

EUROFILE

Palliation to be emphasised in new guidelines for national cancer plans

New guidelines on devising national cancer plans will emphasise the importance of palliative care and survivorship. These areas are often neglected when drawing up cancer plans, according to Professor Tit Albreht, Work Package Leader for National Cancer Plans within EPAAC (European Partnership for Action Against Cancer) which had its working meetings in Malta in May.

A booklet entitled *Guidelines on National Cancer Control Plans and Their Monitoring*, scheduled to be published in January 2014, will draw on the 29-country survey on national cancer plans, on international experience, and on consultation work within the Core Working Group (CWG) of EPAAC.

Albreht (University of Ljubljana, Slovenia) says the European guide will be “a sort of a cookbook” for successful preparation of national cancer plans. It will cover all aspects of cancer management: care, screening and promotion, alongside survivorship issues, rehabilitation, palliative and psychosocial care. “This work will help with the convergence of cancer plans for the future,” he says.

Palliative care provision for patients with cancer was present in the plans of only seven member states, Albreht says: “This is one of the aspects of cancer plans that is often lacking.” Much could be learned from the countries that are providing good palliative care for patients with cancer. “There is a long-standing history of systematic work in Belgium, Germany, The Netherlands, Sweden and the UK, to name just some of the forerunners in this field,” he says

“The issue of survivorship is also of growing importance as more and more people are living with cancer and will require us to make provision for them to fully re-integrate into normal life. The results over the last 8 years have been very encouraging, in terms of survival and the quality of life of patients, because we were all more or less able to secure a high level of cancer care.”

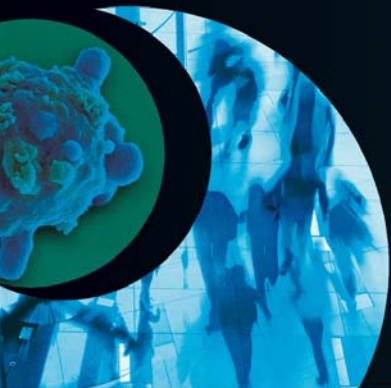


Tit Albreht

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There are currently only four member states that do not have a National Cancer Plan: Austria, Bulgaria, Luxembourg, and Slovakia. All have different preparations underway for the launch of their respective plans. Of the four, Bulgaria was the last to join the EU and, despite shortages in the financing secured for all activities of its cancer plan, Bulgaria began working on its plan last year. In Austria and Luxembourg, preparations have long been underway but each has yet to make a final decision on how to conclude the work. In Slovakia, no political consensus has been reached over its national cancer plan.

But Albrecht points out that developing a cancer plan isn't the end of the story: "It has to be remembered that member states which have formally adopted a national cancer plan or programme may not have everything running optimally."

The Core Working Group (CWG) Steering Committee is comprised of 6 member states that have specifically expressed interest in cancer plans: Belgium, Ireland, Italy, Malta, The Netherlands and Slovenia. "They are doing the bulk of the work in developing the National Cancer Plan Guide for the future," Albrecht says. The second level of organisation, the Advisory Committee, consists of all member states plus Iceland and Norway.

Albrecht believes that the main challenge in future will be to encourage every member to commit to a plan, given the associated on-going expenses. "The soaring costs of cancer care, which has implications for existing patients, is in many countries very severe, particularly for those under austerity measures. There will unfortunately be some selection of what is going to be recognised in public funding and what is not. Cancer requires significant investment in equipment; this may be hampered by the financial crisis in many countries. The rising cost for cancer has been much higher than for GDP. So far we have been successful, in most cases, in containing these rises, but I'm afraid in the future this will become much more difficult."

Cancer plans are extremely difficult to compare due to differences in the content, and even more importantly, in health systems and patient pathways, Albrecht says. Some are multi-dimensional and include different aspects of cancer care and management; others focus solely on screening and care.

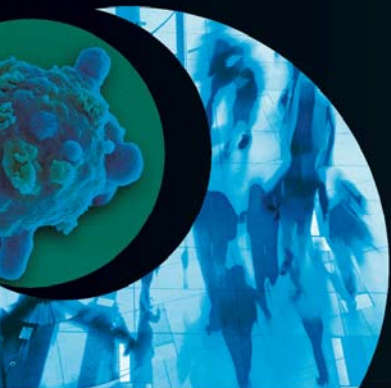
"Among countries with a federal structure, Italy has done comparably well because there was reasonable agreement at the federal level about key points, which is sometimes very difficult to achieve. Secondly, the tradition of monitoring cancer in Italy

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is very strong, and long-standing; registries have been in place, particularly in the northern part of Italy, for many decades now. The regions have been well-motivated to support integrated care and also to support the screening programme.”

Finland is another example of a country with an interesting development, Albrecht says. “In Finland, the authorities did not believe for a long time in vertical strategies. They believed in a comprehensive approach to non-communicable chronic diseases rather than singling out individual health problems. In their favour, they have a very long-standing tradition of screening especially in cervical and in breast cancer. So there we are just seeking some specific things, like allocation of funding, timelines for patient pick-up by the system for treatment. That is what they are now mostly focusing on; it would have been silly to disrupt systems that are in place and working very well.”

Sweden, similarly, has a strategy rather than a plan. “Screening programmes are running very well and cancer care is at the very highest level so in such cases there is little need for policy involvement in the process.”

But elsewhere, a plan is a sort of assurance of reserved funding for cancer care. And in those cases, it helps to put the focus on the key issues. You may have to mobilise political will in order to secure activities and services: “When you don’t have an environment that is so favourable for screening, you will use a national cancer plan as the driver for your screening and health promotion campaigns,” Albrecht says.

‘The main challenge in future will be to encourage every member to commit to a plan, given the associated on-going expenses’

The forthcoming Guidelines will take account of the experience of all member states making this an indispensable document for any country formulating a national cancer plan. It will define the most important outstanding issues and implementation strategies.

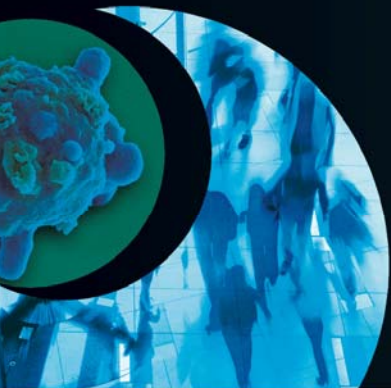
“We believe that the Guidelines should help improve plans overall and that such a tool is an invaluable aid for the future convergence of these important strategic and planning tools for comprehensive management of cancer,” Albrecht says.

Jim McGuigan

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INTERVIEW

'Low risk of cancer' among Chernobyl cleanup workers

Following the explosion at the Chernobyl nuclear power station, in April 1986, 17,040 men were sent from Estonia, Latvia and Lithuania to clean up the environment. Most were military reservists and they worked in the Chernobyl area for various periods between 1986 and 1991. The Baltic countries regained independence in 1991 and each designed a similar cohort study to investigate radiation-induced cancer risk among the cleanup workers. At this stage of analysis, they were followed until the end of 2007.

Delays in reporting were severe due in part to restrictive data protection laws which for years prohibited record linkages and disallowed the use of information from death certificates.



Kaja Rahu (National Institute for Health Development, Tallinn, Estonia) is the lead author of the first analysis of site-specific cancer risk in the combined Baltic cohort of cleanup workers (*EJC* 2013; <http://dx.doi.org/10.1016/j.ejca.2013.04.014>).

What excess cancer did you find?

The excess was in thyroid cancer. The Baltic cohort had a proportional incidence ratio (PIR) of 2.8 compared to the general male population. Those who started work in April-May 1986, soon after the accident, had a much higher PIR, of 6.4. This suggests that the cancers may be due to the radiation but the number of cases is small and the confidence intervals are wide. We can't say for certain that radiation was the cause. In Estonia, there were only two cases of thyroid cancer and they were detected during screening offered in 1995. No new cases were diagnosed after that. Latvia and Lithuania did not run similar screening programmes but Chernobyl veterans were offered surveillance and eight thyroid cancers were reported in each country.

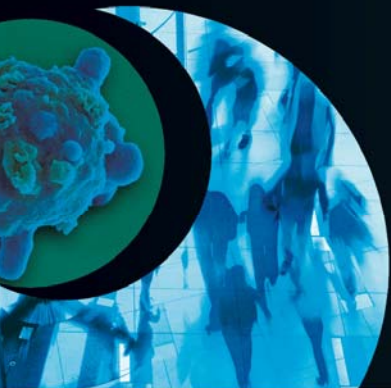
What about leukaemia and radiation-related cancer sites as a group?

There was no obvious excess of leukaemia in this cohort. The higher leukaemia incidence should have emerged 2–5 years after exposure to radiation. But earlier analyses didn't reveal an excess, so we weren't expecting to find it so much later on. The Baltic cohort is too small to detect low risks. An excess risk for radiation-related cancer sites as a group was not seen in the cohort.

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If there was no increase in these cancers, why might there be an excess of thyroid cancer?

The explosion released radioiodines which could increase the risk of thyroid cancer in the first cleanup workers to arrive. They might have inhaled the radioiodines or consumed contaminated food or drink. But radioiodines have a short half-life so it was dangerous at the beginning but not afterwards. Previous studies among the local population found a high incidence of thyroid cancer among those who were exposed in childhood. Our cohort was comprised only of adults.

In general, your findings on cancer risk in this group must be reassuring?

They are. Most of the cleanup workers received quite low doses of radiation, and the associated cancer risks were not high. Other larger studies of cleanup workers from Ukraine, Russia and Belarus have found small dose-dependent risks.

How did the exposure of the cleanup workers compare with that of the population living close to the reactor?

It varies. The local population received a high initial dose during the explosion but they were evacuated quite quickly. The cleanup workers were not present during the accident but were sent there some days afterwards and they stayed in the contaminated area for an average of three months. Their exposure depended on how far they worked from the reactor and what kind of activities they carried out. But the average whole-body dose was 0.1 Gy.

How accurately was the workers' exposure measured?

They had personal dosimeters, which didn't always work properly. Doses were recorded for military passports, because most of the men were military reservists who hadn't gone to Chernobyl voluntarily. When a device recorded a maximum allowed cumulative dose, the man was sent home. But there was falsification on both sides. Some was by officials who reduced recorded doses that were higher than the permitted maximum. On the other hand, some of the men gave their dosimeters to friends who were working close to the damaged reactor building, for example, where radiation was extremely high, so they had an artificially high reading. In more than 20% of the Baltic cohort, the dose was not documented. But doses were evaluated from biological markers afterwards, and even if individual doses did not coincide with those monitored, the average dose was 0.1 Gy so it is clear that in general they did not get high doses. In the case-control studies of thyroid cancer and haematological malignancies among cleanup workers from the Baltics, Belarus and Russia, doses were reconstructed for each worker depending on where they worked, how long they were there, whether or not they had protective clothing, and so on. They also found that the men in general were not exposed to high doses.

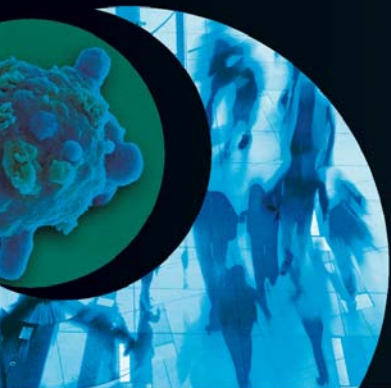
Why did you use PIRs?

The *EJC* paper is to some extent a methodological paper on PIRs, which are quite rarely used and mostly in mortality studies. We could not use standardised incidence ratio, the usually preferred measure, because we couldn't follow the Latvian and Lithuanian sub-cohorts for mortality and emigration, and we did not have person-years

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at risk. But PIRs show the general picture. Paul Aveyard has encouraged the use of proportional analyses. He wrote: "PMR studies are not as bad as you were taught to believe"! (*Public Health* 1998/03; 112:2;77-80) We found that to be true.

What lessons were learnt from Chernobyl?

In the scientific world there is a consensus that the main public health issue associated with Chernobyl was not cancer but mental health problems. They are seen both in the local population, who were evacuated, and in the cleanup workers. In the Estonian cohort, we found that overall mortality is the same as in the general male population, but the risk of suicide was high – 30% higher than in the comparable male population – and has remained so. Alcohol is clearly involved; the men say that they have never drunk as much as when they were in Chernobyl. There they had poor living conditions and inadequate information about radioactivity. We don't have data on mental health from Latvia and Lithuania but we can assume that the picture is similar.

In the EJC paper, you discuss both the importance and vulnerability of registries.

In our institute in Estonia, we have a small but quite strong team of epidemiologists able to perform register-based record linkage studies. But we had a period of 10 years with such a strict data protection law that the cancer registry could not link data to death certificates. It meant we could not include cancer cases which were diagnosed after death, so cancer incidence was underestimated. This period is over and we can now link registries and work normally again, but the cancer registry was damaged and we haven't yet been able to fill all the gaps that emerged over those 10 years. It happened in part because the data protection agency could not find a balance between the interests of individuals and those of society. Latvia and Lithuania went through something similar and Lithuania has now more or less recovered. But in Latvia an attempt to include all data on an electronic health system – and get rid of separate registries – has reduced the consistency of cancer registration.

Interview by Helen Saul

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