

Taking the first step on the road to cancer control

How two proposed registry projects could help

→ Anna Wagstaff

The UN Summit on Non-Communicable Diseases opened a window of opportunity for decisive action to set poorer countries on the road towards sustainable cancer control. Two major international cancer registry initiatives now offer the chance to show governments what can be achieved even with limited resources, and help equip their countries with some vital skills.

September 20th 2011 was the day when the world's governments finally made a commitment to addressing suffering and death from cancer. They were attending the first ever UN Summit on Non-Communicable Diseases (NCDs), the convening of which was a significant achievement in itself: many countries currently have no policies at all for controlling cancer or other non-communicable diseases.

More than 30 heads of State and Government, and at least 100 other senior ministers and experts, participated in the high-level meeting, which ended in a vote for a political statement that committed these governments to: "Promote, establish or support and strengthen, by 2013, as appropriate, multisectoral national policies and plans

for the prevention and control of NCDs." Other commitments, for which no deadline is given, include improving prevention, early detection and access to treatment and palliative care, as well as capacity building and strengthening information systems for health planning and management and the development of population-based national registries and surveys.

It's a good start, but as the UICC (Union for International Cancer Control) noted in a broadly welcoming statement, the declaration avoids specifying targets, indicators or timelines by which to monitor and evaluate how successful member states are at fulfilling these commitments.

The task of formulating such targets and indicators has been ceded to the WHO, which has been asked to "develop before the end of 2012, a com-

prehensive global monitoring framework, including a set of indicators, capable of application across regional and country settings, including through multisectoral approaches, to monitor trends and to assess progress made in the implementation of national strategies and plans on non-communicable diseases."

These would then be presented for agreement at the 2013 World Health Assembly. The UICC is rallying its forces for another two years of determined advocacy to make sure that these recommendations will enable effective global monitoring of trends in the overall cancer burden and the impact of cancer control interventions – look out for the launch of this campaign at the World Leaders Cancer Summit in Dublin this November.

Achieving effective global monitoring of cancer will take more than agree-



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Left: Tanzania's Ocean Road Cancer Institute is one of few such facilities in Africa. It cannot serve the needs of the country's 43 million inhabitants and most patients it does see present too late for effective treatment
Below: UN member states have now committed themselves to developing sustainable policies for controlling cancer



UICC

ment at the World Health Assembly, however. Most countries lack both the capacity to gather, process and analyse cancer data, and the understanding and political will to use that data to inform policy. Tackling this challenge is the goal of two major international cancer registry projects – the CONCORD-2 comparative cancer survival study, led by the London School of Hygiene and Tropical Medicine, and a Global Initiative for Cancer Registry Development, led by IARC (the International Agency for Research on Cancer). Securing the backing to get these projects up and running as quickly as possible could be vital to keep up the momentum created by the UN NCD Summit.

A GLOBAL SURVIVAL STUDY

CONCORD-2 is set to be the most comprehensive international comparative study of cancer survival to date. With backing from key parts of the cancer community including the UICC, IARC and the International Atomic Energy Agency's Programme of Action for Cancer Therapy (PACT), it seeks to provide comparable data on survival, cure and premature avoidable deaths, for 10 major cancers in adults plus leukaemia in children across fifty countries, developed and developing, broken down by age, sex, race/ethnicity, calendar period from 1995 to 2009, and (where

separate registries exist within a country) geographic region.

The full project comes with a price-tag of £3 million (€3.5 million) – not a lot by the standards of international collaborative translational research projects, but on the ambitious side for epidemiological studies. CONCORD's sponsors are now hoping to convince enough funding sources that the project can provide value for money in terms of its contribution to the current concerted efforts to improve cancer control around the globe.

“Some of the most motivating results come from contrasting cancer survival between rich and poor”

Michel Coleman, who is leading this initiative on behalf of the London School of Hygiene and Tropical Medicine, points out that improving global cancer survival rates is one of the 11 targets the World Cancer Declaration (WCD) has set out to achieve by 2020, and CONCORD-2 can provide baseline measurements and hopefully also regular updates on progress towards this goal.

But Coleman believes that the project's biggest contribution will be in developing local expertise in gathering and analysing cancer data, thereby improving the measurement of the impact of cancer control interventions (WCD target no.2) – that and the political leverage generated by publishing comparative figures on survival.

“Some of the most important and motivating results come from contrasting cancer survival between rich and poor or advantaged and disadvantaged,” says Coleman, who points to the importance of the EURO CARE studies first in drawing attention to the serious survival gaps between central/eastern European countries and the rest of Europe, and then charting the gradual narrowing of those gaps as a result of government measures.

He also cites an earlier international survival study, CONCORD-1. This was the first credible large-scale study to confirm that racial disparities in cancer survival are systematically replicated across the US for a wide range of cancers. CONCORD-1 led to renewed efforts

to explain and address this disparity.

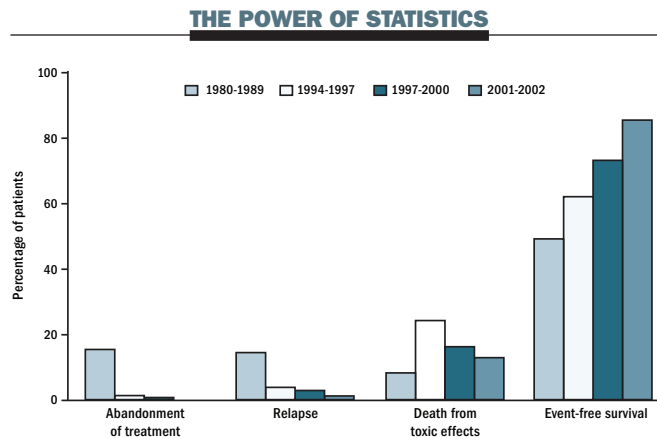
Whether statistics showing vast survival differences between countries at very different levels of development will carry the same shock value is, perhaps, a different question. Coleman is confident they will – if nothing else, he says, it should challenge the myth prevalent in developing countries that cancer is a uniformly fatal disease. “If health ministers in those countries conclude that in some cases it is possible to survive cancer pretty well – and in some cases very well – then that will help educate the public and politicians that something can be done to reduce the adverse outcomes of cancer once it is diagnosed,” he says, pointing out that this will contribute to achieving WCD target no. 5 – the one about challenging damaging

myths and misconceptions.

As a public health specialist at Colombia's National Cancer Institute in Bogota, Marion Piñeros spends a lot of time helping educate the public and decision makers that it is possible to treat some cancers effectively, and she agrees that comparative survival studies can indeed play a very useful role. She finds the example of childhood leukaemia to be particularly instructive, and the CONCORD-2 study – for which she serves on the steering committee – has included this cancer alongside 10 adult cancers at her express request.

“You can see that at relatively low cost in terms of treatment, high-income countries have reached very good survival very fast in children with acute lymphoblastic leukaemia. In fact childhood cancer survival has become one indicator of access to and quality of healthcare. I think that could be relatively easy to achieve in developing countries, if there is the commitment and strong social support.” To illustrate the point, she cites the experience at a public hospital in Recife, Brazil, where outcomes of children with acute lymphoblastic leukaemia were completely transformed between 1980 and 2002 (see figure above).

“With the provision of social support, including help for mothers and families to remain economically active while the child is in treatment, it should be possible to achieve survival close to



These bar charts, charting progress in treating childhood ALL at a public hospital in Recife, show Brazilian decision makers they are doing something right – and show countries with similar socio-economic profiles what they too could achieve with the right policies

Source: R Ribeiro et al. (2005) *NEJM* 352:2158–60, reprinted with permission, © Massachusetts Medical Society 2005

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“80–90% of cancers registered have quality control that is not applied to mortality data at all”

that in many developed countries. So I think the comparison between rich and poor is very important. You can compare within your region, and also compare with other countries.”

For poorer countries, however, the value of participating in international studies goes beyond the impact of the comparative statistics, says Piñeros. It is a way of giving ‘visibility’ to the data that their own registries gather and collate. “We can make a lot of effort, but the staff is scarce, and we have less time to prepare and write up scientific articles. Often you have very good people who don’t speak English, and translating the articles is very costly. In Latin America, it is only really Brazil and Mexico that have relatively good visibility in terms of published scientific papers.”

Data published in the context of major international studies also carry more weight with decision makers, adds Piñeros, “It is not only more visible, but it also puts on more pressure, and that makes a difference to what you can do afterwards.”

The heavy focus on survival does have its critics, however. One criticism is that population-based mortality statistics, which show the number of deaths from different cancers per 100,000 population, provide a more useful picture of a country’s overall cancer burden than survival statistics, which only capture information about people diagnosed with cancer. Other criticisms focus on the complexity of collating and interpreting survival data, which – so the critics argue – make them less reliable than mortality statistics, which are collected from official death certificates.

THE MORTALITY VS SURVIVAL DEBATE

This mortality versus survival debate tends to bubble up from time to time in heated exchanges in academic journals and epidemiological gatherings, often to the dismay of advocates who feel it offers an excuse for doing nothing.

Piñeros argues that to get a good picture both are needed. Trends in cancer mortality provide a good indicator of the impact of overall cancer control plans, because they reflect prevention as well as survival. However, survival statistics are better for monitoring access to early detection and treatment – aspects of cancer control that many feel are given insufficient attention by governments who find it easier to focus purely on promoting lifestyle changes.

The issue of relative credibility of mortality and survival statistics is, of course important – you don’t change minds, or policies, when there are serious doubts about the accuracy of the data. But arguments held in the context of western health systems, where serious efforts have been made to ensure that all deaths are recorded accurately according to the latest WHO international classification of diseases, do not readily transfer to the developing world.

As David Forman, head of the section of cancer information at IARC explains, “You have to remember that in most African countries, for example, there are no reliable mortality data whatsoever – and even when they are available, they are often not helpful in monitoring cancer. The same is true in a number of Asian countries. I was talking recently to a colleague from India who said that, although

there is a process for recording deaths, officials writing death certificates are under real pressure from families not to mention cancer as a cause.

“So you’ve got, particularly in the developing world, many populations where death certification is either inadequate, unreliable or non-existent. In that context, to pose mortality as an alternative to survival doesn’t really get you anywhere.”

Coleman is confident that he can convince backers of the quality of the data that will be used in CONCORD-2. “To the extent possible, those data are subject to quality control that beggars belief in comparison with mortality statistics. When a cancer is registered the clinical data are checked at the point of tumour registration, and if they fail local checks in the registry they are corrected from the original source records by the registry concerned.

“After that, they are subject to internal quality control in the registry, often using standardised checks such as those produced by IARC. And finally, when they are brought to collaborative international comparative analysis, they are subject to further quality control checks, and the same standards are applied internationally and registries are required to meet them.

“That level of quality control, based on hard pathological data in something like 80–90% of registered cancers is simply not applied to mortality data at all.”

THE CHALLENGE OF SUSTAINABILITY

While prospective funders may be reassured by all this, they will undoubtedly also be looking at sustainability – will this

“District officials have to take decisions, but they don’t know how to follow a logical path to develop policies”

effort just give us a one-off survival snapshot (valuable in itself as a comparative exercise and a baseline assessment) or will it also give decision makers a better understanding of the value of measuring cancer indicators and develop an enhanced capacity to carry out the data gathering and analysis?

“This is a topic very close to my heart,” says IARC’s David Forman. “Report after report is identifying the absence of basic vital statistics as a significant black hole in our understanding of the worldwide patterns of cancer. One of IARC’s primary objectives is to produce global statistics on cancer [e.g. the Globocan database <http://globocan.iarc.fr/>], and we more than anyone are aware of areas of the world where the statistics are, at best, very crude estimates because of the absence of cancer registration data – largely Africa, parts of Asia and parts of Latin America.”

In response to a request from the director of IARC, Chris Wild, CONCORD-2 now includes a commitment to capacity building that may be a drop in the ocean in terms of global need, but nonetheless represents a substantial commitment in terms of the project as a whole, says Coleman.

“In terms of training development and technology transfer, capacity building represents roughly 10% of the overall budget. We’re planning to offer training for cancer registrars in 30 developing countries, which is in line with what IARC asked for, costing roughly £300,000 [€350,000] – not at all trivial. We are also looking for fellowships from agencies such as the UICC and IAEA, which supported three fellowships a

year ago on our cancer survival course, to enable registrars from developing countries to come and learn how to improve their skills in cancer survival analysis.

“We are also committed to support courses that IARC would lead, in Africa, Asia and possibly Latin America. We have a group of experienced scientists and teachers in cancer survival analysis, who have taught courses all over the world, so we are confident that if we get the budget for CONCORD-2, we will be able to make, over the three-year span of the programme, a substantial difference to the capacity of registries or institutions working with cancer data in developing countries to perform survival analysis to the highest standards locally.”

However, a three-year survival analysis project is not designed to address the ‘black hole’ of global cancer data that Forman talks about. That task falls to IARC, which is gathering support for a Global Initiative for Cancer Registry Development, to be launched at the UICC’s World Cancer Leaders’ Summit in Dublin this November.

“We are trying to establish a system of regionally based support, rather than the entire world looking to IARC in Lyon for support, as happens at the moment,” explains Forman. “We want cancer registry hubs in Asia, Africa, and Latin America, staffed by those with expertise in registration and registration methods, and the software that we use, who can then provide support to registries within their region.

“The idea is to build up a network of six or seven such regional hubs around the world as a step towards improving cancer registration capacity in those

areas.” Like CONCORD, this project will rely on support from an array of partners, says Forman, including the UICC, the International Network for Cancer Treatment and Research, the International Association of Cancer Registries, the American Cancer Society and Centers for Disease Control, the US National Cancer Institute and the IAEA Pact programme. “All of them, and others, have said in many recent statements that something needs to be done about improving cancer registration in low- and middle-income countries. This initiative is to try to put substance behind that particular demand.”

Piñeros welcomes any efforts to develop cancer registration capacity in developing countries. She cautions, however, about the need for strategic thinking to avoid the investment in capacity building being wasted. In particular, she argues, it is preferable to keep the funding base of registries as independent as possible.

“We have seen that when registries depend heavily on local public health institutions or governmental agencies for their funding, they are very vulnerable to political changes. Some of the registries that started up were not given funds some years later, because the political figures changed. What has worked relatively well in the Colombian case has been to set them up in a university setting.”

She talks too about the need for advocates or ‘ambassadors’ who can demonstrate the value of cancer statistics to decision-makers and explain how they can be used to shape effective health policies.

“At local level, districts and cities, there is a need to take decisions, but their capacity of analysis, particularly for chronic diseases like cancer, is usually very low. They may well have information from the vital statistics system, but they don’t know how to group the cancers or follow a logical pathway to develop appropriate policies.”

To help with this, Piñeros and her colleagues are set to publish a handbook on analysing the cancer situation, which gives “an easy and practical pathway to prioritising cancer control objectives, and taking evidence-based actions”.

“It is a stepwise approach where you say, for instance, if cervical cancer is showing as a major burden you can orientate resources according to scientific evidence. If you set up cervical cancer screening, you then have to evaluate how effective it is. You have to plan using a long time frame and go through logical steps according to your distribution of cancer burden in your particular locality.”

This approach has worked well, she says, in Cali, and some other major cities where she and her colleagues have been working with the health minister to put together a programme, hopefully a long-term one, based on a situational analysis, where registry data are of particular value. The data showed that, in Cali, breast cancer has overtaken cervical cancer in significance, and this has led to more resources being directed towards breast cancer control, particularly early detection.

This sort of stepwise logical progression, from data gathering and analysis to the formation of sustainable plans and policies, followed by monitoring and evaluation, is what the World Cancer Decla-

Strengthening cancer surveillance across the globe

The CONCORD-2 study will draw data from up to 160 registries in up to 50 countries in every continent (participants in Asia and Latin America are shown below). IARC wants to set up regional hubs to support cancer registration in the many countries where information is limited or non-existent

ration roadmap is all about. With the NCD Summit still fresh in the minds of policy makers, projects like CONCORD and the Global Initiative for Cancer Registry Development offer the opportunity to take a leap forward in global cancer control that should not be squandered. Of course, the current economic turmoil may not be the ideal time to be searching for funds, but as the UN Summit on NCDs recognised in point 1 of the political declaration, “the global burden and threat of non-communicable diseases constitutes one of the major challenges for development in the twenty-first century, which undermines social and economic development throughout the world.” Looked at in this way, helping countries get the information they need to tackle those diseases most effectively could be seen not as a drain on hard-pressed resources, but as part of the solution to the global economic crisis.



This sort of stepwise logical progression is what the World Cancer Declaration roadmap is all about