Closing the survival gap

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EU countries from Central and Eastern Europe are trying to close the gap with Western Europe in cancer prevalence and survival rates. In Ljubljana, politicians, experts and patients came together to debate cancer plans, political will, funding and ways to stop skilled staff leaving home.

It had been a year since the signing of the Warsaw Declaration on cancer services in Central and Eastern Europe – long enough perhaps for politicians to have forgotten their undertakings and moved on to other issues.

Instead, a critical mass of MPs, MEPs and health administrators gathered in the Slovenian capital, Ljubljana, in November 2006 to renew their commitment to closing the gap between cancer outcomes in the east and west of Europe, and to discuss ways of making it happen.

This was a working conference, organised by the European Cancer Patient Coalition, at which politicians, cancer experts and patients groups from all over Europe dedicated time to working out how to ensure that the aims of the Warsaw Declaration are fulfilled.

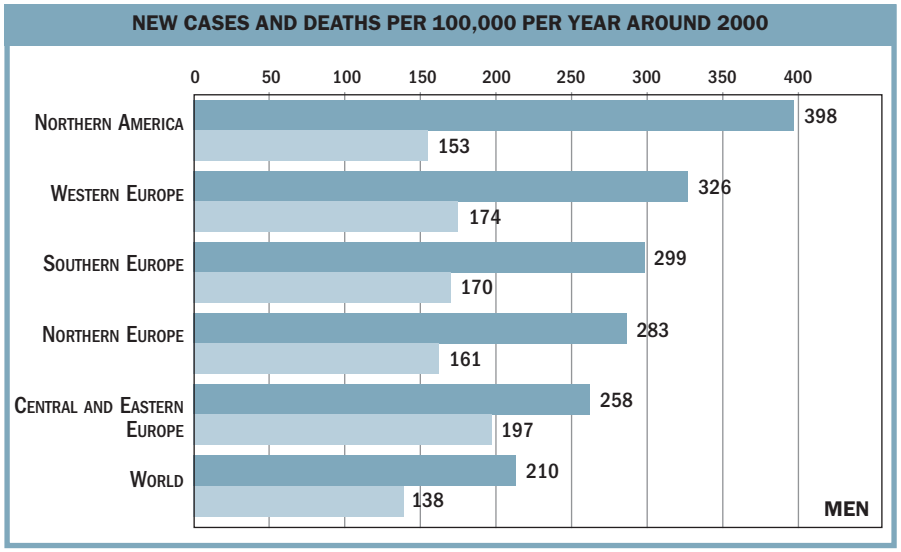
Given equal services, people in Central and Eastern European (CEE) countries should be at lower risk of dying of cancer, because these countries have the fewest diagnosed cases in the whole of Europe. However, women in CEE countries are only slightly less likely to die of cancer than their sisters in Western and Northern Europe, while CEE men are much more likely to die than their counterparts.

In the period 1983–1994 the survival statistics in some CEE countries improved, but more slowly than the average for the rest of Europe. In some CEE countries, survival rates actually fell. So, the gap between east and west is growing rather than narrowing.

"Do our governments know about these figures?" asked a representative from the Institute of Patients Rights in Poland. "Where can we find copies of these statistics?" asked another delegate (answer: www.eurocare.it). Irena Belohorská, medical oncologist and Slovakian MEP, had heard the statistics for the first time at the October conference of the European Society for Medical Oncology. Two days before travelling to Ljubljana, she presented them to her health minister. "He was shocked," she said.

The conference heard presentations about the two most comprehensive programmes implemented in Europe to date. The French and UK Cancer Plans both tackle cancer from prevention and early detection to training, guidelines, organisation of care and rehabilitation. The French plan also addresses social issues such as rights at work. Many delegates cited these contributions as giving helpful information to take home.

Ariana Znaor from the Croatian National Institute of Public Health valued the precision of the UK experience. "What I found useful was the setting of very specific targets," she said. She was also impressed by the patient-orientation of the



Unacceptable. Men in Central and Eastern Europe have a lower incidence of cancer than men in other parts of Europe, but mortality rates are significantly higher *Source: Globocan 2002, IARC*

French plan – "Cancer care in many places ends after the patient is sent home from hospital."

Mihály Kökény, chair of the Health Committee in the Hungarian parliament, was similarly inspired. "Many of our currently good and valid national cancer plans and programmes should be much more citizen- and patient-centred. We need to support patient groups, and involve them. Cancer is an important issue but it cannot just be left to the medical people."

A PLACE ON THE AGENDA

In many CEE countries, cancer remains taboo, denied a profile in public life and the media, with no chance of becoming a political priority. Both Mike Richards, architect of the UK Cancer Plan, and Brigitte Guillemette from the French National Cancer Institute, stressed that advances had only been possible with top-level, sustained political support. The Ljubljana gathering was itself in part the result of political backing from former Slovenian President, Alojz Peterle, the founding spirit and vice-chair of MEPs Against Cancer.

Countries struggle to break free of a negative mind-set. Simone Ene, who works with the Association of Cancer Patients in Romania, says that people and politicians "are blind to the issue of cancer. They treat cancer as a fatal disease not a chronic one."

But there is evidence that things are beginning to change. Evgenia Adarska, president of the cancer patients group, APOZ, reported a political and media storm in Bulgaria, when a member of the parliamentary health committee said: "It is immoral to ask for more money for oncological treatment because cancer patients are already dead." The MP was disciplined – and Bulgaria's cancer patients now stand to gain from the 30% increase in the health budget they had been fighting for.

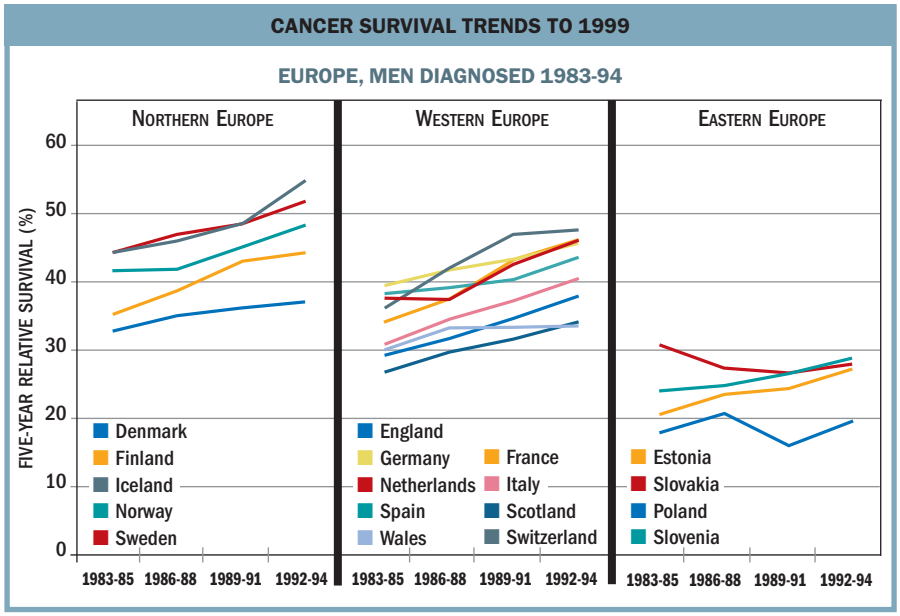
In Hungary too, Kökény says that people have started talking publicly about cancer – as part of a general climate of greater openness. "Developing cancer care was not an area that local politicians and the government felt should be a priority. It was swept under the carpet. Now everyone has to face the statistics."

RESOURCES AND STAFF

However, there remains a problem with funding. Znaor, from Croatia, points out that CEE countries missed out on support from Europe Against Cancer because it ended before they joined. "Organised screening programmes are major undertakings that don't give quick results, and cost a lot of money."

Transformation from the old socialist systems has taken its toll, while countries involved in the fighting that accompanied the break-up of Yugoslavia are still trying to rebuild their infrastructure.

Fatmire Mulhaxha-Kollçaku chairs the Committee on Health, Labour and Social Reform in the Kosovan parliament. As part of Yugoslavia, Kosovo was progressively starved of resources, she said. The unresolved separation from Serbia left Kosovo without any oncology centre or even a radiotherapy facility. These are having to be constructed from scratch, by an administration that is struggling even to get its telephone system functioning properly. Infectious diseases account for much of the Kosovo health budget, as many villages still lack sources of clean water. Her entire



A growing gap. Survival rates are improving faster in Northern and Western countries than in Eastern Europe, which means the survival differences are increasing *Source: Coleman et al, 2003*

budget for chronic diseases, including cancer, heart disease and diabetes is 3 million euros, for a population of 2 million people.

Even peaceful change has brought problems. In Slovakia, transformation brought decentralisation of the health service. Belohorská says that one result is that poorer regions get a poorer quality service, while a shortage of nurses has led to the closure of many beds. "The plan is not the problem. There is not the money."

Belohorská sees staff shortages as the single greatest threat to cancer care and cancer screening, as specialists and nurses exercise their EU labour mobility rights to work in better paid parts of Europe. Patients, she points out, are not so mobile and are left high and dry. Ene from Romania agrees. "You have to give [doctors and staff] a reason to stay – increase their salary and improve their working conditions. You can't just give them the opportunity to run off and leave the patients to die."

Can the EU add value?

Belohorská asserts that a failure to allow the EU a greater role in health policy in the member states amounts to "punishing the people" and says that "without healthcare it is not the Europe of the people."

However, the Ljubljana conference explored some of the ways in which the EU can help to move things forward. The 10 EU countries that joined in 2004 can choose six priority areas for structural funds, which could be put towards revamping and reorganising health services, screening programmes or staff training, and could free up money for increased salaries to keep doctors and nurses in the country. Hildrun Sundseth, conference organiser and head of the Brussels office of the European Cancer Patient Coalition, appealed to MEPs, MPs and patient groups alike to argue the case for investing in cancer. Cancer plans, she said, were also on the agenda for the next meeting of MEPs Against Cancer.

An acute awareness of the benefits of national, quality-assured screening programmes, including one for colorectal cancer, was evident across all the countries.

Joaquim Gouveia, Portugal's first National Coordinator for Oncology Diseases, emphasised the importance of creating a "common language of indicators and effectiveness studies", and said that benchmarking could be crucial to bringing cancer control in all countries up to the level of the best.

Kökény supports the need for standardised data, even down to individual hospital level on waiting times, caseloads, complication rates and so on. He mentions three areas where he would like the EU to take a lead. On smoking – Hungary has by far the highest incidence of male lung cancer in Europe – Kökény would like to see a binding directive. On drug prices, he wants an EU discussion about how to make new cancer drugs more accessible. On research, he believes Europe should be far more ambitious, and cites the opportunities presented by ideological opposition to genetic research in the USA.

This was an important milestone in the process of getting cancer onto the public and political agenda

Jan Potočnik, EU Commissioner for Research, welcomed a discussion on the merits of research, and assured the conference that cancer has been steadily moving up the agenda for allocation of funds from EU framework programmes.

Two years ago, the EU Clinical Trials Directive caused widespread dismay as it failed to take account of the need to conduct independent, academic clinical research. Potočnik made it clear that he does recognise the vital role of such work. He said that the forthcoming Research Framework Programme would link research, prevention, diagnosis and treatment, emphasise translational research, back the identification of best clinical practices and optimise the use of cancer registries for cancer research.

He acknowledged concerns over the failure to agree a Europe-wide validation system for continuing medical education (CME) to keep physicians up to date in a rapidly changing field.

Top priority

The Ljubljana meeting was another important milestone in the long process of getting cancer onto the public and political agenda. The journey has included the emergence of patient advocates, national cancer plans, the Europe Against Cancer programme (1985–2000), the development of a European network of cancer registries, the establishment of the European Cancer Patient Coalition (2004), the first meeting of EU health ministers on cancer (Paris, 2005), and the launch of MEPs Against Cancer (2005). Ljubljana brought many elements that reflect this progress together in the same room.

Slovenia's secretary of state for health, Dorjan Marušič, said that there was clearly a strong will "to continue on this track, to share ideas, to find solutions – not just at the level of experts and citizens but also at a political level." During a political roundtable discussion, MEPs, MPs, experts and patients decided to meet again in 2007 to continue the dialogue.

For Marušič, this is part of the build-up to the Slovenian EU Presidency in 2008, which they intend to use to give the fight against cancer a top priority. This will offer an unprecedented chance for patients, experts and politicians to push the issue up the agendas in their own countries.

It could also give a boost to patient power across Europe. Alojz Peterle, a prime mover behind the conference, has himself been diagnosed with prostate cancer and is standing for the Slovenian Presidency. Were he to win, the EU would, in 2008, have a cancer patient advocate at its head for the first time.

THE WARSAW DECLARATION

The Warsaw Declaration was launched at the second summit of cancer patient and advocacy groups in Central and Eastern Europe in November 2005, and called for urgent action to close the gap between CEE countries and the rest of Europe in cancer prevalence and survival rates.

1. Develop national cancer plans, setting priorities and allocating resources, for improving cancer control and research in all CEE countries and assure patients' groups monitoring over the implementation of these plans.
2. Invest in cancer prevention by promoting awareness, information and education campaigns about the risk factors of cancer, building on the ***European Code against Cancer***.
3. Invest in national screening programmes as recommended by the European Union; and implement high-quality EU standards to support early diagnosis.
4. Make high-quality up-to-date treatment, rehabilitation and care attainable for all cancer patients throughout Europe.
5. Encourage and ensure patient participation in all decisions on health policy and health care affecting cancer.
6. Advance cancer control as a priority for action where necessary to qualify for grants from the EU Structural Funds.
7. Oppose discrimination because of age, race, gender, domicile and economic status in respect of the latest cancer treatment.
8. Encourage and adopt national Charters of Patients' Rights according to European guidelines.

The full text plus a list of signatories can be found at www.cancerworld.org/ecpc