Improving cancer outcomes through better cancer data in Poland

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ABSTRACT

Based on NFZ published aggregate data, the public spending on cancer care in Poland was 6.3 billion PLN in 2011 (or approximately 10% of total public health spending). Poland is one of the few large countries in the world that has two centralised and public data sources for cancer, namely the National Cancer Registry (NCR, pol. Krajowy Rejestr Nowotworów – KRN) and activity expenditure database run by the National Health Fund (NFZ, pol. Narodowy Fundusz Zdrowia). We show in our article that having a population-based registry **and** a complete treatment/clinical care dataset is a necessary condition to have a useful cancer strategy data set that can in turn lead to evidence based health policies in the area of cancer. Lack of audited and publicly available cancer data means that a coherent cancer strategy, assessing service provision and cost effectiveness of treatments and monitoring outcomes is, in our opinion, currently not possible in Poland. We postulate that Poland should create a task force to create cancer data strategy based on NCIN (National Cancer Intelligence Network) in the UK or Cancer Australia.

KEY WORDS: evidence based health policy, cancer, NFZ, cancer data strategy

International experience from the past 10–15 years shows that good cancer data is one of the key success factors leading to improving cancer outcomes. The need to improve data consistency, quality and availability has been widely raised, and subsequently addressed through national programmes as part of various national cancer strategies. Development of cancer data capacity and analysis has consistently been nominated as a leading priority in all international consultations.

The key competencies for a successful cancer data strategy can be defined as:

1. Data acquisition
2. Data analysis and audit
3. Data provision.

Data analysis in this context means designing and performing analysis that for the purpose of drawing meaningful conclusions and to aid decision-making. It seems that each statutory body in Poland, such as the National Cancer Registry (NCR, pol. Krajowy Rejestr Nowotworów – KRN) or NFZ (National Health Fund, pol. Narodowy Fundusz Zdrowia) does its own analysis, but these analyses remain fragmented and therefore cannot easily be utilised by policy makers to drive health strategy. The main payor (NFZ) is not mandated to perform the data analysis but is not prohibited either.

Provision of up-to-date, complete and accurate basic data is critical to all the users of cancer data including patients and decision makers. There must be a set of performance standards in data provision, particularly to address the issue of improving timeliness, accuracy and completeness of data. The performance of entities involved in obtaining and disseminating cancer data should be monitored and should be subject to an independent appraisal.

A recent paper by Kozierkiewicz et al. [1] states that "it is an exceptional opportunity in Poland to run two good quality cancer data sources", and that Poland is one of the few large countries in the world that has two centralised and public data sources for cancer, namely the National Cancer Registry (NCR) and Disease Treatment Register (RLC) system run by the National Health Fund (NFZ). The authors state that majority of countries have decentralised and fragmented cancer registration databases and these are often voluntary. In many countries there are many healthcare providers and/or payors and treatment data often does not include treatments in both public and private sector.

We agree with the authors of the above paper that having a population-based registry and a complete treatment/clinical care dataset is a necessary condition to have a useful cancer strategy data set. However it is not sufficient.

Our analysis shows that access to any aggregate health data in Poland (not just cancer data but any disease or hospital activity data) is limited and/or very time consuming, the data that is available is not always consistent, the methodology of aggregating data is not always clear and therefore the quality of publicly available data is difficult to assess. This lack of methodology further makes international comparison and benchmarking difficult.

We therefore postulate that a coherent strategy for data collection and analysis in cancer should be an absolute priority for Poland. As we will present in this paper, lack of data means that a coherent cancer strategy, assessing service provision and cost effectiveness of treatments and monitoring outcomes is, in our opinion, currently not possible in Poland.

Cancer is often in the headlines of the Polish press, probably for the wrong reasons such as lack of certain chemotherapy drugs and lack of access to care. We believe that the Ministry of Health has not clearly explained to the population, doctors or patients the importance of a coherent and national cancer strategy as a tool of management that can lead to better delivery of care.

The prevailing argument is (and will be in the media) that we should not spend any more on administration or systems or data collection or analysis, but this money should be spent on direct care. The international evidence actually points to a completely opposite argument: because not enough is spent on administration and analysis, we do not know if the limited resources we are spending could actually be better spent.

Based on NFZ published aggregate data, the public spending on cancer care in Poland was 6.3 billion PLN in 2011 (or approximately 10% of total public health spending). As a proportion of healthcare spending it is much higher in Poland than in either Australia or UK where spending on cancer is 6–7% of total healthcare expenditure[1].

In order to compare and benchmark the level of spending on cancer, one should not use population size (per capita) or even new cancer incidence but prevalence. Prevalence is the best measure of disease burden. Short-term prevalence is usually close to incidence but medium (5 years) and long-term (25 years) prevalence are linked to the age structure of the population and more importantly to the quality of care.

Poland has a total population of 38 million and cancer incidence of 140,000 per annum. As the prevalence figures in Poland are not regularly published, we have assumed a 5-year prevalence figure of 425,000 (NCR had estimated 5 year prevalence at 380,000 in 2006). Australia has 22 million population, 115,000 new cancer cases, 340,000 people diagnosed with cancer in the past 5 years (5 year prevalence) and 775,000 people diagnosed with cancer in

[1]In both countries includes primary, specialist and community care as well as costs of prescription pharmaceuticals. In Australia it includes private sector spend whilst in Poland it excludes private sector spend.

the previous 25 years. Australia is known to have one of the best cancer survival rates in the world.

In Australia cancer spending (excluding research and administration) was approximately 3.4 billion AUD, which translates into approximately 10 billion PLN at today's exchange real exchange rate. So at the prevailing exchange rate cancer spending is 3 times lower in Poland than in Australia (500 PLN vs. 170 PLN in Poland). But it is only 2 times lower when we look at spending per new cancer case or prevalent cancer case (15,000 PLN in Poland vs. 33,000 PLN in Australia).

When comparing Poland internationally one should look at Purchasing Power Parity (PPP)[2]. This ratio, also referred to as the national price level, makes it possible to compare the cost of the bundle of goods across countries. Applying this ratio to cancer spending we obtain similar cancer spending per capita but spending at PPP equivalent level, excluding private sector spend in Poland on a new cancer case as well as on people living with cancer is higher in Poland than in Australia![3]

So could the PLN 6.3 billion in Poland be spent better? Probably… but we do not know as we do not have the data to analyse. However we have found no evidence that anyone, including at the highest level of healthcare strategy planning, actually knows the answers to the following questions (or that answers can be found in public sources):

1. What is the current 5 year and 25 year prevalence of cancer in the population?
2. What is the expenditure on cancer care in more detail than the NFZ analysis shows?
3. Is there equal access to care?
4. What is the pattern of care, patient pathway and waiting times?
5. Are there any targets and are those being met?
6. What is the outcome of treatment in relation to cancer stage? Is the spending on different treatment modalities optimal?
7. Is the cancer care appropriate for the disease stage and does it take into account patient preferences?
8. How do we improve cancer survival and what are the priorities if resources are limited?

Poland does indeed have an excellent starting point, with a very comprehensive data set. What it lacks is a clear and coherent analysis and audit. The additional resources required to analyse and audit the available data, and to create a National Cancer Data Network, would be limited compared to the resources already invested in data collection. Any such process should start with a comprehensive data review, which might in the short term require additional resources. If such comprehensive review identifies inefficient spending and/or care, which contradict international best practice, this will have a much larger and quantifiable benefit for the population as a whole.

CANCER DATA IN POLAND: CURRENT STATUS AND ISSUES

We have based our analysis solely on publicly available data sources

The impetus for this analysis has been the first debate on the future of cancer care in Poland organised by Polskie Towarzystwo Onkologiczne and held on 4th April 2013. After the meeting we reviewed 3 recent publications (1,2,3) that state that "it is an exceptional opportunity in Poland to run two good quality cancer data sources", and that Poland is one of the few large countries in the world that has two centralised and public data sources for cancer, namely the National Cancer Registry (NCR) and the system run by the National Health Fund (NFZ). There is also a subsystem of NFZ database named Disease Treatment Register (RLC) system, which is available to authorised users only.

The authors of the articles rightly surmise that that the basis of any analysis is good data, which is the condition *sine qua non* for evidence based medicine and evidence based health policy. Based on the data provided in these three publications we make some critical analysis and suggest potential solutions to some of the data gaps that we have identified. Our remarks need to be taken in the context of limited resources available in Poland, and we would like to stress that given the resource constraints the outcome is better than one could expect. However international experience points to some easy, and not always resource intensive solutions, that could lead to better outcomes for patients, planners, providers and payors.

1. Population based cancer registry – NCR

The legal basis for the National Cancer Registry as of January 1, 2012 is the Act on the health care information system of April 18, 2011 (Dz. U. [Journal of Laws] of 2011 No. 113, item 657). Data needs to be sent from all healthcare entities (public, private, pathology laboratories etc.) on a monthly basis to one of the 16 regional centres, which is then in turn sent once year to the Central Registry based at the Institute of Oncology in Warsaw. Since July 2013 the system has changed and involves real time data entry and updates to the central server. It is not clear though when such data will be published or made publicly available.

The records of new cases of cancer in Poland are collected on the basis of the cancer registration forms and the registration is then

[2]Purchasing power parity conversion factor is the number of units of a country's currency required to buy the same amount of goods and services in the domestic market as in another country. We have used the conversion factor from World Bank for 2011.

[3]PLN 75,000 Poland vs 66,000 Australia per new case and PLN 25,000 Poland vs 22,000 Australia for 5 year prevalence

carried out in two stages. Each regional centre receives data from its regional healthcare providers either in paper or in electronic format. Although data collection is mandatory, it is not clear what are the consequences for incomplete entries. Each regional centre is based in a public hospital selected arbitrarily for historical reasons. It would seem that the new central system will have a wealth of data stored in real time but it would seem that no-one outside the system administrator will have access to data in real time. This creates asymmetry of information where one provider, historically selected, has access to the data whereas other providers in the area do not.

The decision whether to register a cancer case is made by the treating unit or the treating doctor, and the case is marked as suspected or confirmed. The old server system was based on PROGRESS whilst personal data is based on HL7 protocols. It was "flat" and did not create links between records for a given patient. The first registry card was filled in at diagnosis or suspected case, and with each additional treatment a new record was filled. In this way any given patient could have between 1 to 10 registry forms, filled by different providers. The new system, based on SAS, should remedy some of those issues.

We have not seen any analysis of inter-regional migration. One would assume that a first visit for a patient with suspected cancer would be close to where he lives, but given the regional discrepancies in healthcare provision it is feasible that first registration is sent by the provider to patient's place of residence regional centre but that any medical care (and therefore follow-on entries) are made in other regions and that the main record is therefore not always updated. In international experience inter-regional migration usually accounts for 1–2 % of cases.

The annual datasets are then transferred (once a year) in an electronic format from the regional centres to the National Cancer Registry, where data are combined and analysed. These data are verified in terms of the logical and essential correctness and are added to the annual dataset.

Any cancer data needs to be credible. NCR annual report [6] and one of the publications [2] have assessed the credibility of data based on completeness of cancer registration in the studied population. They both note a substantial increase in completeness of registration, which has been measured by under-registration. The under-registration has decreased from an estimated 30% in the early 1980s to the currently estimated 9%. In order to calculate

TABLE 1.
Key statistics by region.

REGION	Popn`000	Mortality 2010	Incidence 2010	I/M	Completeness	M/I % 2010
01 - DOLNOŚLĄSKI	2,917	7,359	11,704	1.59	95%	63%
02 - KUJAWSKO-POMORSKI	2,099	5,737	8,114	1.41	84%	71%
03 - LUBELSKI	2,179	4,635	8,007	1.73	100%	58%
04 - LUBUSKI	1,023	2,359	3,535	1.50	89%	67%
05 - ŁÓDZKI	2,542	6,843	10,199	1.49	89%	67%
06 - MAŁOPOLSKI	3,337	7,394	11,020	1.49	89%	67%
07 - MAZOWIECKI	5,267	12,959	17,217	1.33	79%	75%
08 - OPOLSKI	1,017	2,332	3,733	1.60	96%	62%
09 - PODKARPACKI	2,128	3,933	7,365	1.87	100%	53%
10 - PODLASKI	1,203	2,774	3,620	1.30	78%	77%
11 - POMORSKI	2,275	5,553	9,577	1.72	100%	58%
12 - ŚLĄSKI	4,635	11,752	16,915	1.44	86%	69%
13 - ŚWIĘTOKRZYSKI	1,283	3,008	5,253	1.75	100%	57%
14 - WARMIŃSKO-MAZURSKI	1,454	3,450	5,087	1.47	88%	68%
15 - WIELKOPOLSKI	3,447	8,218	13,581	1.65	99%	61%
16 - ZACHODNIOPOMORSKI	1,724	4,305	5,637	1.31	78%	76%
POLAND	**38,530**	**92,611**	**140,564**	**1.52**	91%	**66%**
Female				1.73		58%
Male				1.35		74%
UK 1999						
Female				1.72		58%
Male				1.56		64%
Overall				1.64		61%

the under-registration NCR takes the incidence/deaths ratio observed in countries similar to Poland in terms of cancer risk and cancer care (Slovenia, the Czech Republic, Slovakia).

In 2010, in Poland there were 140,000 new malignant cancer cases registered. Based on the calculated completeness level of 91%, the NCR estimates that the true number of new cases was about 155,000. The overall I/M ratio in Poland was 1.52, with 1.35 for men and 1.73 for women. In order to compare with the UK we inverse the ratio into M:I and we obtain overall M/I of 66%, with 58% for women and 74% for men respectively. The report also notes that the I/M ratio shows very large variability between regions and that only 4 regions show overall M/I % compatible with good completeness of data.

The total budget for all cancer registries in Poland is approx. 1.5M PLN, which translates into PLN 10 per case. Even adjusting for PPP, the very low cost per registration implies that the resources are limited.

There is one comment or suggestion for further discussion: although for historical reason, and even for future healthcare resource planning, each region has kept its own local registry office, we would recommend an independent report of the current system. In order to be cost efficient and have economies of scale a registry office needs to cover a population base larger than 4 million and/or have at least 40,000 registry cases per annum. Poland should therefore consider using its resources more efficiently and considering having 6-8 large registries that might also decrease the current regional variation.

The report further notes that in some diagnoses less incidence than mortality is recorded (i.e. ratio is less than 1). This occurs within categories as "other and unspecified" within several organ systems but more importantly in metastatic sites such as liver, lung or bone. The standards for cancer registry recommend that all such categories be audited.

Another key measure of accuracy is % MVI or histo-pathological confirmation of diagnosis. In 2010 the reported MVI% in Poland is 84% for men and 87% for women. This has doubled over the past 20 years. This proportion is lower with increasing age (80% for over 65 in both sexes) and it also varies significantly between regions.

We would argue that it might be time for Poland to compare its performance indicators to countries other than its central European peers if it wants to make progress in cancer care, and to make best use of available resources. We have therefore compared the Polish cancer registry against UK Cancer Registry performance indicators from 2000 (the time of the Gillis review) and the latest data form Thames Cancer Registry (2012 report on 2011 datasets). Thames Cancer Registry is the largest in the UK, covering a population of over 15 million and registering approximately 60,000 new cases per annum.

Reminder: in the Gillis report (2000) the quality of the data was assessed by:

1. Timeliness by % registrations where initial notification was received within 18 months from the end of a calendar year: 80%
2. Completeness by the Mortality to Incidence ratio (M:I ratio) for males (expected 60-65% with lesser values for females): male 64.1%, female 58.1%
3. Completeness and accuracy. Death certificate only (DCO) registrations should be low: for 1999 these were at 5.5% for both males and females
4. Accuracy: Registrations are said to be microscopically verified (%MV) when they are supported by histology, cytology, bone marrow or haematology reports. Average for England was 78% but some registries were below 70%.

Based on our benchmarking, the data seems accurate. However, the timeliness is a real issue as there is a lag of 2.5 years before any new data are available. The target is completion by 18 months but the case of Thames Cancer Registry shows that it is possible to improve the timeliness of data without compromising data quality by 100% (from 18 months to 9 months between 2009 and

TABLE 2.
Preformance indicators.

	Timeliness	Completeness	Completeness and accuracy	Accuracy	Staging
Measure and Target	100% in 18 months	M/I ratio 60–65% for males, lower for females	DCO % <3	%MVI	
UK 1999	80%	M 64% F 58%	5.50%	78%	n/a
Thames Cancer Registry 2011	100% in 9 months		2%	88%	all stageable to be completed by end 2013
Poland 2010	0% (1)	M 74% F 58%	n/a	84–87%	not done

(1) 91% in 30 months.

2012). The completeness also seems to be an issue, particularly for males. In general M/I ratio above 65% for males is considered indicative of poor quality.

There is no information on staging in Poland, although these entries exist on the Cancer Registration forms. This is an issue for all cancer registries worldwide and the UK has a target of 100% staging for all tumours diagnosed in 2012. As we will describe below the proposals in Poland's registration system, this could be a great opportunity for Poland to leapfrog in terms of quality standards internationally.

The NCR has a dedicated staff of 3 (three). This is well below what comparable institutions have in the West. The cost of not investing in more resources, and of not having better quality and timely data available, should be estimated.

Despite having such limited staff, the NCR has been successful in obtaining a grant under "Innovative Economy" to create an IT platform for data sharing in cancer. The project was finished in June 2013 and was presented to the public in September 2013. Unlike the old system of data collection, this one will be based on most modern data collection techniques (relational databases and SAS system) that should allow tracking of patients through the diagnostic and therapeutic pathway. At this stage it has not been communicated how, to whom, when and on what basis the raw data will be made available although the project description has a stated aim to make the data as widely available as possible, including members of the public.

We believe that the implementation of the new system provides a unique, once in a lifetime opportunity to change the cancer data collection in Poland. This would in turn lead to evidence based health policies in the area of cancer.

The new IT system does not in itself address several of the issues that we had identified:

- The quality and timeliness of the data
- Lack of histopathology and staging data
- Data linkage with activity database.

2. Activity data

In Poland healthcare is financed through a national health fund (NFZ) – similar to NHS in the UK. The Health Ministry has decreed the list of items that need to be collected in the NFZ database. The most important data collected are patients ID number (PESEL), JGP* product code (equivalent to HRG system, which is the basis for payment to the health provider), the ICD-10 code and for admissions that include a diagnostic and/or a surgical procedure also ICD-9 code for the main and sometimes secondary procedure.

By definition this activity data, at an aggregate and anonimised level, should be publicly available. We absolutely agree with the authors of several publications that there probably is a lot of data available. We however strongly disagree that this data is publicly available. We contend that only limited data is publicly available, that the data available is not in any user-friendly format and the resources required to analyse the publicly available data are therefore beyond the reach of most academic institutions, patient–right organisations, or even research organisations. We believe that this unequal access may have led to a secondary commercial market in data or that such data is available to organisations with large research and/or marketing budgets.

We are not sure who collects the data on the private sector not funded by NFZ i.e. paid out of pocket and/or through private insurance schemes. Although it is unlikely that in cancer care a lot spending is self-funded, this may not be true in other health services such as orthopaedics, ENT or gastroenterology. In terms of cancer care, specialist ambulatory care and/or diagnostic procedures almost certainly happen in the private sector but it is difficult to estimate what proportion. This is a major data gap.

Most importantly the quality of the data is not audited by an independent, external body that would be able to crosscheck data sources and confirm their completeness. As we will show on several examples, even basic check at very aggregate top-line numbers shows that there are several data gaps that need to be explained before such data can be accepted as accurate and used for benchmarking.

Based on several informal discussions it seems that the statutes of NFZ have its role as "allocation" of health expenditure and that its role is not to "create a health strategy, analyse data or publish any statistics". If that is indeed the case, the question is which body is or indeed should be responsible?

Even if such body exists, or is in the future created, another issue will be analysis of the database. In order to obtain good analysis it would make sense to use the existing NFZ resources, as the current employees are familiar with the system, can extract and analyse data and suggest future improvements. However here we come across an insurmountable obstacle: according to Article 112 on financing from public sources NFZ employees are forbidden to do any ad-hoc project work, even it is for another public or government agency. So they cannot do it for the National Statistical Office as a project, but at the same time they cannot do it for NFZ, as NFZ does not have analysis or publication of data within its statutes…

What is the outcome? Lack of public data that would allow benchmarking even at a very aggregate level – for example how many admissions for cancer there are in Poland as a total and by main "cancer stream", how much is spent on various treatment modali-

*JGP stands for „jednorodne grupy pacjentów" and is based on UK HRG classification

ties, where are patients treated (type of hospital, type of unit) etc.

Example 1: total cancer activity in Poland in order to benchmark against UK and Australia

NFZ does NOT publish data by ICD-10 or ICD-9 codes at an aggregate level. It is therefore impossible to ascertain how many hospital admissions are for cancer care. Indeed it is impossible to check how many admissions are due to cardiovascular disease, strokes or trauma.

NFZ does publish on its pages a summary of healthcare services contained in catalogues 1a (inpatient care) and catalogue 1b (certain specialised services that also include inpatient stays). So by definition there is no activity data from catalogues 1c–1j, which will contain a wealth of data on oncology care, in particular data on chemotherapy and radiotherapy activity and spending!

The inpatient data from catalogue 1a (inpatient hospital activity) needs to be "downloaded" separately for each JGP category. Within "each" JGP group there is a wealth of data such as number of admissions for a given JGP code, average and median length of stay, average cost, patient age band and sex, type of admission, unit of admission, discharge mode, primary ICD-10 code (for non procedural admissions), primary ICD-9 code (for procedural admissions) and in this case primary ICD-10 code as well. It does not have % of day cases. Regional data contains headline figures only, specifically it does not contain ICD-10 or ICD-9 split. As the data is available through web pages only it cannot be analysed - i.e. when one looks at JGP catalogue it is impossible to calculate how many admissions there were in Poland in years 2008-2012 or for which disease and/or procedure.

In order to be able to analyse this data it needs to be copied from the JGP pages manually (each JGP group separately) into excel and then collated into a database. This way one should be able to sort admissions by ICD-10 code to obtain a global picture of activity. This by definition will be an incomplete picture, as it will exclude:

- Any hospital or other activity for catalogues 1c and beyond i.e. all radiotherapy and chemotherapy.
- Based on selected JGP groups that we have checked, anywhere between 2% and up to 10% are uncoded for medical admissions; for surgical admissions where primary code is ICD-9 up to 30% do not have an ICD-10 code.

In terms of data input, each JGP category for each given year takes on average 5-7 hours for a data entry person. This means that to obtain a database for analysis, incomplete as per bullet points above, will take 200 hours. We can compare that with 5 minutes for other countries that provide data sets in Excel or even SAS data formats.

We therefore come back to our initial point: we absolutely agree with the authors that there probably is a lot of data available in the NFZ database. We however strongly disagree that this data is **publicly available**. We have not been able to find any audits, reports or analyses of the data or source data in format that allows an independent analysis.

Example 2: total cancer spending in Poland

Another way to look at cancer care is to analyse spending. This is not available through the NFZ database or JGP groups, but we came across an NFZ presentation [4]. The presentation is available in pdf format and therefore the authors of this paper "transcribed" the data into Excel so that some calculations can be performed. The results are presented in Table 3 below.

As we can see, one-third of total cancer spending is in "units/services" that are primarily qualified as "non-oncology" care. Furthermore it is impossible to calculate the total admissions, as 1/3 of hospital inpatient care does not have breakdown of admissions number and average cost. It is also impossible to calculate the total spending on chemotherapy and/or radiotherapy as we assume that an unknown proportion of the category "services contracted separately" is likely to include chemotherapy and/or radiotherapy services. Any further analysis, for example spending on new cases versus existing cancer cases, by region of residence and region of treatment, or by cancer "stream", is impossible based on this summary dataset.

Example 3: total hospital activity in Poland in order to benchmark against UK

We then tried to look at data sources other than NFZ.

1. Once a year Central Statistical Office (GUS) publishes an annual review of health and healthcare where it collates data from various sources [8,9]. For cancer data it uses statistics supplied by the cancer registry (2009 data in 2011 review) – notably it uses the "low" confirmed number and not the estimated number that takes into account the 9% of non-reported cases.
2. GUS data contains bed and unit numbers, admissions and total bed days by specialty. As we saw above about 1/3 of cancer patients are treated on non-oncology units such as general surgery, ENT, urology, internal medicine etc. therefore any disease related data cannot be extracted. Day case data is contained in separate tables and does not have a split by unit of admission in publicly available summaries.
3. GUS data excludes inpatient activity from Ministry of Defence and Ministry of Interior Hospitals (17 and 22 hospitals

TABLE 3.
Oncology spending 2009-2011 (NFZ)

	2009	2009 %	2010	2010 %	2011	2011 %
AOS/Outpatiant care Oncology	158,089,218		155,013,047		173,002,753	
AOS/Outpatiant care NON ONCOLOGY	142,385,925		156,158,382		182,610,293	
AOS subtotal	300,475,143	5.4%	311,171,429	5.3%	355,613,046	5.7%
% non-oncology outpatient/AOS	47.4%		50.2%		51.4%	
Oncology hospital care (2)	911,147,902		920,323,260		953,187,589	
Chemotherapy	1,357,550,349		1,304,960,441		1,355,222,821	
Radiotherapy	535,939,419		659,620,965		722,167,755	
Therapeutic programmes (4)	491,493,053		682,837,753		781,739,957	
subtotal inpatient care oncology	3,296,130,723		3,567,742,419		3,812,318,122	
#admissions	*797.233*		*813.305*		*850,479*	
average cost per admission	*4.134*		*4.387*		*4,483*	
Inpatient care NON ONCOLOGY	1,461,158,857		1,485,415,521		1,556,305,144	
Inpatient care subtotal	4,757,289,580	85.9%	5,053,157,940	85.9%	5,368,623,266	85.3%
% non-oncology inpatient care	30.7%		29.4%		29.0%	
services contracted separately Oncology	110,431,540		124,090,638		146,484,749	
services contracted separately NON ONCOLOGY	8,050,970		10,535,565		12,667,070	
services contracted separately subtotal	118,482,510	2.1%	134,626,203	2.3%	159,151,819	2.5%
% non-oncology services contracted separately	6.8%		7.8%		8.0%	
palliative care – NON ONCOLOGY	221,510,961	4.0%	234,487,131	4.0%	250,824,275	4.0%
% non-oncology paliative care	100%		100%		100%	
other care – NON ONCOLOGY (5)	21,480,230	0.4%	23,409,879	0.4%	24,166,577	0.4%
% non-oncology other care	100%		100%		100%	
prophylactic screening programmes	119,867,612	2.2%	123,981,151	2.1%	133,135,060	2.1%
% non-oncology prophylactic screening programmes	0%		0%		0%	
spending oncology	3,684,519,093		3,970,827,258		4,265,240,684	
spending NON ONCOLOGY	1,854,586,943		1,910,006,478		2,026,573,359	
total cancer spending (NFZ)	5,539,106,036		5,880,833,736		6,291,814,043	
% non-oncology cancer spending	33.5%		32.5%		32.2%	

Assumptions listed in NFZ document:
1. Oncology provision: assumed that 100% is oncology.
2. Oncology hospital care induces oncological surgery, hematology, gynaecological oncology, clinical oncology, paediatric haematology and oncology.
3. Other provision: include all health services for codes C00-97 malignant cancer, D00-09 cancer in situ, D37-48 neoplasm of unknown or uncertain origin.
4. Non standard chemotherapy is included in theraputic programmes from 2010 onwards.
5. Includes psychiatric care, rehabilitation and nursing care.
in red: own calculations

respectively). GUS statistics are based on Ministry of Health data electronic system CSIOZ, which compiles data sent from hospitals on formulary MZ-29.

4. CSIOZ also supplies data for its own publications and their activity statistics include Ministry of Defence Hospitals but still exclude activity for hospitals managed by the Ministry of Interior.
5. National Institute of Hygiene (PZH) data contains a summary of inpatient activity data by "groups" of ICD-10 diagnostic codes. PZH collates its data from activity data sheet Mz/Szp-11filled by each hospital. This database has only admission numbers, ALOS, sex and age group by band. No other information is given.

The first step in any analysis is to ensure that databases have been audited and "quality-checked". For example in HES datasets for England the total number of admissions between HRG classification, specialty classification and ICD-10 classification is always the same.

As we can see in Table 4 both GUS and PZH datasets are incomplete. In addition day cases are treated separately and not in the "same" analysis table (in HES datasets day cases are part of admissions so it is easy to see what proportion of a given diagnosis, HRG or specialty is treated as a day case).

We have then compared cancer admissions from the PZH database against the numbers taken from NFZ spending presentation. Again we see that there is a substantial difference in the total activity. Once again, our conclusion is that it is impossible to make any reasonable analysis or benchmarking in the absence of good quality data.

3. **Non-public oncology data**: RLC (Rejestr Leczenia Chorób)

The paper on data comparison between Cancer Registry and NFZ [2] describes a separate module within NFZ database, called

TABLE 4.
Database total comparison.

	2007	2008	2009	2010	2011
Source 1: GUS					
Total number of inpatient admissions (1)				7,911,563	7,888,995
Total number of inpatients (2)			7,240,711	7,344,307	7,468,749
Total number of daycases (3)				1,562,606	733,150
Source 2: PZH					
PZH database ICD-10 code (4)	7,728,709	7,968,578	7,740,121	7,792,176	7,899,789
difference between GUS and PZH				119,387	-10,794

(1) Total number of "hospitalisations" i.e. including patient flow between wards. For benchmarking needs to be compared with FCEs in UK.
(2) Total number of patients admitted, some patients may have more than one episode during one admission (on different units).
(3) Excludes ambulatory and outpatient treatments.
(4) Total inpatient hospitalisations including patient flow between wards. EXCLUDES V,W,X and Y ICD-10 codes.

TABLE 5.
Database cancer total comparison.

Source 2: PZH database cancer admissions						
All Cancer	**C00-D48**	**854,231**	**828,493**	**715,601**	**703,049**	**688,765**
Colorectal	C18–C21	95,013	85,780	61,079	55,678	49,814
Lung	C33–C34	96,115	82,007	61,170	59,429	51,465
Melanoma other skin cancer	C43-C44	13,984	12,480	12,708	12,183	12,890
Breast	C50	78,165	75,789	56,465	55,195	52,310
Uterus + cervix	C53–C55	26,567	22,178	17,049	16,456	15,872
Ovary	C56	31,339	27,821	17,784	17,057	15,065
Prostate	C61	22,668	20,074	15,736	13,789	13,760
Bladder	C67	37,287	39,924	43,618	42,070	39,632
cancer adminissions as % total admissions		11.1%	10.4%	9.2%	9.0%	8.7%
Source 3: NFZ presentation						
#admissions in oncology specialties (5)				797,233	813,305	850,479
#adminissions in NON ONCOLOGY specialies (6)		30%		239,170	243,992	255,144
TOTAL estimated # admissions for cancer				1,036,403	1,057,297	1,105,623
diference between NFZ and PZH database				320,802	354,248	416,858

(5) Assumes hospitalisations i.e. including patient flow, although not made clear in the presentation.
It is also not stated if daycases and ambulatory care episodes are included.
(6) Calculated as 30% of admissions in oncology specialties i.e. it assumes same cost per admission.
Cost per admission could be lower (excludes specialised treatments) but unlikely to be higher so this is a bottom estimate.

disease register (RLC, Rejestr Leczenia Chorob). This internal database is not publicly available, and is actually very difficult to find. It does not come up on search engines, or on NFZ pages. It can be located though the publication that mentions it, but afterwards even inputting RLC into search engines does not result in any tangible output. So once again in theory it is public knowledge… but in practice to find it you actually have to know that it exists and what it does.

We have since been able to find out some limited information about the system infrastructure and capabilities from a public flyer produced from a cervical screening coalition and as a case study from Asseco, a large listed IT provider. Asseco describes a modular system, called CSM (Central Medical Systems), which is linked to the central NFZ database as well as other centralised databases such as the register of all people insured, the register of services provided and payments; each module can be accessed through the internet by registered users in participating institutions and each module has its own in-built audit, statistical monitoring and quality control systems for the funding entity (NFZ).

The first module is SIMP, created in 2006, for screening programmes in cervical cancer and breast cancer. It now seems there is also a prophylactic programme in cardiovascular disease. The second module has been recently added: SMPT, which is based at the Ministry of Health and is used to monitor specific patient

approval for drug therapy in rare conditions such as psoriasis and autoimmune disease. The ASSECO case study does not mention RLC.

RLC can only be "seen" by people who already have been registered to use it and have access to it. In simple words: even a hospital provider who has access to CSM module for screening (SIMP) cannot even see that RLC exists as it does not appear on the "dropdown menu"…

We believe that the President of the NFZ can grant permission for access. Based on several interviews it seems that getting access, on a named person basis and after an undertaking on data protection, can take up to 12 months. We have not been able to ascertain who has access to the database and whether access to the database is monitored and summary of data usage collated by the NFZ. We have not been able to ascertain whether the register has other modules for diseases other than cancer. We believe that national consultants have access to the database but we have not been able to confirm it independently.

It would seem that commercial entities such as pharmaceutical companies have or have had access to the database. This is not an issue as long as equal access is granted to providers and commercial organisations. For example in the UK there is a similar database run by NCIN. NCIN defines 2 types of users: NHS entities (providers or at-length organisations such as NAO) and non-NHS entities (management consultancies, pharmaceutical companies). The approval takes few weeks, once an appropriate Data Access Agreement has been signed. The system is transparent.

This intranet system seems to have[4] a wealth of data. As far as we understand cancer patients in the RLC systems have unknown, suspected or confirmed status. The migration form suspected to confirmed is done automatically in the system when an individual patient has a health service clearly linked what cancer such as chemotherapy, radiotherapy or a surgical procedure. We are not very clear how the list of procedures that move a patient from a suspected to a confirmed case has been established. There is currently no module in the RLC that distinguishes between radical and adjuvant treatment. It is also not very clear how new cases can be defined – we believe that at the moment this can be done by going "backwards" to the beginning of the database i.e. 2004. Once a patient has been identified, all the data on such a patient is made available and through ICD-10 and/or ICD-9 codes the "first cancer episode" can be then detected.

The data to be analysed needs to be well defined upfront and the download of large datasets is in HTML format. This means that for pattern of care analysis for a single cancer (breast) data download and analysis takes 1 month. This prevents more extensive and timely analyses and should be addressed urgently by the system provider i.e. ASSECO, in collaboration with NFZ and the Ministry of Health.

Another major data gap is the ICD-10 definition of cancer. The RLC only contains data on C00-97 and D00—D09 diagnostic codes. Similarly by law only cases with C00-97 and D00—D09 diagnostic codes must be notified to NCR.

Yet NFZ analysis on cancer care [4] also includes C37-48 codes (unknown or uncertain neoplasms). If this diagnostic category represents only 1-2% of cases and spending it can probably be ignored (it is approximately 1% in the HES database for England). However if it accounts for a significant proportion of cases then its exclusion may invalidate analysis and conclusions that are based solely on NCR and RLC data. Logically, if NFZ has included this category in its own spending analysis it probably "knows" that these cases account for a significant proportion of activity. So the question remains: is analysis based on RLC and CSR, that by definition excludes 10% of cases, accurate or not?

SUMMARY OF CANCER DATA AVAILABILITY UK AND SELECTED CANCER TARGETS

1. Population based cancer registries and the Office for National Statistics (ONS): incidence, mortality, and 1 and 5 year survival by primary site, age and region. Latest available 2010, with survival for patients diagnosed 2006-2010 till 2011. All data available with clear methodology in either pdf or Excel (xls) format.
2. Activity data: details of all NHS inpatient treatment, outpatient appointments and A&E attendances in England. Activity can be categorized by specialty, main diagnosis, main procedure, provider or geographic area. All data available with clear methodology in either pdf or Excel (xls) format.
3. Linked databases for cancer
   a. National Cancer Data Repository (NCDR) is a merged dataset of cancer registration data and extracts of HES activity data. It is based on Merged English Cancer Registry Data (1990–2010) and ONS Minimum Cancer Dataset (1990–2010). HES data includes inpatient and day case hospital episodes for patients with a diagnosis of cancer. This dataset provides information about diagnoses, operations, demographic, administrative details and has been matched to the ONS dataset. It currently includes over 8.5 million cancer registry records linked to 34 million hospital records. There are full audits of non- linked records, and quality assurance analyses of linkage performance.
   b. Clinical Practice Research Datalink (CPRD) collects data from primary care practices throughout the UK. Access

[4]All the conclusions are based on limited interviews.

to linked datasets is currently more restricted than to NCDR.

The current focus in the NHS is expanding patient choice so that by 2013 there will be a presumption of choice and "any willing provider" for majority of NHS-funded services.

In cancer such choices are not simple and exercising informed choice assumes patient access to information and support to make the most appropriate decision such as when to have treatment, where to have the treatment and which organisations and teams deliver the treatment. The patients should be able to choose different providers for treatments along the care pathway: for example travel for surgery to a specialist provider with better outcome followed by chemotherapy and/or radiotherapy locally. In cancer decisions about which treatment to have may have different options and therefore it is essential that patients have information on a range of different, clinically appropriate and evidence-based treatments available.

The providers will therefore need to make the following information publicly available:

- The range of cancer services provided by each provider.
- Whether each MDT team[5] has core members from all the relevant disciplines.
- Whether the MDT team has a clinical nurse specialist.
- How many patients by equality characteristic were diagnosed/treated in the previous year and how they were treated.
- Compliance with waiting time standards.
- Compliance with peer review measures.
- Major resection rates.
- Mortality rates within 30 days of treatment.

When relevant to their service, providers should also specify:

- The rate of laparoscopic versus open colorectal cancer surgery.
- The rate of immediate versus delayed (or no) breast reconstruction.
- Surgery, radiotherapy, active monitoring or other treatments for localised prostate cancer.
- The availability of Intensity Modulated Radiotherapy (IMRT).

Selected waiting time standards, peer review and cancer audit measures in UK are listed below:

- Overall time: 100% of patients should commence treatment within 62 days of GP referral.
- GP referral date until first outpatient visit: 14 days.
- Clinic correspondence with GP: 7 days from clinic attendance.
- Biopsy arrival in pathology department: within 24 hours.
- FNA reporting: 80% same day.
- Time for frozen section results: 30 minutes for one section, 45 minutes for multiple sections.
- Biopsy until report issued: 90% within 7 days.
- Surgical resection until reporting: 80% within 14 days.
- General clinic until MDT meeting (MDTM): 14 days.
- Decision to treat until radiotherapy or chemotherapy (curative intent): 31 days to start radiotherapy, 21 days to start chemotherapy.
- Decision to treat until radiotherapy or chemotherapy (palliative intent): 14 days.
- From decision to treat at MDTM until ablative surgery: 31 days.
- Surgery until post-operative radiotherapy: 42 days.

SUMMARY OF CANCER DATA AVAILABILITY IN AUSTRALIA

1. Population based cancer registries

In Australia all new cancer diagnoses are required by law to be reported to state-based cancer registries. The Australasian Association of Cancer Registries (AACR) is a collaborative body representing the eight Australian state and territory cancer registries, the New Zealand Cancer Registry and the Australian Institute of Health and Welfare (AIHW).

AIHW administers the National Cancer Statistics Clearing House (NCSCH), which is the national repository of cancer incidence and mortality statistics. NCSCH maintains the Australian Cancer Database that contains all primary malignant cancer cases diagnosed in Australia since 1982 (except basal cell and squamous cell carcinomas of the skin). It also adds data from the National Mortality Database, which records all deaths where cancer was the underlying cause since 1968.

Publicly available data include:

1. AIHW cancer publications (latest Cancer in Australia: an overview 2012).
2. Excel pivot table with all cancers, but with less detail than ACIM books.
3. Australian Cancer Incidence and Mortality (ACIM) Excel workbooks with summary statistics and raw data for incidence and mortality since 1982 and 1968 respectively.
4. Data cube contains the same data as pivot table but in different interface (SAS datasets available for download).
5. General Record of Incidence of Mortality (GRIM) Excel data on selected causes of death by age and sex for each year.

Additional data is available on application and is charged on a cost-recovery basis. To obtain identified unit data additional

[5]Every new cancer case (100% target) needs to be discussed at MDT and this is a key audit measure

clearance and ethics permission is required.
Important note: there are currently no national data on cancer stage or treatment.

2. Activity data

Similar to HES in the UK, Australia provides aggregate summary records for episodes of care in public and private hospitals. The database contains records for years 1993/94 through to 2010/11. The national hospital morbidity database (NHMD) contains data from almost all hospitals in Australia (public acute and psychiatric hospitals, private acute and psychiatric hospitals, and private free standing day hospital facilities).
Summaries are available in Excel format and include principal diagnosis (ICD-10), Diagnosis Related Group and procedure (ICD-9) aggregate data. In order to help analysis some of the information is available direct through SAS data cubes (up to 2010).

3. Linked databases for cancer

Unlike UK, Australia does not currently have a national linkage model. The linkage models currently exist in 2 states.

- *Western Australia (population 1.7 million) has WA Data Linkage System*–a statewide linkage model for research purposes. It brings together birth records, midwives' notifications, cancer registrations, in-patient hospital morbidity, in-patient and public out-patient mental health services data and death records and in the future should also include data on primary, residential and domiciliary care. The system took more than 3 years to develop and to link seven million core data records. Access is currently restricted to research.
- *New South Wales: NSW Centre for Health Record Linkage (CHeReL) and NSW Clinical Cancer Registry Model (pilot),* which is run by the University of Sydney Cancer Epidemiology and Services Research Team. All the data are anonimised and come from 3 sources:
    a. NSW Central Cancer Registry (CCR) - cancer is notifiable due to Public Health Act.
    b. NSW Admitted Patient Data Collection (APDC) - all hospital separations (discharges, transfers, deaths) from all public and private hospitals and day procedure centres.
    c. Emergency Department Data Collection (EDDC).

CONCLUSIONS AND RECOMMENDATIONS:

Poland is one of the few large countries in the world that has two centralised and public data sources for cancer, namely the National Cancer Registry (NCR) and Disease Treatment Register (RLC) system run by the National Health Fund (NFZ) and "it is an exceptional opportunity in Poland to run two good quality cancer data sources". However we have shown that having a population-based registry **and** a complete treatment/clinical care dataset is a necessary condition to have a useful cancer strategy data set.
We believe that the implementation of the new cancer registration system provides a unique, once in a lifetime opportunity to change the cancer data collection and analysis in Poland. This would in turn lead to evidence based health policies in the area of cancer.

Recommendation 1: create a task force to create cancer data strategy, define quality standards, targets and audits, assess the current state and make recommendations to the Minister of Health. Such task force should in a very short time (3-6 months) become the equivalent of NCIN (National Cancer Intelligence Network) or Cancer Australia and should therefore include all the staff from Central Cancer Registry, representatives from National Hygiene Office (PHZ), National Statistical Office (GUS), Data Protection Agency (GIODO), Strategic Planning Department of the Health Ministry. As part of the report the task force should assess how many regional offices are required to best meet the demand for good quality and timely data in the most cost effective manner.

Recommendation 2: the task force for cancer data strategy should in turn be "converted" as an independent body reporting to the Ministry of Health and working as the future "Cancer Poland/Cancer Intelligence Network". Such entity should clearly define data requirements and reporting for cancer and institute a transparent analysis, audit and publication programme. It should review the RLC module and establish the data and information parameters. It should confirm the parameters of audit, statistical monitoring and quality control systems. It should establish clear and transparent access guidelines. It should publish the list of registered users. It should define the format of data downloads for further external analysis so that it can be obtained in a timely and user-friendly format. It should clearly define analysis, audit and publication programme from the RLC so that it can be used to drive cancer strategy. It should make it **an absolute priority** to create a linked database for cancer, in the first instance linking NFZ database with Cancer Registry database, and as soon as possible with pathology database (or entry of histopathology and staging direct into a future NCIN-equivalent database). If required this should be legislated if current legal regulations are not sufficient.

Recommendation 3: the National Cancer Registry should become an independent body, arms' length from any provider or another health agency and should report directly to the Ministry of Health.

Recommendation 4: full data entry, including any histopathological data and staging data, should be made compulsory. If required this should be legislated if current legal regulations are not sufficient. To ensure compliance we would strongly recommend that correct data entry be linked with payment to providers. In order to ensure that data is compatible we would recommend cross check through linkage with activity database.

Recommendation 5: pathology reporting (and therefore cancer staging) seems to be the weak link in Poland, not just in cancer registration but also along the cancer treatment pathway. Under the JGP system the cost of histopathology is borne by the provider, which anecdotally leads some of the providers to limit the purchasing of histopathology services. As this is key in any cancer strategy we would recommend that histopathology becomes a separate service item within NFZ payment system. This will not necessarily add to the total cost, although a task force could estimate the current "cost" borne by providers and shift it to a direct spending model in exchange of strict quality and timeliness targets.

Recommendation 6: prevalence data should be made available, as it is required to calculate cancer burden, assess effectiveness of spending and to benchmark Poland versus international peers.

Recommendation 7: there is a clear need for a legal opinion pertaining to public health activity data availability from the NFZ database, the duty of NFZ to perform and publish analysis, the duty of other administrative bodies to command, audit or produce its own analyses. A legal opinion should also establish on what basis NFZ employees can and indeed should contribute to strategic healthcare planning and can provide raw data and/or analysis to other administrative bodies, research institutions or patient associations. There should be a clear definition of data access, how ad-hoc requests can be made and the time of response to access queries.

Recommendation 8: NFZ should publish aggregate activity data from all catalogues in a user-friendly manner and with clearly stated methodology and exclusions. At the least, the activity should be presented in 3 formats to make international comparisons easier: by JGP (HRG) group, by ICD-10 diagnosis and by ICD-9 diagnosis. All hospital data should include day case activity, separately accounted for, in the same groupings.

Recommendation 9: the NFZ should publish the methodology of RLC, including the codes that move the patient from suspected to confirmed category. In order to make data analysis possible NFZ should clearly state whether codes D37-48 are or are not included in oncology spending and should include them in the RLC.

Recommendation 10: given the discrepancy in data we have identified, NFZ or Ministry of Health should analyse cancer spending though a linked dataset for 2010 or 2011 (last cancer registry data available) including regional analysis. These results should be published. In our opinion such an analysis can be done within a few weeks, starting from last available cancer registry dataset and matching NFZ procedures. It would also allow for the first time to establish a pattern of care for new cancer cases, patient pathway and actual waiting times. It would also clearly demonstrate how many diagnostic procedures and admissions are required for each new cancer case.

Additional background information in more detail is available online (http://www.mededu.pl/periodical/18/oncoreview) [TBC] as follows:

1. Benchmarking and case studies- comparator countries in Appendix 1
2. The importance of cancer data in Appendix 2
3. Uses and sources of cancer data in Appendix 3
4. UK case study detail in Appendix 4
5. Australia case study in Appendix 5

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