

interview

“And having got, for example, lung cancer, people in poorer areas are less likely to survive. Some of this may be down just to poorer health and some may be due to poorer access to diagnostic services,” said Dr Comber.

Work done by other groups showed that delays in, for example colonoscopy, were related to whether or not people had private health insurance.

“It has always been important to us to highlight that this is not just a matter of personal choice – it is also a matter of your socio-economic circumstances. Some people have fewer choices in terms of diet and exercise. Sometimes there is an element of almost blaming the patient in terms of diet and lifestyle. But people on lower incomes have fewer dietary choices than people on high incomes. Things like fruit and vegetables sometimes seem very expensive to people. They don’t see them as being staples of the diet.”

Obesity was another area that particularly concerned the Registry.

“It is an increasing problem and there is very little public awareness about the link between obesity and cancer,” said Dr Comber. “It is a big public health problem. People certainly think of smoking and alcohol in relation to cancer, but they rarely think of the risk factor of being overweight.”

In particular renal cancer, lymphoma, breast cancer and prostate cancer were all related to obesity.

Another group of people who may fare less well in relation to cancer was older women. The Registry did some research for the Women’s Health Council some years ago and in a follow-on report they looked at treatment of various cancers in women.

“We noted that over and over again, older women were much less likely to be treated. Less likely to have surgery, radiotherapy or chemotherapy. And generally as women get older they stay relatively fit. We couldn’t see that this lack of treatment was necessarily determined by their physical state,” said Dr Comber.

They looked at similar data for the US and discovered that they didn’t have the same falloff in treatment rates with age as we did in Ireland.

“We were intrigued by this and have just started a project to look at why this is so.

“Another interesting thing that we see over and over again is that married patients are much more likely to be treated than single patients in Ireland,” said Dr Comber.



It is important that someone coming in with cancer has an advocate to speak on their behalf, said Dr Comber.

“This interests us very much because one of the reasons we think we might have a poorer cancer survival is because there is a much less aggressive attitude towards treating elderly patients in Ireland than there is for example in the US and Canada,” said Dr Comber.

“The evidence is that patients who are treated aggressively don’t really have much more in the way of side-effects, but they definitely have a better survival rate. But there is very much an attitude in Ireland ‘Ah sure for God’s sake they are 75 can’t you let him die in peace?’,” said Dr Comber.

Generally, there was going to be a big increase in the numbers of people with cancer due to the ageing population. A recent report from the Registry estimated that the numbers would double between 2005 and 2025.

The Registry has published a number of papers on inequalities of treatment and have more planned.

Ongoing research

The Registry carries out research on an ongoing basis, both in-house and in collaboration with other people. Much of their research now focuses on economic issues. They are looking at the financial

impact of cancer on patients and the health services.

They are also doing an economic evaluation for the Health Information and Quality Authority (HIQA) on colorectal cancer screening.

The Registry are also researching the causes of cancer and have been looking particularly at cancer of the oesophagus, the pancreas and lymphomas.

In terms of cancer trends the Registry has found that most cancers are increasing a little bit.

“Kidney cancer has been increasing quite a bit in both males and females. We published a paper recently suggested that some of the increase in kidney cancer is artificial. These are very slow growing cancers that are picked up on routine CT scans which otherwise might never have become apparent. The same is true for prostate cancer with the more widespread introduction of PSA screening; and breast cancer with Breast Check,” he said.

Lymphomas and melanomas were increasing; while stomach and bladder cancers and cancer of the oesophagus were getting rarer.

Dr Comber said he had been very lucky with his staff.

“They are very good, very dedicated and work very much with the interest of the Registry at heart.”

Ireland has no mandatory national standards or guidelines for cancer treatment says Harry Comber

Sheila O'Kelly

Major inequalities in cancer care

THERE ARE major inequalities in terms of treatment and in terms of survival for cancer sufferers in Ireland, according to Dr Harry Comber, director of the National Cancer Registry.

This issue highlighted by the Registry influenced the proposals for setting up eight specialist cancer centres. The Registry highlighted the absence of any sort of standardisation of treatment and that each cancer unit operated entirely independently of every other unit.

"For Ireland, to a large extent, there are no standards. There aren't any national guidelines. So all we can say is that you're more or less likely to have a particular treatment in a particular place," said Dr Comber who has been with the Registry since it was set up in 1991.

"If you take men of 70 with bowel cancer who are diagnosed in different parts of the country. In some cases they are very likely to have chemotherapy, in some places they are not. In some places they are likely to have radiotherapy, and in

some places they are not. This is not based at all on the type of cancer they have, but on the hospital they go to. People are being under-treated or over-treated and we need to look at that in more detail."

The Registry has also shown that geographic location is not the deciding factor for treatment.

"We showed that there was no huge relationship between how far people had to travel and their ability to access a particular service. Whether or not they received radiotherapy was due to the influence of their consultant."

Dr Comber said decisions should not be made by individuals, Ireland needed to move towards evidence-based, multi-disciplinary management of cancers. This would lead to consistent care across the country.

The fact that most patient and case notes were still handwritten also contributed to inconsistency of care, said Dr Comber.

"A lot of the big international hospi-

tals, for example Sloan-Kettering, have protocol-driven records. Once you put in the patient's characteristics, it prompts you for certain information and that the standard treatment for this patient would be such and such."

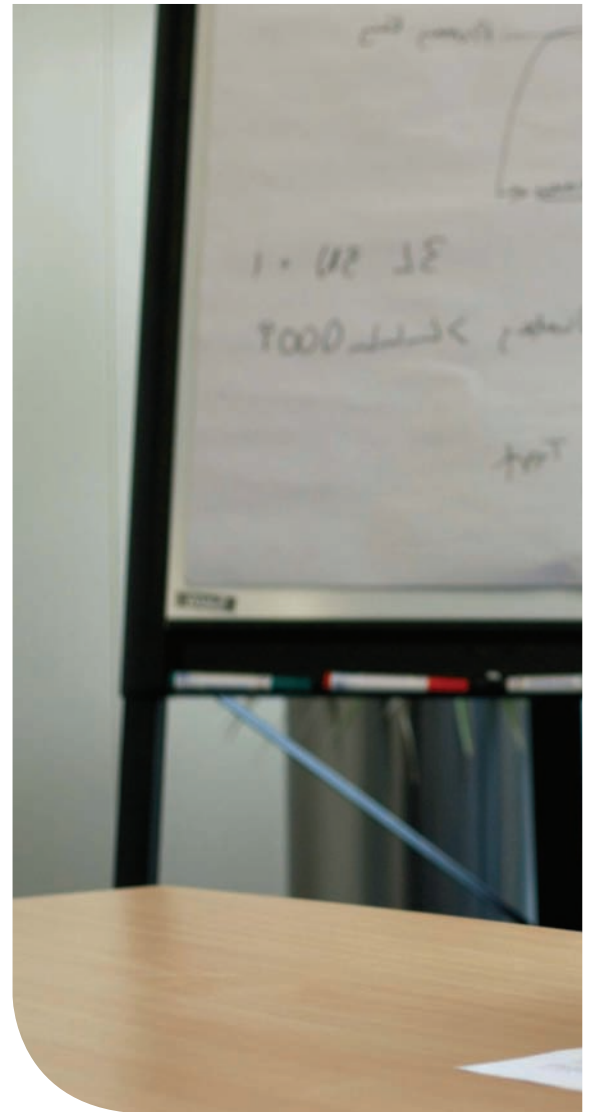
While most of the laboratories were largely automated and radiology had moved on to the PAC (picture archiving and communication) system there was a lack of standardisation of pathology systems.

Agreed national dataset

"Even if the pathology systems are not all identical, they should be able to share information. There are plans to do that at the new specialist centres," said Dr Comber.

The Registry does not publish data it collects until it is sure they are complete.

"About 80% of medical records are easy to get hold of, the other 20% vanish. We may spend two to three years trying to track down a relatively small number of records," said Dr Comber.





This means that the Registry may be two-three years behind in terms of being able to publish treatment data.

“One of the projects I have been working on with the Cancer Control Programme is to develop a minimum dataset at each cancer centre for general use. We would specify all the items that the hospitals could produce on demand for statistical purposes. That would be a major step forward and I would hope that by early next year we would have an agreed national dataset.

“Hospitals vary hugely in their level of development. Some, like St James’s, have very highly developed data structures. Many of the others, and some big cancer centres, really have no data collection structures at all.”

However, the future was much brighter because of the National Cancer Control programme, Dr Comber said.

“Information is going to be absolutely essential to the way things are done in the future. It is no longer going to be done

on a sort of a wing and a prayer. It will be evidence-based. We have been pushing for this since 1992. It is great for me now to see that for the first time people are detailing what is actually going on and what is the best way to do things. People are beginning to question for the first time. I think that is very positive.”

Dr Comber said we would have a national cancer information system whereby all the management information that was needed to plan the cancer services would be available.

“In the same way as the CEO of any big enterprise would have the necessary information so should the director of cancer services in Ireland.”

Amalgamating with HSE

Gathering information will remain central to the Registry if, as is proposed, it merges with the HSE over the next year or two. Currently, the 1996 Health Provision Information Act exempts the Registry from some data protection provisions. It can collect data, but the Act restricts

what it can do with it.

Dr Comber hopes that the Health Information Act due to go before the Oireachtas next year, will give the Registry the same exemptions when it becomes part of the HSE. “We would argue very strongly that we need legal protection so that we can continue. We register about 25,000 cancers a year. There is absolutely no way in which consent could be obtained from that number of people.

“We have drawn up very detailed guidelines on what we do with the data; how we preserve it and so on. Essentially we do not pass on any information to third parties unless the individual patient consents to it. Information that comes in here does not go out unless somebody consents.”

The Registry is very conscious of the need to preserve its autonomy and independence if it merges with the HSE. But Dr Comber said it was important for the Registry to be an integral part of the cancer services.

“We have been independent since our foundation and we collect a lot of very useful information, but there has never been an agreed mechanism for this information to actually feed into the planning of the services or the evaluation of the services. From this point of view becoming part of the HSE is a very positive thing.

“At the same, we do not serve just the public sector – we serve the entire population. We have to be sure we will still be in a position to produce reports that the HSE or part of the HSE might not be comfortable with. We have had assurances that we will still be able to control what information we can or cannot publish as part of the HSE.”

Gathering and publishing information has been at the core of the Registry since it was set up in 1991. By the early 2000’s, it was studying things like treatment patterns and cancer survival. Their reports cover information like:

- Where people are seen
- Who they are seen by
- What treatment they get
- What stage the cancer is at when they are diagnosed
- What the outcome is.

Poverty is key risk factor

One of the Registry’s important conclusions is that poverty is a key risk factor for cancer.

“One of the biggest factors we have found in terms of cancer incidence is economic deprivation. Over and over we find that the poorer areas have more cancer than better-off areas irrespective of environmental pollution or anything like that.