralistic, religious or paternalistic prejudice.

# 9. Indicators and data sources for EPCI 2014

As of methodology, the EPCI 2014 relies on publicly available information and information provided by the EPCI Expert panel. Interviews and correspondence with in-country experts as well as national and/or regional cancer registries have added valuable information, especially if the information came out of further analysis and not part of the annual (national) public reports on cancer. Some of the information strictly related to pancreatic cancer was simply not presented to the public or could not be retrieved from public sources and had to be further requested from various national entities (for instance, the number of certified HPB surgeons where HCP then approached UEMS). On the other hand, information on palliative care was readily available in the public domain; the same could

be said about most of the sub-disciplines except for what HCP believes is the most important sub-discipline: Outcomes.

If a user/consumer/pancreatic cancer patients wants to find out which country has the best outcomes in terms of survival, that piece of information could with some efforts be obtained in the public domain; however, information on median survivals be it curative, palliative chemotherapy or best supportive care is still tucked away in the scientific domain or in cancer registries; this is also the case with data on in-hospital mortality after surgery.

Table 5: Indicators and da	ta sources for the EPCI 2014
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discipline	Indicator	Comment	Score 3	Score 2	Score 1	Main Information Sources
	1.1 Oncology facilities p.m.p.	Total number of medical and radiation oncology facilities in cancer centers and university hospitals p.m.p.	> 6 facilities p.m.p.	1 < x > 3	> 1	ESMO (2008): Medical Oncology Status in Europe Survey (MOSES); National agency data.
	1.2 Clinical guidelines		Nationalor ESMO guidelines; accessible on internet.	Guidelines available only to professionals.	None formally used.	Website/internet search; Interviews with incountry experts; copies of clinical guidelines.
	1.3 Pancreatic cancer society	Dedicated pancreatic cancer professional societies.	Existence of society with website.	Existence of society but no website.	No society.	European Pancreatic Club E-P-C.org; Internet; interviews with incountry experts.
	1.4 Direct cancer research spending		> 50 MIO EUR	50 < x > 25	> 25	Eckhouse S, Sullivan R (2006): A Survey of Public Funding of Cancer Research in the European Union. PLoS Med 3(7): e267.
1 Patient rights	1.5 Pancreatic cancer registry	Pancreatic cancer in national cancer registry.	Yes; in National Cancer Registry; or stand alone.	Only in regional cancer registries.	No registries with pancreatic cancer.	CUTS: EUREG, eu-cancer.iarc.fr/EUREG.
and information, accessibility	1.6 Pancreatic cancer patient org:s	National pancreatic cancer patient organization(s) / group(s).	Yes, stand-alone.	Shared pancreatic cancer patient organization.	None.	Internet; Face-to-face meeting.
	1.7 Multidisciplinary teams	Different definitions exist if at all - but for the highest score specialist nurses should be included.	Team of medical professionals including the specialist nurse.	Team of medical professionals only.	No team or team is formed ad hoc.	Interviews with incountry experts; PubMed; Internet.
	1.8 Specialist dieticians p.m.p.	Encompasses all specialized dieticians.	More than 160 p.m.p.	Between 80 and 160 p.m.p.	Less than 80 p.m.p.	International Confederation of Dietetic Associationss (ICDA), www.internationaldietetics.org .
	1.9 Waiting time for CT or MRI exam		< 7 days.	7 < x > 21 days.	> 21 days.	EHCI 2013.
	1.10 # of certified HPB surgeons p.m.p.	Hepato-Pancreato-Biliary surgeons, certified by UEMS and national bodies.				European Union of Medical Specialist (UEMS).
	1.11 Waiting time for treatment	Waiting time between decision to treat and start of treatment (chemotherapy / surgery).	Most patients (90%) get the treatment within 3 weeks.	50% of patients get the treatment within 3 weeks.	50% of patient wait for more than 3 weeks for treatment.	EHCI 2013.
	2.1 Smoking per capita		< 25%.	25 < x > 30	> 30%.	ETPI 2012; WHO e.c. data 2006-2008; GCS data 2009.
2 Drevention	2.2 Alcohol intake		> 9,20 litres per capita.	9,20 < x > 12 litres per capita.	> 12 litres per capita.	CUTS: WHO HFA Database (pure alcohol consumption litres per capita, age 15+, July 2013).
2. Prevention	2.3 BMI		Less than 40 % of total population.		More than 45 % of total population.	WHO World Health Statistics, 2013.
	2.4 Screening of high-risk groups		Formal / routine with high-risk groups.	Selectively.	Not all.	EUROPAC; interviews with incountry experts.

(to be continued)

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Sub-					V	
discipline	Indicator	Comment	Score 3	Score 2	Score 1	Main Information Sources
	3.1 5-year survival rate	Availability and rate of 5-year survival rate.	More than 5 %.	Between 3 % and 5 %.	Less than 3 % / not collected / o older than year 2004.	National Cancer Reports; Papers.
	3.2 Median survival - curative	Median survival months after curative surgery.	More than 18 months.	Between 12 and 18 months	Less than 12 months / not collected.	Cancer registry information.
3. Outcomes	3.3 Inhospital mortality after surgery	Inhospital mortality rater after pancreatic resection.	Less than 5 %.	Between 3 and 10 % (5-year survival).	Not available / not collected.	Cancer registry information; scientific papers.
	3.4 Median survival - palliative chemotherapy	Median surival days with palliative chemotherapy.	More than 5,5 months.		Not available / not collected.	Cancer registry information.
	3.5 Median survival - supportive care	Median survival days with best supportive care.	More than 1,5 months.		Not available / not collected.	Cancer registry information.
4.	4.1 Endosonography (+/- FNA)		Yes, mostly routinely.	Yes but with limitations.	Not available / not collected.	Interviews with incountry experts; PubMed; Internet.
Diagnostics	4.2 Diagnostic laparoscopy	Normally, it is used in less than 5% of cases.	Yes, mostly routinely.	Yes but with limitations/special cases.	Not used.	Interviews with incountry experts; PubMed; Internet.
	5.1 Evidence-based chemotherapy		Yes.	Yes but with limitations.	Not available / not collected.	Interviews with incountry experts; PubMed; Internet.
5. Treatment /	5.2 % of intended curative surgery	If the % is high it tells us how successful the diagnostics was (normally patients in stage I or II would undergo surgery).	More than 10%.	Between 7 % and 10 %	Less than 7% / not collected.	Cancer registry information.
Pharmaceuticals	5.3 Monoclonal antibodies	ATC code L01XC (monoclonal antibodies) Use per capita, MUSD p.m.p.	< 150 days.	<300 days.	>300 days.	EHCI 2013; IMS MIDAS database.
	5.4 Adjuvant chemotherapy	Yes-no scale (matter of availability).	Yes.		No.	Interviews with incountry experts; PubMed.
	6.1 Palliative care beds p.m.p.	Inpatient palliative beds.	> 1800 beds p.m.p.	380 < x > 1800 beds p.m.p.	< 380 beds p.m.p.	EAPC Atlas of Palliative Care in Europe 2013.
6. Palliative	6.2 Availability of homecare delivery	Integration of homecare delivery with coordination of GP hospital, nursing or residential care.	, Homecare well developed and integrated on all levels.	Homecare provided to a limited degree in some areas.	Homecare absent or hardly anywhere.	Home care across Europe (2012).
care	6.3 Palliative care pathways	Palliative care pathway or pain management pathway established.	y Yes, freely available on Internet.	Yes, but not available on the Internet.	No.	Internet; European Pathway Association.
	6.4 Access to palliative care	Total number of inpatient hospices, home care teams, hospital services mixed teams p.m.p.	> 15 facilities/resources p.m.p.	8 < x > 15 facilities/resources p.m.p.	< 8 facilities / resources p.m.p.	EAPC Atlas of Palliative Care in Europe 2013.

(continued)

# 10. The EPCI 2014 definition of indicators

As already mentioned, the EPCI 2014 is built upon 30 indicators that are spread across six so-called sub-disciplines. In the following, is explained the sub-discipline framework and the content of the indicators within these sub-disciplines that were carefully identified and developed by the researchers and the members of the Expert panel to provide the best possible picture in terms of pancreatic cancer healthcare provision in the 28 EU member states, Norway and Switzerland from the point of view of the user/consumer/pancreatic cancer patient and/or carer.

For reader's clarity, the indicators come numbered in the EPCI 2014 Report and Matrix.

# 10.1 Sub-discipline: Patient rights, information and accessibility

This sub-discipline combines items in the field of patient rights, information on pancreatic cancer care that is possible to obtain and important issues around access to healthcare providers if affected with pancreatic cancer.

This sub-discipline is the largest containing 11 indicators to stress the importance of how important it is for a patient with pancreatic cancer to get an earliest possible diagnosis and quickly access and get the needed healthcare provision, and also how well the healthcare system functions towards providing proper care for patients affected with pancreatic cancer (e.g. Are there pancreatic cancer guidelines in place? What is the number of HPB surgeons? What is the access time between the decisions to treat to the actual treatment? and so on) to give an estimate of how good healthcare delivery is developed for pancreatic cancer patient.

# 10.1.1 Indicator: 1.1 Oncology facilities with radiation/medical treatment p.m.p.

Initially, the Expert panel were eager to get an overview of how many specialized centres for pancreatic cancer there were across the countries. This formulation of this indicator soon dropped as it would have meant that small countries with a few cases a year would soon drop out and score Red. Also it raised the question: how would such centre be financially sustainable, say in a country like Latvia?

Another reason was that most often across the countries observed pancreatic cancer care is provided in either university clinics or oncology facilities. Thus, the number of oncology facilities with radiation and medical treatment p.m.p. was researched, which gives an indication for the provision of pancreatic cancer.

Countries providing good access are Austria, Croatia, Czech Republic, Finland, Hungary, Ireland, Italy, Luxembourg, the Netherlands, Poland and Sweden.

Data source(s): CUTS: ESMO<sup>23</sup> (2008): Medical Oncology Status in Europe Survey; incountry national representatives.

<sup>&</sup>lt;sup>23</sup>www.esmo.org

### 10.1.2 Indicator: 1.2 Clinical guidelines for pancreatic cancer

It goes without saying that a country that does not make use of clinical guidelines for specific diseases greatly jeopardizes the health outcomes. In the case of EPCI 2014, the use of pancreatic cancer clinical guidelines gives an indication of the level of development of healthcare provision for pancreatic cancer and that there are in-country discussion on the level of the pancreatic cancer experts. This is important for ensuring equity of care within countries as well as across the observed European countries.

It is said that if there is a professional association or society for a specific medical area, there normally are clinical guidelines. This was not the case for pancreatic cancer. Some countries were yet to develop clinical guidelines for pancreatic cancer. In some other countries, especially countries with limited resources, reached out for the ESMO clinical guidelines which is also a sign of efficiency.

Optimally, clinical guidelines should be freely accessible to the public (these countries got a Green); most observed countries keep this source of information freely accessible.

Feeds for this indicator came through PubMed, interviews with in-country experts for pancreatic cancer and professional societies.

Data source(s): ESMO<sup>24</sup>; PubMed; interviews with in-country experts

#### 10.1.3 Indicator: 1.3 Pancreatic cancer professional societies

This indicator data is pure CUTS. All professional stand-alone pancreatic cancer societies are members of the European Pancreatic Club. Some smaller countries, with less than a critical mass of pancreatic patients, may have professional pancreatic cancer societies as stand-alone entities but will be organised under a GI (gastroenterology) cancer professional society. This was also seen as a positive initiative.

This indicator provides some kind of reassurance to pancreatic cancer treatment seekers that there are actually professionals out there actively researching different manners to treat pancreatic cancer; and could at the same time provide an information platform to pancreatic cancer patients or carers<sup>25</sup>.

Worth noting is that countries like Luxembourg and Malta with a very small population cannot be expected to run stand-alone professional societies for pancreatic cancer, thus the n.ap. (not applicable) score.

As illustrated in the EPCI 2014 there are hardly any countries without a professional society or section that tackles pancreatic cancer.

Data source(s): European Pancreatic Club<sup>26</sup>; Internet

#### 10.1.4 Indicator: 1.4 Direct cancer research spending

Figures for direct pancreatic cancer research spending cannot be retrieved in the open access literature. The HCP team has repeatedly asked the European Commission to provide us with the latest figures. No response could be obtained and the explanation

<sup>&</sup>lt;sup>24</sup>www.esmo.org

<sup>&</sup>lt;sup>25</sup> This report often refers to pancreatic cancer patients or carers; because of the nature and course of the disease, carers often take up a very active role in the search of information and guidance.

<sup>&</sup>lt;sup>26</sup>www.e-p-c.org



most likely lies in the fact that pancreatic cancer research spending may be less than existent or not worth publishing publically. One will find information on direct cancer research spending for the general field of cancer, such as breast cancer, lung cancer, prostate cancer, and so on. Although incidence rates for pancreatic cancer is rising over the years, pancreatic cancer seldom appears on any lists for site-specific cancer research funding.

The only CUTS paper found is the paper by Prof Dr Richard Sullivan from year 2007, where UK (the highest spending level), followed by Germany, France, Italy and Sweden invested quite some money in researching cancer in general and it can only be assumed that these are also the countries that are spending the most on pancreatic cancer research.

Data source(s): Eckhouse S, Sullivan R (2006): A Survey of Public Funding of Cancer Research in the European Union. PLoS Med 3(7): e267

### 10.1.5 Indicator: 1.5 Pancreatic cancer in national cancer registry

The source of information for this indicator came from a CUTS: EUREG, and for countries not included in there, officials were identified. The results for this indicator provide an indication whether the disease is being monitored or analysed. Interestingly, not all countries have national cancer registries; some geographically bigger countries have regional cancer registries only; and not all registries (national or regional) offer information on pancreatic cancer.

It can be concluded that there are mechanisms to report and monitor pancreatic cancer but it seems that priority is given to other more common cancers.

Data source(s): CUTS: EUREG<sup>27</sup>; official cancer registry websites

### 10.1.6 Indicator: 1.6 National pancreatic cancer patient organisations/groups

An initial web search found little information on pancreatic cancer patient organisations across many of the observed European countries. HCP has also contacted cancer patient organisations to ensure that no pieces of information were missed. There are only five patient organisations that were identified in the following countries: France, Germany the Netherlands, Spain, and the UK that also covers Ireland. It was also found that a pancreatic cancer patient organisation was about to be established (but until established with a proper website, it could not be acknowledged by HCP).

France:

• Aide et Recherche en Cancérologie Digestive -ARCAD<sup>28</sup> - a not 100% stand-alone patient organisation but a patient organisation that is putting great emphasis on pancreatic cancer as seen from the extent of their website dedicated to pancreatic cancer patients and involvement

Germany:

• TEB Sebsthilfe, Tumore und Erkrankungen der Bauchspeicheldruesse<sup>29</sup>

<sup>&</sup>lt;sup>27</sup><u>http://eu-cancer.iarc.fr/EUREG</u>

<sup>&</sup>lt;sup>28</sup>www.fondationarcad.org/le-cancer/les-cancers-digestifs/cancer-pancreas
<sup>29</sup>www.teb-selbsthilfe.de

### The Netherlands:

- Alvleeskliervereniging<sup>30</sup> covers pancreatitis (acute and chronic) as well as it provides information and support to pancreatic cancer patients
- Dutch patient organisation for cancer of the GI tract SPKS<sup>31</sup> with a separate group for pancreatic cancer
- Lisa Waller Hayes Foundation<sup>32</sup> patient organisation with which the Dutch Pancreatic Cancer Group developed a specific website for patients<sup>33</sup>.

#### Portugal:

 Associação de Luta Contra o Cancro do Intestino (no website at the time of writing this report)

Spain:

 El Grupo Español de Pacientes con Cáncer - GEPAC<sup>34</sup>, an umbrella organisation providing support to pancreatic cancer patients

UK:

- Pancreatic Cancer UK<sup>35</sup>
- Pancreatic Cancer Action<sup>36</sup> (this organisation also covers Ireland).

This indicates a varying level of support and information for patients across the observed European countries.

Data source(s): Official pancreatic cancer patient organisation websites; pancreatic cancer patient organisation group discussion

# 10.1.7 Indicator: 1.7 Multidisciplinary teams for the treatment of pancreatic cancer

Most countries have multidisciplinary teams (MDT) for the treatment of pancreatic cancer; however, definitions differ from country to country. Some countries may include a specialised nurse whereas other countries do not include the nursing staff. Countries that include nurses are those countries that scored highest. According to the Expert panel nursing and nurses are seen as very important members of the MDT as pancreatic cancer patients most often need intensive nursing and the support that nurses can give to both patients and their carers is critical

It could be deduced that the more disciplines are in charge or involved in the treatment of pancreatic cancer patients the better the outcomes. One could say that those countries

<sup>&</sup>lt;sup>30</sup>www.avkv.nl

<sup>&</sup>lt;sup>31</sup>http://www.spks.nfk.nl/

<sup>&</sup>lt;sup>32</sup>http://www.lwhfoundation.com/

<sup>&</sup>lt;sup>33</sup>www.allesoveralvleesklierkanker.nl

<sup>&</sup>lt;sup>34</sup><u>www.gepac.es</u>

<sup>&</sup>lt;sup>35</sup>www.pancreaticcancer.org.uk

<sup>&</sup>lt;sup>36</sup>www.pancreaticcanceraction.org

with multidisciplinary teams (including specialized nurses), the better the outcomes. These countries are Denmark, France, Ireland, Netherlands, and the UK.

Data source(s): Website; interviews with in-country experts

### 10.1.8 Indicator: 1.8 Specialist dieticians p.m.p.

There is plenty of evidence that patients with pancreatic cancer need a special diet and nutritional advice that may not be straightforward. There are various definitions for specialist dietician. What is counted for the indicator is the type of specialist or clinical dietician who could provide advice on the diet to pancreatic cancer patients or their carers. Specific to pancreatic cancer, searching for registered clinical / medical specialist dieticians would make more sense but for the purpose of this first EPCI, it was decided to look at the broader picture. It is hoped with the next Index to be able to readily find the list of officially registered clinical dieticians in each country.

Some countries keep track of the number of specialist dieticians but not all. A partial CUTS wasthe International Confederation of Dietetic Associations (ICDA).

Data source(s): ICDA<sup>37</sup>

### 10.1.9 Indicator: 1.9 Waiting time for CT or MRI examination

The worst thing that can happen to any patient is too wait far too long for a CT or MRI exam. In particular, anyone with slightest symptoms or indication of pancreatic cancer would want to undertake this type of exam as soon as possible as delays in diagnosis is the reason why long-term survival (>5) is so low.

The focus of this indicator is *the time to get a CT scan after getting a doctor's referral to do so.* As noted in the Euro Health Consumer Index 2013, waiting times for a CT or MRI exam is both poor service quality and also increases costs, as the procedure of keeping track of patient for weeks/months is by no means costless, and the examination itself is if anything cheaper if the patient and the care provider has the underlying cause fresh in their minds.

For this indicator, was used an indicator from the very recent Euro Health Consumer Index 2013 (the score for CT was extrapolated also to MRI).

<sup>&</sup>lt;sup>37</sup><u>www.internationaldietetics.org</u>



**Figure 6:** Waiting time for non-acute CT scan from patient organisation survey. (Source: EHCI 2103<sup>38</sup>)

### 10.1.10 Indicator: 1.10 Number (#) of certified HPB surgeons p.m.p.

HPB (Hepato-Pancreato-Biliary) surgeons are crucial in the treatment of pancreatic cancer. These surgeons are highly specialized and trained in removing pancreatic cancer. There have been attempts to keep track of the number of certified HPB surgeons but it is not yet available.

HCP decided to keep this indicator in EPCI 2014 to make a point. Pancreatic cancer patients have the right to know where to seek access to HPB surgeons as this type of surgery is complex and highly specialised. Outcomes improve considerably when patients are treated by HPB surgeons in specialist centres with a high throughput of patients. The European Union of Medical Specialists (UEMS) is putting lots of efforts to keep record of registered HPB surgeons in Europe. The numbers of registered of HBP surgeons is not yet available.

Data source(s): UEMS<sup>39</sup>

# 10.1.11 Indicator: 1.11 Waiting time between decision to treat and start of treatment (chemotherapy/surgery)

Similarly to the indicator 1.9 Waiting time for CT or MRI exam, also this indicator indicates the functionalities of the healthcare provision. To a pancreatic cancer patient where time is counted in minutes, this waiting time needs to be a short as possible to obtain better healthcare outcomes.

<sup>&</sup>lt;sup>38</sup><u>www.healthpowerhouse.com</u>

<sup>&</sup>lt;sup>39</sup><u>www.uems.net</u>



The indicator measures the time to get radiation or chemotherapy after decision to treat (DTT). The time limit for a Green Score is much tighter for cancer treatment than for elective surgery.

Also for this indicator, data from our very recent Euro Health Consumer Index 2013 was used.

Data source(s): CUTS: EHCI 2013<sup>40</sup>

## **10.2 Sub-discipline: Prevention**

The main question to the Expert panel was: how can pancreatic cancer be prevented at all? Although a simple question, the answer is still today not so clear. Supposedly, the main risk factors for pancreatic cancer are smoking, alcohol consumption, and BMI. Possible preventive screening programmes for high-risk groups were also looked into.

### 10.2.1 Indicator: 2.1 Smoking per capita

This indicator is fairly straightforward: the prevalence of smoking per capita for the observed countries. As is shown by Fig. 2 (section 2.2 above), on national level, there is no strong correlation between cigarette consumption and pancreatic cancer incidence. The connection between tobacco smoking and pancreatic cancer is most certainly a lot weaker than that for lung cancer.

In the UK, for instance, smoking makes up 29% of pancreatic cancer cases (Cancer Research  $\rm UK)^{41}$ .

According to Jang (2012) "primary prevention through life style changes of established risk factors like smoking has considerable potential to reduce the number of pancreatic cancer deaths."

Data source(s): CUTS: ETPI<sup>42</sup> 2012, data from Confederation of European Community Cigarette Manufacturers (CECCM)<sup>43</sup>.

### 10.2.2 Indicator: 2.2 Alcohol intake

Unlike cigarette smoking, alcohol as a risk factor is not always harmful. It has been illustrated in several studies that a modest alcohol intake (the equivalent of one glass of wine per day for women, and 1-2 glasses per day for men) reduces the risk of death from CVD enough to result in a lower mortality than for total abstainers.

This indicator is based on the total consumption of alcohol per capita.

Data source(s): CUTS: WHO HfA Database

<sup>&</sup>lt;sup>40</sup><u>www.healthpowerhouse.com</u>

<sup>&</sup>lt;sup>41</sup><u>http://www.cancerresearchuk.org/cancer-info/cancerstats/types/pancreas/riskfactors/pancreatic-cancer-risk-factors</u>

<sup>&</sup>lt;sup>42</sup>www.healthpowerhouse.com

<sup>43 &</sup>lt;u>www.ceccm.eu</u>

### 10.2.3 Indicator: 2.3 Body Mass Index (BMI)

Also this indicator is a straightforward indicator. Body mass index (BMI) is considered a risk factor for pancreatic cancer.

Data source(s): CUTS: World Health Statistics (2013)

### 10.2.4 Indicator: 2.4 Screening for high-risk groups

There were serious discussions among the members of the Expert panel around this indicator due to the lack of evidence that screening for high-risk groups can help detect pancreatic cancer early enough. Nevertheless, this indicator was kept. Support for that was found through the European Registry of Hereditary Pancreatitis and Familial Pancreatic Cancer (EUROPAC) project and via interviews with in-country experts.

In a recent study, Bruno (2013) observes that "secondary prevention by screening the general population for pancreatic cancer is not feasible at present because of its low incidence and the lack of a non-invasive, reliable and cheap screening tool." However, it is estimated that about 10% of all pancreatic cancer cases are caused by inherited (genetic) factors with some individuals carrying a life time risk up to 55% (Harinck, 2010). According to Bruno (2013) only a small minority of symptomatic pancreatic cancer patients present at stage Ia.

In general, the lack of a non-invasive test or diagnostic biomarker prevents large scale screening for those at risk (hereditary, for example) It is generally felt that in non-symptomatic patients that the regular use of contrast-enhanced CT and its associated radiation could in fact increase that person's overall risk of getting cancer (of any type)

Data source(s): PubMed, EUROPAC<sup>44</sup> correspondence.

### **10.3 Sub-discipline: Outcomes**

For the EPCI 2014 it was found important to insert this sub-discipline in the middle of the Index to make a point and emphasize the lack of data across the observed countries and call for attention, especially among policy-makers and healthcare providers!

This sub-discipline is composed of five indicators. These are indicators to which it was close to impossible to find information in the literature and had to be sought after with National/Regional Cancer Registries as it is not in the public domain! This is crucial information for pancreatic cancer patients as on the basis of this information they can make an informed choice about their treatment options.

As noted in the EPCI 2014 Matrix, there are many **n.a.** which is an unfortunate reality. Many countries indicated that their country or region did not keep track of these pieces of information but does not necessarily mean that this information is not collected somewhere by an individual or an institute. This data is of great importance to pancreatic cancer patients and carers.

<sup>44</sup>http://www.europac-org.eu/

The International Agency for Research on Cancer (IARC) <sup>45</sup> through its programmes of collaboration with population-based cancer registries in Europe, members of the European Network of Cancer Registries (ENCR) 46 provides estimates of cancer burden in Europe over the last 25 years.

For any of these indicators it was difficult to set scores as only 8 countries were able to provide data.

The data source for all five indicatorsare mainly based on national or regional cancer registry reports.

### 10.3.1 Indicator: 3.1 5-year survival rate

Initially, data for 1-3-5-year survival rates were soughtand then it was decided to base the indicator on 5-year survival data. There are platforms such as EUROCARE<sup>47</sup> 4 (where this data can be retrieved for patients diagnosed 1995 – 1999). Unfortunately, at the time of writing this report, EUROCARE 5 with data for patients diagnosed up until 2007was not available. The numbers for 5-year survival rates were retrieved from national reports from cancer registries or from scientific papers.

About one third of the observed countries could not report their 5-year survival rate which indicates that this information is not systematically collected. One of the observed countries which reported its 5-year survival rate is the UK but it is doing poorly in comparison to the other countries. This is a surprising observation as the UK is the country that invests greatest in pancreatic cancer research. On the other hand, the British healthcare is characterized by the typical public sector-streaks of being generous with allowing large numbers of staff, but being mean on investment and capital investment. This hits particularly hard on oncological specialities, needing expensive drugs and radiation therapies.

Data source(s): National Cancer Registry Reports; papers

### 10.3.2 Indicator: 3.2 Median survival – curative

Median survival rates for curative procedures were provided by only 5 countries, most scoring high and ranging within the same range.

Data source(s): Cancer registry correspondence

### 10.3.3 Indicator: 3.3 In-hospital mortality after surgery

In-hospital mortality after surgery was provided by six countries, ranging from 3% to 7.5%. The lowest in-hospital mortality scored GREEN, slightly higher a YELLOW.

Data source(s): Cancer registry correspondence and reports

<sup>45</sup>http://www.iarc.fr/

<sup>&</sup>lt;sup>46</sup><u>http://www.encr.com.fr</u>

<sup>&</sup>lt;sup>47</sup><u>http://www.eurocare.it/Database/tabid/77/Default.aspx</u>

### 10.3.4 Indicator: 3.4 Median survival – palliative chemotherapy

The median survival rate for palliative chemotherapy was provided by 6 countries only. As it was not possible to benchmark, all these 6 countries were scored with a GREEN as the median survival rates for all six countries were very close to each other.

Data source(s): Cancer registries

### 10.3.5 Indicator: 3.5 Median survival – best supportive care

The median survival rate for best supportive care was provided by 5 countries only, and similarly to the above indicator (3.4), the rates for each country came close to each other, thus all scoring a GREEN.

Data source(s): Cancer registries

# **10.4 Sub-discipline: Diagnostics**

The Expert panel identifies two very pancreatic cancer specific indicators: availability of endosonography (+/- FNA) and diagnostic laparoscopy. With this first EPCI, it was decided to limit the search to availability or non-availability of these two diagnostics technologies. With the next Index it would be worth identifying the concentration of such diagnostics approaches p.m.p.

### 10.4.1 Indicator: 4.1 Endosonography (+/- FNA) availability

Diagnosis of pancreatic tumours can be problematic and when prior biopsies performed by CT guidance are negative for pancreatic malignance, the next technology that can be of great use is the performance of endoscopic ultrasound-guided fine needle aspiration (FNA) biopsy.

This indicator tries to answer whether endoscopic ultrasound-guided fine needle aspiration or endosonography (+/-FNA) is offered as a diagnostic option or not. In the years to come, it would be worthwhile exploring the level of access to such type of diagnostics.

It turns out that almost all countries make use of endosonography (+/-FNA). The intention is then with the next index to further investigate into the concentration of such diagnostics procedure and the case may be that despite the fact that the equipment may be there, it may not be used to take biopsies which can then result in the lack of turnour staging.

Data source(s): PubMed; in-country experts interviews.

### 10.4.2 Indicator: 4.2 Diagnostic laparoscopy

Diagnostics laparoscopy makes sense to be carried out under the assumption that there is evidence of the malignant disease. It is matter of not only if this technique is available but whether it is routinely done or only in specific cases.

Data source(s):PubMed; in-country experts interviews.

## 10.5 Sub-discipline: Treatment / pharmaceuticals

This sub-discipline is composed of four indicators to cover the main issues in terms of the treatment of pancreatic cancer.

### 10.5.1 Indicator: 5.1 Availability of evidence-based chemotherapy

It was decided to keep this indicator fairly simple and straightforward. The indicator illustrates whether evidence-based chemotherapy is available in the observed countries. Most countries scored a Green score. With the next index the intention is to further investigate the level of penetration of evidence-based chemotherapy.

Data source(s): PubMed, Internet, interviews with in-country experts.

### 10.5.2 Indicator: 5.2 Percentage (%) of intended curative surgery

Again, also with this indicator, as noted in the EPCI 2014 Matrix, there are many **n.a.** which is an unfortunate reality. Only 8 countries were able to provide inputs towards this indicator, most scoring Green.

Data source(s): Cancer registry reports or correspondence.

### 10.5.3 Indicator: 5.3 Monoclonal antibodies deployment p.m.p.

This indicator measures the use, in MUSD p.m.p., of the ATC code group L01XC (monoclonal antibodies). The measure DDD (Defined Daily Doses) rather than monetary value would have been preferable, but unfortunately the volume data contained inconsistencies.

Data source(s): CUTS: EHCI 2013<sup>48</sup>, (IMS Health MIDAS database<sup>49</sup>).

### 10.5.4 Indicator: 5.4 Adjuvant chemotherapy availability

This is fairly straightforward indicator. It was of interest to find out whether adjuvant chemotherapy is available in the observed countries. Almost all countries scored a Green on this indicator. Similarly to the indicator 5.1 above, HCP looks forward to further investigate in the level of penetration or availability of adjuvant chemotherapy.

Data source(s): PubMed, Internet, interviews with in-country experts.

### **10.6 Sub-discipline:** Palliative care

This sub-discipline was easier to feed compared with many other indicators of the EPCI 2014. It seems that it is easier to get palliative care than treatment for pancreatic cancer! It could be that the poor survival chances caused by the usually late diagnosis of the disease inspire a sense of hopelessness about cure and, therefore, more focus is given to palliation.

<sup>&</sup>lt;sup>48</sup><u>www.healthpowerhouse.com</u>

<sup>&</sup>lt;sup>49</sup><u>http://www.imshealth.com/</u>



The availability of palliative care is indicative of the fact that the majority of patients are diagnosed too late for potentially curative surgery and most patients therefore will be on a palliative care pathway.

### 10.6.1 Indicator: 6.1 Palliative beds p.m.p.

This indicator provides the number of palliative beds p.m.p. The results vary across countries. Only five countries provide more than 1800 p.m.p. Countries scoring Red are those with less than 380 beds p.m.p.



Figure 7: Palliative care beds p.m.p. (source: Centeno et al. 2013)

Data source(s): CUTS: Centeno, C., Pons, J.J., Lynch, T., Donea, O., Rocafort, J., & Clark, D. 2013. *EAPC Atlas of Palliative Care in Europe 2013 - Cartographic Edition*. Milan: EAPC Press (pp. 62-105)

### 10.6.2 Indicator: 6.2 Availability of homecare delivery

This indicator is about the integration of homecare delivery with coordination of general practitioners, hospital, nursing or residential care. Countries that excel are Denmark, Finland, Malta, Slovakia, Slovenia, Spain and Sweden reflecting that homecare is well developed and integrated on all levels of national healthcare system; whereas, those countries scoring a Red are those countries with absent homecare or hardly anywhere present and the palliative patient is very much on his/her own.

Data source(s): CUTS: Genet N., Boerma W., Kroneman M., Hutchinson A. and Saltman R-: Home Care Across Europe, Observatory Studies Series 27, 2012.

#### 10.6.3 Indicator: 6.3 Palliative care or pain management pathway

Pancreatic cancer can be very painful and it was of interest to find out whether there are any kinds of palliative care or pain management pathways in place. The well-known palliative care pathway is the Liverpool palliative care pathway that has been adopted in many countries in Europe. This gives an indicator as to how well healthcare staff is trained in managing pain of a pancreatic cancer patient needing palliative care.

It was surprising that some countries were not aware of the existence of care pathways as such and only a very few countries make use of such care pathways or similar (Austria, Belgium, Estonia, France, Ireland, Malta, the Netherlands, Slovenia, Spain and the UK).

Data source(s): European Pathway Association<sup>50</sup> (EPA) country contacts, Internet, PubMed.

#### 10.6.4 Indicator: 6.4 Access to palliative care p.m.p.

This indicator provides an insight as to the total number of inpatient hospices, home care teams and hospital services mixed teams p.m.p. It is important that a pancreatic cancer patient has proper access to palliative care and pain management. Only 6 countries have more than 15 facilities/resources such as inpatient hospices, homecare teams, hospital services mixed teams p.m.p. On the other side of the spectrum, a little more than half of the countries observed have less than 8 such facilities/resources p.m.p.



Figure 8: Facilities/teams for palliative care p.m.p. (Centeno et al., 2013)

Data source(s): CUTS: Centeno, C., Pons, J.J., Lynch, T., Donea, O., Rocafort, J., & Clark, D. 2013. *EAPC Atlas of Palliative Care in Europe 2013 - Cartographic Edition*. Milan: EAPC Press (pp. 62-105)

<sup>&</sup>lt;sup>50</sup>www.e-p-a.org

# 11. How the EPCI 2014 was built

The EPCI 2014 project lasted 11 months. The timeline of the EPCI 2014 project (more details on the phases of this project is provided in the last section of this report):

- April 2013 kick-off and desk-research
- June 2013 First Expert panel meeting, drawing up the list of indicators to feed the EPCI 2014
- June November 2013 interview and further research, compiling information and feeding the indicators
- October 2013 Second Expert panel meeting; fine-tuning the list of indicators
- November 2013 Patient organisation meeting
- December 2013 developing single indicator score sheets and single country score sheet; sending out single country score sheets for validation
- January February 2014 validation; updating the scores; report writing
- March 2014 Publication of the EPCI 2014 and dissemination activities

The indicators facilitate cross-national comparison and function as benchmarks to enable individual countries to understand their level of pancreatic cancer care development compared with others in their region. The way the indicators are composed will enable the tracing of changes over time. Most indicators are specific to pancreatic cancer care but some could be even further fine-tuned to pancreatic cancer care. However, due to the lack of information a broader view was adopted (more information on this is provided under the description of each indicator in Section 10).

The HCP is working with its long-standing and verified methodology to produce further valuable information in the future for policy-makers, providers and users/patients. However, the HCP for the first time embarked on directly tackling cancer registries for the lack of vital information for pancreatic cancer patients were astonishing. By doing so, it is envisaged that the scores in the Index can be turned into a practical way to develop future policy and practice.

The fact that there is a lack of information does not necessarily mean the quality of care is poor. However, there is no way to transparently monitor the progresses of pancreatic cancer care. There is a need to provide vital information in the public domain for pancreatic cancer patients.

The EPCI 2014 builds on available and non-available information in the public domain (thus the need to contacting national and regional cancer registries).

The HCP team drew up and fed 30 (thirty) indicators for all EU countries, Norway and Switzerland.

In brief, the work method of the EPCI 2014 (more under Section 5) lies upon four production phases. In the initial phase, a systematic review was conducted – it covered articles published in the period between 2005 and 2013 on the state of pancreatic cancer care in the EU, Norway and Switzerland; and inputs towards the indicators for the EPCI

2014. The main database for the first was PubMed; for the second, the world-wide-web. This type of review helped identify the source of information, key experts in different, overview of available information and data in the public domain. It provided summaries and references that were of use for further research.

The other methods used were in-country interviews and correspondence with experts to be able to better tackle the indicators especially when no information could be retrieved in the public domain. The only method that was not used for the EPCI 2014 is the patient survey that is normally conducted alongside. The reality is that pancreatic cancer patients are difficult to identify given the nature of the disease. For this reason, the Expert Panel included Ms. Alison Stunt of Pancreatic Cancer Action who is herself an active pancreatic cancer survivor, and thus relied on her views as a former patient.

After the first round of information search, a second meeting was organised with the Expert panel. Given the challenges some indicators were dropped, and the others were reformulated. This reformulation was necessary so as to be able to feed the outcomes indicators and some other ones – these had to be retrieved from cancer registries as they were not readily available in the public domain.

Once all the information and data was gathered for each country, and the score sheets, the so-called "single indicators score sheets" and "single country score sheets" were ready, these were then sent out to national bodies, who were given the opportunity to review their data prior to publication of the EPCI 2014.

The identification and definition of indicators towards the Index is a compromise between indicators that were judged to be most significant for providing information about different national healthcare systems from a user/consumer/pancreatic cancer patient's point of view and the availability of data for these indicators. As for all other Indexes, the classical question arose "Should we be looking for the 100-Euro bill in the dark alley, or the 50-cent coin under the lamppost?"

Throughout the EPCI 2014 project it has been crucial to have a mix of indicators in different sub-disciplines or areas of service attitude and consumer orientation as well as "hard-fact-nature" indicators to illustrate healthcare quality in outcome terms.

Although there is ample patient information on what pancreatic cancer is all about, there is an amazing lack of crucial information in the European scientific literature and websites for pancreatic cancer patients. HCP decided for the first time ever to go beyond and try retrieving information from Cancer Registries in Europe and providing feeds for all of the indicators of the Outcomes, Diagnostics and Treatment / Pharmaceutical Sub-disciplines.

It was intentionally decided not to include indicators measuring public health status, such as life expectancy, pancreatic cancer mortality and incidence indicators. Such indicators tend to be primarily dependent on lifestyle or environmental factors rather than healthcare system performance or delivery of healthcare of a specific healthcare system. These types of indicators offer very little information to the user/consumer/pancreatic cancer patient wanting to choose among therapies or care providers, being put on the waiting list for planned surgery, or worrying about the risk of post-treatment complication or finding viable information for the treatment of pancreatic cancer.

### 11.1 The role of the EPCI 2014 Expert panel

As is the standard working mode for all HCP Indexes, an external Expert panel was set up. The panel met for two 6-hour sittings during the course of the project, the members of the panel were sent the Index working material in advance. The following persons have taken part in the Expert panel work for EPCI 2014:

- Dr Boris Belev, Clinical Hospital Center Zagreb, Croatia
- Dr Rossana Berardi, Università Politecnica delle Marche, Ancona, Italy
- Dr Marc G.H. Besselink, Department of Surgery, AMC Amsterdam, Netherlands
- Dr Carmen Guillen, Hospital Ramon y Cajal Madrid, Spain
- Dr Peter Hegyi, University of Szeged, Hungary
- Dr Michael Bau Mortensen, Odense University Hospital, Denmark
- Dr Colm O'Morain, Trinity College Dublin, Ireland
- Dr Lojze Šmid, University Clinic Ljubljana, Slovenia
- Mrs Alison Stunt, Pancreatic Cancer Action, United Kingdom

The Expert panel for a HCP Index has two core tasks:

- To assist in the design and selection of sub-disciplines and indicators. This is obviously of vital importance for an Index, if the ambition is to be able to say that a state scoring well can truly be considered to have good, consumer-friendly healthcare services.
- To review the final results of research undertaken by HCP researchers before the final scores are set. If the information obtained seems to clash too violently with the many decades of healthcare experience represented by the panel members, this has been taken as a strong signal to do an extra review of the results.

## 11.2 Four production phases of the EPCI 2014

The Index does not take into account whether a national healthcare system is publicly or privately funded and/or operated. The purpose is health consumer empowerment, not the promotion of political ideology. Aiming for dialogue and co-operation, the ambition of HCP is to be looked upon as a partner in developing healthcare around Europe.

The EPCI 2014 was constructed under the following project plan:

#### 11.2.1 Phase 1: Start-up

Phase 1 begins with a start-up meeting with the Expert Panel to map out existing data and brainstorm on the possible indicators crucial towards the Euro Index under development.

The major area of activity was to evaluate to what extent relevant information is available and accessible for the selected countries. The basic methods were:

- Web search, journal search
- Telephone and e-mail interviews with key individuals, and

• Personal visits when required.

Web search involves searching for relevant bylaws and policy documents and actual outcome data in relation to policies.

Reach out to information providers such as national and regional health authorities; various institutions and organisations (for example, in the case of EPCI 2014, contacts were taken with ESMO, ECCO, EUREG, EUROPAC, and so on); and private enterprise such as IMS Health.

Interviews are also carried out to evaluate findings from earlier sources, particularly to verify the real outcomes of policy decisions, and this is normally carried out over the phone and / or e-mail correspondence, and on the basis of personal visits to key information providers.

### 11.2.2 Phase 2: Data collection

Phase 2 involves data collection to assemble presently available information to be included in the EPCI 2014. These tasks involve:

- Identification of vital areas where additional information needed to be collected
- Collection of "raw" data for these areas.

Regular contact was established with the Expert panel to discuss the indicators, the criteria to define them and the data acquisition problems. Finally, after a second panel meeting the details of each of the indicators were discussed and the set of indicators were then fine-tuned where some of the indicators had to be deleted from the list due to an obvious lackof data in the public domain; however, as mentioned, some indicators were kept but the information had to be sought in the national or regional cancer registries. Also, the discrepancies between data from different sources were analysed. Sub-discipline relative weights were discussed and defined.

### 11.2.3 Phase 3: Patient advocates & Validation

Phase 3 is set up of *two parts: part one* is about consulting European patient advocates and citizens through HCP survey performed by external research facility; the *second part* of phase 3 is sending out Single Country Score Sheets (SCSS) to respective countries for validation purposes.

Going back to the first part of Phase 3, normally, the HCP makes use of patient surveys in phase 3 of the production of a specific Euro Index in partnership with the UK-based organisation Patient View<sup>51</sup>. Surveys for a specific Euro Index are normally available on the Internet during the production phase in different languages: English, German, French, Spanish, Russian, Greek (for the benefit of CEE responders) and Scandinavian (Swedish).

However, as already mentioned in the Introduction of this report, it was not possible to carry out a patient survey, not even a carer's survey given the nature of the disease and lack of patient organisations in EU member states, Norway and Switzerland. HCP has managed to identify 5 pancreatic cancer organisations and also had the opportunity to learn of their struggle to keep up and ensure a platform for pancreatic cancer patients and their carers. Interestingly, an initiator of such an organisation in Sweden is a HPB

<sup>&</sup>lt;sup>51</sup><u>http://www.patient-view.com/</u>

surgeon who understands the needs of pancreatic patients and their carers and sees the benefit of such a stand-alone organisation.

The second part of Phase 3 is inviting Ministries of Health and / or national agencies to review the scores for the indicators for their respective countries. The national representatives receive their respective preliminary score sheets, with no reference to other states' scores, via e-mail where they are kindly asked to review and send updates or corrections within a period of 4 to 6 weeks (where in-between a reminder was sent out). Corrective feedbacks from all the countries involved in the EPCI 2014 were accepted till within the given period. Only those sound suggestions backed with references and data were taken into consideration and thus the scores were updated.

### 11.2.4 Phase 4: Report writing

Phase 4 is the preparation of the final results and writing up the Index Report with its Matrix.

- This EPCI 2014 Report describes the principles of how the EPCI 2014 was constructed, interprets the results and uncovers or roles out the EPCI 2014 Matrix, which is HCP's distinctive product,
- The EPCI 2014 Report and Matrix are presented at a seminar and web conference in Brussels.
- On-line launch of EPCI 2014 on HCP's official website<sup>52</sup>.

# **12. About the authors**

Project Management for the EPCI 2014 has been executed by **Anne-Marie Yazbeck** (Ph.D. candidate) as senior researcher. She has worked with the Health Consumer Powerhouse since 2008 and co-authored the Euro Consumer Heart Index 2008 and the Euro Headache Index 2012. Her experiences include working at the Ministry of Health of Slovenia, National Institute of Public Health of Slovenia, WHO, EPOS Health Management Consulting.

**Arne Björnberg, Ph.D.**, Chairman and Chief Operating Officer of the Health Consumer Powerhouse. Dr. Björnberg has previous experience from Research Director positions in Swedish industry. His experience includes having served as CEO of the Swedish National Pharmacy Corporation ("Apoteket AB"), Director of Healthcare & Network Solutions for IBM Europe Middle East & Africa, and CEO of the University Hospital of Northern Sweden ("Norrlands Universitetssjukhus", Umeå). Dr. Björnberg was also the project manager for the EHCI 2005 – 2013 projects, the Euro Consumer Heart Index 2008 and numerous other Index projects.

<sup>&</sup>lt;sup>52</sup>www.healthpowerhouse.com

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