THE CONCORD PROGRAMME: WHY WE NEED GLOBAL SURVEILLANCE OF CANCER SURVIVAL

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Millions of cancer patients will continue to be diagnosed each year for the foreseeable future. They all need to access optimal health care. Population-based cancer survival is a key measure of the overall effectiveness of health systems in managing cancer. Survival varies very widely around the world. Global surveillance of cancer survival is required, because unless these largely avoidable inequalities are measured, and reported regularly, nothing will be done to ameliorate them.

The burden of cancer

In 2008, an estimated 12.7 million patients were diagnosed with cancer, and 7.6 million cancer deaths occurred. More than half (56%) of the cancer diagnoses and 64% of the deaths were among people living in low- and middle-income countries (LMIC)[1]. The annual number of newly diagnosed cancer patients will rise substantially by 2030 because of ageing of the world's population, growth in population size and for many persons, an increase in their risk of developing cancer at each age (age-specific risks). All three factors will affect poorer countries more.

Prevention remains preferable to cure, especially for such a lethal constellation of diseases. The need for long-term investment in primary prevention to reduce age-specific cancer risks for future populations remains equally inescapable. However, since we cannot expect the manufacturers and purveyors of tobacco to fall on their swords any time soon, the responsibility for primary prevention falls to politicians and other leaders of society with the courage, the selflessness and the long-term vision to develop and implement policies for cancer prevention that will probably not bear fruit during their political life-time. The Framework Convention for Tobacco Control (http://www.who.int/fctc/about/en/index.html) offers a good starting point. Long-term reductions in tobacco consumption have led to long-term declines in lung cancer incidence in a number of countries.

Where we do know the cause(s) of cancer, the latency between causative exposure(s) and clinical disease is often measured in decades, not years, and for around half of all cancers, we do not know the cause, so primary prevention is not yet possible.

Thus, even if every cancer prevention measure that we know to be effective today were applied to every person, worldwide, tomorrow, and even if those measures were instantly and completely effective, in every person overnight – for example, abolishing the 20-fold lung cancer risk in heavy smokers – millions of people would continue to be diagnosed with cancer each and every year for the foreseeable future. Unfortunately, cancer prevention is not even close to being that prompt, that effective, or that widespread: the Framework Convention for Tobacco Control was adopted by the World Health Assembly in 2003, more than 50 years after the discovery that tobacco smoking causes cancer.

The millions of cancer patients diagnosed every year will continue to need ready access to optimal treatment to optimize their chances of survival, wherever they live. The provision of adequate health care is a responsibility for governments everywhere. The survival of all cancer patients diagnosed with cancer in a given population is one of the most important measures we have of the overall effectiveness of the health care system for the treatment and management of cancer.

Unsurprisingly, there is huge global inequity in access to cancer care[2]. The first CONCORD study showed for the first time that global disparities in cancer survival were equally wide[3]. CONCORD-2 will bring those estimates up to date. It will initiate global surveillance of cancer survival (Figure 1).

Variation in survival

Much of the global variation in survival is likely to be attributable to differences in access to diagnostic and

treatment services, and lack of investment in health resources[3]. This is also true for children: about 80% of childhood cancers arise in low-income countries, where low survival is associated with failure either to start treatment, or to complete it, in up to 60% of cases[4]. Variation in survival within Europe is associated with national wealth (gross domestic product), total national expenditure on health and the level of investment in health technology such as CT scanners[5,6].

International differences in survival can be viewed through the same lens as the differences in survival within a given country between rich and poor[7,8] or insured and under-insured[9] patients. Survival also varies widely between countries of low- and middle-income[10]. The priorities for improving outcomes differ between these economic groups of countries[11].

Cancer control plans

Inequalities in cancer survival revealed by the EUROCARE studies[12-14] are partly responsible for the re-appearance of cancer control on the political agenda of the European Union[15-17]. Survival trends have also provided an instructive backdrop for the evaluation of cancer control strategies in Europe and the USA[18].

Today, some national cancer plans are explicitly focused on improving survival. Within the last 15 years, also, international disparities in survival have underpinned cancer plans in Denmark (2005)[19], Northern Ireland (1996)[20], England (2000, 2007)[21,22], Wales (2006)[23], Victoria (Australia) (2008)[24] and Sweden (2009)[25].

Cancer survival trends are now also being used to evaluate the effectiveness of national cancer plans once they have been implemented, by assessing their contribution to improving overall survival[26,27] or reducing socioeconomic inequalities in survival[28].

Global surveillance of cancer survival

Population-based cancer survival provides one measure of progress in cancer control. It is important to evaluate patterns and trends in incidence and mortality alongside those for survival[29]. Comparisons of incidence, survival and mortality have been published for many cancers in Europe[30,31], and for Europe, Australia and Canada[32], but not worldwide. Where possible, incidence, survival and mortality trends will be compared for countries participating in CONCORD-2, to help improve the interpretation of survival comparisons[29,30,32,33].

Reliable information on global trends and disparities in cancer patient survival can be expected to help focus debate on reducing geographic and racial or ethnic inequalities[11]. Long-term surveillance of worldwide trends in cancer incidence has provided information for aetiological research and the basis of prevention and screening since the 1960s[34,35].

Figure 1: Aims of the CONCORD-2 study

To provide quantitative and directly comparable estimates of cancer survival in many countries world-wide, for 10 malignancies that are common in adults, and childhood leukaemia, using individual data from population-based cancer registries, supplied to agreed standards and analysed centrally.

To document world-wide trends in cancer survival since 1995 as the basis for systematic global surveillance of cancer survival, to enable examination of the underlying causes of survival differences, and to derive measures such as the population "cure" fraction, cancer prevalence and the number of avoidable premature deaths as a basis for informing national and global policy for cancer control.

Figure 2: The CONCORD programme is endorsed by

- WHO Regional Office for Europe (WHO-EURO) (Copenhagen)
- Organisation for Economic Co-operation and Development (OECD) (Paris)
- Canadian Association of Provincial Cancer Agencies (CAPCA) (Toronto)
- Jolanta Kwaśniewska Foundation (Warsaw)
- Members of the European Parliament Against Cancer (MAC) (Brussels)
- Association of European Cancer Leagues (ECL) (Brussels)
- Danish Cancer Society (Copenhagen)
- European CanCer Organisation (ECCO) (Brussels)
- Asociación Española contra el Cáncer (aecc) (Madrid)
- North American Association of Central Cancer Registries (NAACCR) (Chicago)
- US National Cancer Institute, Center for Global Health (Washington DC)
- Many other bodies (list on request)

We can predict that continuous, global surveillance of cancer survival will become equally valuable: a reliable information source for cancer patients and researchers, a stimulus for change in health policy and health care systems, and a key metric for the global surveillance of cancer control. Global surveillance of cancer survival is seen as important by many national and international agencies (Figure 2).

At the World Cancer Congress in Geneva in 2008, the Union for International Cancer Control (UICC) updated the World Cancer Declaration[36,37], with 11 ambitious goals to be achieved by 2020, including: "there will be major improvements in cancer survival rates... in all countries". UICC is committed to providing progress reports every two years. The CONCORD programme for surveillance of cancer survival supports several of the goals in the UICC World

Cancer Declaration (Figure 3).

The Organisation for Economic Co-operation and Development (www.oecd.org), Paris, endorses the CONCORD programme, which will provide cancer survival information for 30 of its 34 Member States (Figure 4).

CONCORD-2 study: Global trends in cancer survival since 1995

CONCORD was the first world-wide study to provide direct comparisons of cancer survival between high-income and low-income countries, using standard quality control criteria and the same analytic method for all data sets[3]. It provided estimates of five-year survival for 1.9 million adults (aged 15–99 years) diagnosed during 1990–94 and followed up to 1999. Individual tumour records were supplied by 101 population-based cancer registries in 31 countries on five continents. Sixteen of the 31 countries provided data with national coverage. Global variation was wide: 5-year relative survival for breast (women), colorectal and prostate cancers was generally higher in North America, Australia and Japan, and in northern, western and southern Europe, and lower or much lower in Algeria, Brazil, and eastern Europe.

CONCORD-2 will quantify international differences and trends in survival since 1995 in 50 or more countries on all five continents. It will include 10 common malignancies: cancers of the stomach, colon, rectum, liver, lung, breast (women), ovary, cervix and prostate in adults (15-99 years), and leukaemia in adults and children (0-14 years). These 10 cancers represent 63% of all new cancer cases and deaths, both in developed and developing[38] regions of the world (Table 1). The proportions for individual cancers differ widely between rich and poor countries: whereas prostate cancer comprises 22% of new cases among men in high-income countries, the proportion is only 7% in low- and middle-income countries, while liver cancer comprises 9% of cancers in LMIC but only 2% in high-income countries.

Of 350 population-based cancer registries invited to participate, over 220 registries in 60 countries have registered their intent to contribute data. Participation from low- and middle-income countries is expected to include 26 of these countries: 8 in Africa, 8 in Central and South America, 7 of the 13 Asian countries and 3 of the 24 in Europe. About half the countries will contribute national data (100% population coverage).

Most registries have indicated they will provide data for patients diagnosed during all or part of the period 1995-2009. The end of follow-up will be 31 December 2009, or a later year if adequate data are available from most registries. Data from more recent years of diagnosis and follow-up will be accepted as the programme develops.

By 2013, CONCORD-2 will start to provide regular information on world-wide cancer survival trends.

Figure 3: CONCORD programme fits UICC World Cancer Declaration goals

- To provide information on world-wide survival trends since the 1990s (goal 11).
- To help measure the cancer burden and the impact of cancer control interventions (goal 2).
- To help dispel myths about the inevitability of death from cancer (goal 5).
- To provide training opportunities for cancer professionals (goal 9).

... and UICC high-priority health policies:

- to bridge gaps in worldwide cancer surveillance.
- to increase the number of health professionals with expertise in cancer control.

Figure 4: Organisation of Economic Co-operation and Development (OECD) endorses CONCORD

" ... [the first CONCORD study] has contributed to a sea-change in how national policy makers are using international comparisons to improve their health systems".

"... [OECD considers the] proposals for a CONCORD-2 study, with its objective of producing data on cancer survival trends up to 2009 for 10 major cancers, to be extremely important. We are excited by the prospect of being able to use your data to address the contribution of health system characteristics in explaining international differences in cancer survival. This is one of the tasks which our Member countries have given us for the next few years."

Inequalities in survival and avoidable premature deaths

Equal treatment for a given cancer should yield equal outcome, regardless of race[39], geography or socio-economic status[40]. Racial, ethnic and socio-economic differences in survival can reflect differences in access to optimal health services for population groups within a country[41,42].

The wider public health impact of cancer survival disparities can also contribute to the formulation of health strategy[43], and these aspects will be examined in the CONCORD programme where data are available. Thus, estimates of avoidable premature cancer deaths in Britain since the mid-1990s, derived from the persistent UK survival deficit identified in the EUROCARE studies[44], have become central to the initiative for earlier diagnosis in the UK[45]

International, regional and socio-economic disparities in

survival represent large numbers of avoidable premature deaths[44,46]. Even in the Nordic countries, where survival is high, some 5,300 (2.5%) of the deaths from 12 common cancers during 2008–2012 would have been avoidable by elimination of regional variations in survival[43]. In Europe more widely, disparities in five-year survival between the Nordic countries and other European countries may have represented up to 150,000 avoidable premature deaths a year during 1995–99, or 12% of the 1.3 million cancer deaths a year that happen within five years of diagnosis[47].

Estimation of the number of avoidable premature deaths among cancer patients in a wider range of populations will contribute to the UICC World Cancer Declaration (goal #2) of improving measurement of the cancer burden, and of the impact of cancer control interventions[36].

The proportion of patients who are "cured"

Identifying individual cancer patients who may be considered clinically cured is problematic. However, the proportion of all cancer patients who may be considered "cured" can still be estimated from the point when a curve of relative (or net) survival reaches a plateau. This indicates that, as a group, the cancer patients who have survived up to that time after diagnosis no longer have significant excess mortality over that of the general population[48-50].

Estimates of "cure" have been made for patients with cancers of the bowel, breast and cervix in Europe[51]. Similar approaches will be used to estimate the proportion of patients who may be considered cured, and the mean survival time of patients who die before the point of cure is reached. It may be possible to estimate "cure" for cancers of the bowel and cervix, and for childhood leukaemia[52], but probably not for breast[53], lung or liver cancers. "Cure" estimates are not affected by lead-time bias.

Training and capacity development

The statistical methodology for cancer survival is undergoing rapid development. The CONCORD programme contains a

Table 1: New diagnoses and deaths from cancer in 2008: Number and proportion by sex and level of economic development

		Overall				Developed countries				Developing countries			
		Cases		Deaths		Cases		Deaths		Cases		Deaths	
		No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Stomach	Males	640,600	9.7	464,400	11.0	173,700	5.8	110,900	7.3	466,900	12.8	353,500	13.1
	Females	349,000	5.8	273,600	8.2	102,000	3.9	70,800	5.8	247,000	7.2	202,900	9.6
	Persons	989,600	7.8	738,000	9.7	275,700	5.0	181,700	6.6	713,900	10.0	556,400	11.5
Colorectum	Males	663,600	10.0	320,600	7.6	389,700	13.1	166,200	10.9	274,000	7.5	154,400	5.7
	Females	570,100	9.4	288,100	8.6	337,700	13.1	153,900	12.6	232,400	6.7	134,100	6.3
	Persons	1,233,700	9.7	608,700	8.0	727,400	13.1	320,100	11.6	506,400	7.1	288,500	6.0
Liver	Males	522,400	7.9	478,300	11.3	81,700	2.7	75,400	4.9	440,700	12.1	402,900	14.9
	Females	225,900	3.7	217,600	6.5	40,300	1.6	39,900	3.3	186,000	5.4	177,700	8.4
	Persons	748,300	5.9	695,900	9.2	122,000	2.2	115,300	4.2	626,700	8.8	580,600	12.0
Lung	Males	1,095,200	16.5	951,000	22.5	482,600	16.2	412,000	27.0	612,500	16.8	539,000	20.0
	Females	513,600	8.5	427,400	12.8	241,700	9.4	188,400	15.4	272,000	7.9	239,000	11.3
	Persons	1,608,800	12.7	1,378,400	18.2	724,300	13.0	600,400	21.8	884,500	12.4	778,000	16.1
Breast (F)		1,383,500	22.9	458,400	13.7	692,200	26.8	189,500	15.5	691,300	20.0	268,900	12.7
Cervix		529,800	8.8	275,100	8.2	76,500	3.0	32,900	2.7	453,300	13.1	242,000	11.4
Ovary		225,500	3.7	140,200	4.2	100,300	3.9	64,500	5.3	125,200	3.6	75,700	3.6
Prostate		903,500	13.6	258,400	6.1	648,400	21.8	136,500	8.9	255,000	7.0	121,900	4.5
Leukaemia	Males	195,900	3.0	143,700	3.4	79,000	2.7	48,600	3.2	116,500	3.2	95,100	3.5
	Females	155,000	2.6	113,800	3.4	61,700	2.4	38,700	3.2	93,400	2.7	75,100	3.5
	Persons	350,900	2.8	257,500	3.4	140,700	2.5	87,300	3.2	209,900	3.0	170,200	3.5
Cancers included in CONCORD-2 study	Males	4,021,200	60.7	2,616,400	61.9	1,855,100	62.4	949,600	62.1	2,165,600	59.3	1,666,800	61.8
	Females	3,952,400	65.5	2,194,200	65.6	1,652,400	63.9	778,600	63.7	2,300,600	66.6	1,415,400	66.7
	Persons	7,973,600	62.9	4,810,600	63.5	3,507,500	63.1	1,728,200	62.8	4,466,200	62.8	3,082,200	63.9
All cancers except skin	Males	6,629,100	100.0	4,225,700	100.0	2,975,200	100.0	1,528,200	100.0	3,654,000	100.0	2,697,500	100.0
	Females	6,038,400	100.0	3,345,800	100.0	2,584,800	100.0	1,223,200	100.0	3,453,600	100.0	2,122,600	100.0
	Persons	12,667,500	100.0	7,571,500	100.0	5,560,000	100.0	2,751,400	100.0	7,107,600	100.0	4,820,100	100.0

Sources:
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commitment to training analysts in cancer survival techniques. The training programme is designed to help improve the capacity of cancer registries to undertake survival analyses independently. The Cancer Survival Group at the London School of Hygiene has run annual courses since 2006. Over 300 students from 40 countries have attended these courses, and a further 350 or so have attended our courses and advanced workshops in seven other countries in the last few years. The capacity-building component of the CONCORD programme is growing, and we are seeking training fellowships to support cancer registry scientists from low- and middle-income countries.

Global spotlight on noncommunicable disease

The United National General Assembly High-Level Meeting in New York in September 2011 set new strategic objectives for worldwide control of noncommunicable diseases[54]. The UN resolution emphasized the need for wider research into global prevention and control of all noncommunicable diseases, including cancer, because of their rapidly growing impact on public health in developing countries in particular. At a preparatory conference in Russia in April 2011, Dr Margaret Chan, WHO Director-General, said: "Without global goals or targets, this is not going to fly – what gets measured gets done." Global inequalities in cancer survival are wide, and potentially avoidable. Unless they are measured, and reported regularly, nothing will be done to ameliorate them.

Global surveillance of cancer survival will shine a new light on the effectiveness of national health systems in managing the world's growing cancer burden. Surveillance will highlight international differences, national trends and racial/ethnic inequalities in cancer survival. The information will stimulate cancer patients, the wider public and politicians to seek improvement. ●

Professor Michel P Coleman qualified in medicine in Oxford last century and practised in internal medicine and general practice before deserting to epidemiology. He worked in the Cancer Epidemiology Unit in Oxford (1984–87), at WHO's International Agency for Research on Cancer in Lyon (1987–1991), and as Medical Director of the Thames Cancer Registry in London (1991–95). He has been Professor of Epidemiology and Vital Statistics at the London School of Hygiene & Tropical Medicine since 1995.

His research has focused on time trends and socioeconomic inequalities in cancer incidence, mortality and survival, and their application to improve public health policy for cancer control.

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