Ulster Medical Society

21 October 2010
Dr Anna Gavin
Early Diagnosis of Cancer in Northern Ireland
Cancer Registry of Northern Ireland

Professor Margaret Cupples:

Can I welcome everybody to the Ulster Medical Society this evening, and I apologise to you first of all for the change of the speaker. Unfortunately, Professor Debbie Sharp would very much have liked to have been here, has sent her very sincere apologies, but she had a close friend die and the funeral's this afternoon, and she just couldn't quite make it. And I think in the circumstances, we have to accept her sincere apologies. She would like to come again, but unfortunately I don't think our programme can accommodate it this year. Perhaps another year she might come and share her information with us.

However, in no way should this detract from our current speaker for this evening who has stepped up at the last minute, and I'm extremely grateful to her. And she is going to talk on the same area of cancer diagnosis, and she's going to tell us about it in a home theme. And Dr Anna Gavin, I think, needs no introduction to the audience. She is the current Director of the Cancer Registry in Northern Ireland, and she is the Founder Director of the Cancer Registry in Northern Ireland, and she tells me this evening it's been there for sixteen years, and I find that hard to believe. But I know that she has a wealth of interesting information to tell us, and I think it's just great to hand over to her.

Dr Anna Gavin:

Thank you very much, and it's lovely to see so many people in the audience that I know. I am nearly more afraid because of an audience that I know. When Margaret asks me to do something in her usual nice way, it's very hard to refuse. I've been a member of the Ulster Medical Society for a long, long time, and one of the things that I've often thought was, wouldn't it be nice to be an invited speaker, and I think that sometimes you should watch what you wish for!

I am going to follow on, on the theme, because it's a very interesting theme, and it's about the promise of earlier diagnosis in Northern Ireland, and any of you who are following things, the CR [Cancer Research] UK have a programme now which is called NAEDI, and is the National Awareness and Early Diagnosis Initiative, and they have actually made early diagnosis a priority, and have identified funds that we all scrabble for in trying to get.

So, we have been in the Registry, thinking about this as well. So, what I want to do is I want to lead you through this evening, and look at international survival differences, then patient delays that we know about in Northern Ireland. I want to mention a wee bit about screening, because I don't think you can talk about any diagnosis without mentioning screening, to talk about our system targets within Northern Ireland for waiting times, and how that's operating, and what we hope to achieve from that. And then mention at the very end, a very exciting project that Northern Ireland is involved with which is the International Cancer Benchmarking Project.

So, because, as Margaret says, we now have a Registry, and a very good Cancer Registry, even though I say it myself. We are able now to compare ourselves internationally, and we have sent data to Europe in a common way with all the other countries, and we are able to see where our survival lies in terms of all of Europe.

I'm not sure if there's a pointer here? But it doesn't matter I'll just use this. So, here you can see where Northern Ireland is, and what I'll do is I'll show you a few of these. This is colorectal cancer, and you can see we're bumping along the middle. This is very good, and that is not so good. And the European average, say for males, is 53, and we're below that, 51. For females the European average is 55, and we're below it at 52. Now we're around the very same as the rest of the UK, but compared to other countries in Europe, the UK is not actually doing that well.

Professor David Hadden:

Sorry, can I ask a question? Do you mind if I ask a question?

Dr Anna Gavin:

Oh, you're very welcome to ask a question.

Professor David Hadden:

As we're such a small group. What do you actually mean by five-year, age-adjusted relative survival?

Dr Anna Gavin:

Well, first of all, if we look at relative, okay? That is takes account of other deaths. So, heart disease and things like that are taken into the equation. So, relative means, these are deaths due to that particular cancer, okay? Because perhaps Poland have a higher rate of deaths from heart disease than we have or vice versa, so you have to adjust for that.

The other thing is the age-adjusted means that it takes account of the fact that we have a younger population say than England, and if you just do this without age-adjusting, then you would have more deaths in England, but it wouldn't be a true reflection of what's happening, as it would be related to the age of the population. So, age-adjustment takes account of age—so age is not reason for these differences, nor is the background rate of disease, such as heart disease or road traffic accidents or anything like that, okay?

And five-year means… you could look at it as one-year, or two-year, or three-year or four-year, five-year. So, five-year, these are how many people are alive after five years, taking account of the background mortality.

Professor David Hadden:

So, it's a percentage of the original number?

Dr Anna Gavin:

It's not quite. If we were to look at just observed survivals… so, if we had 100 people in the room, and we came back in five years and saw how many of those were still alive, that would be observed survival. But if, for example, out of that 100, 10 died of heart disease, and maybe another 10 died of something else, you would be looking at the survivors out of 80, rather than 100.

So, relative survival is actually higher than observed survival, because we take account of the background deaths. Okay? It's a very complicated concept, so early in this, and so late in the day!

Professor David Hadden:

Is that a percentage at the bottom.

Dr Anna Gavin:

It is still expressed as 100.

Professor David Hadden:

Out of a hundred.

Dr Anna Gavin:

Well, yes, it's expressed out of 100, yes. If everybody was alive, then it would 100%. If nobody had died from colorectal cancer, then it would 100%. So, if we were to look at this for testicular cancer, we would see it's much higher up the scale, because survival is very good for that. And you can watch the scale as it varies for the different diseases. I'll be showing you a few of these, okay?

Professor David Hadden:

Thank you.

Audience member:

Carrying on just with that, when does the five-year kick-off? Is it from the date of treatment, date of diagnosis?

Dr Anna Gavin:

It's from date of diagnosis, yes. And these are for different periods. I can't remember the exact period. Obviously, this is not recent data, because you have to wait for five years and then you can analyse it. So, these patients could have been diagnosed ten years ago, okay? All right? Good.

So, this is it for lung cancer, and here, remember the colon was way up, we have adjusted the scale, and it's only 15% here. And the European average for a male is 11.7, and if you remember for colon, it was 53. So that relates to the survival of them. So, if we look at lung, again we're sort of sitting around here, very poor five-year survival. And it's slightly better for women, but there are countries that have much better survival for lung cancer.

In a way, if we're looking at early diagnosis, we also should be looking at six-month survival and one-year survival, because that's the ones that show where gains can be got in early diagnosis.

Audience member:

Sorry, can I just ask you? Does the type of lung cancer come into it?

Dr Anna Gavin:

Well, these are all lung cancers. So, you're right, the survival for different sub-types would be different, but this is just all of them. But you could if you wanted, we could look at different sub-types. Obviously, the numbers would be smaller, I think, for small cell or something like that, and you might have bigger error ranges.

These lines here are the accuracy with which we predict that figure. So, you can see here in Malta, that's a very big line, because the population's quite small. Whereas say Italy has a much smaller line. Iceland, with a smaller population, again has a big error line. So, that's how you would read those. But you could do it for the sub-types of lung cancer, because the survival does vary by sub-type.

Audience member:

The female small cells does very, very badly.

Dr Anna Gavin:

Yes, that's right.

So, if we then look at breast cancer. And here we see Northern Ireland, 77.4, and we're just about touching… this is the European line, and you can see your little error bars on there. So, we're just about the European average, but there are countries which are much better than us in terms of survival for breast cancer. This is ovarian cancer, and you can see that we're in the middle again.

So, for all of these, because we are able to compare with Europe, we're able to get a feel for where we're at. But in terms of improving survival, we now have a feel that there are places which have better survival. And if I was to put America on this graph, Europe is behind America. So, there are huge gains to be got in terms of survival from the various cancers, if we compare ourselves internationally.

This is melanoma, and I show this because we're not bad! We're actually the best. So, we're the best for men, and we are almost the best for women. And we have had initiatives in that area, and very good treatment and things like that. And while we have an increasing number of cases of melanoma, and an increasing number of deaths, our survival for patients is actually better than the rest of Europe.

So, this is stomach cancer. Again, the same sort of diagram. Here, we see, it's a bit like lung; the numbers here… the percentage who are alive after five years is much lower, and we're still sitting all the time around the middle.

Audience member:

Anna, do you mind if I just interrupt on that?

Is there anything interesting that you would comment on in terms of differing incidence? Today, we're looking at survival, but obviously the incidence is very different because lifestyle… Japan, they used to

have a high rate of stomach, for example. Does that have any bearing on things?

Dr Anna Gavin:

There are differences, which sometimes relate to lifestyle. There are big differences in lung cancer incidence, which relate to smoking, and particularly in differences between men and women. And I think some of this background… even though we have taken account of the background mortality, say for heart disease and things like that, if you've a high proportion of your population who smoke, then they're not going to do as well if you treat them, because they will have chronic obstructive airways disease, they may have heart disease, that might not appear in the death certificate. They may have heart disease, which means they can't then have specific treatment, or whatever.

Yes, there are lifestyle things, and they're not taken account of in this, but there are descriptive studies which actually go into deaths in these [?] things, and they would look in depth at some of those things. High-resolution studies.

New Male Speaker:

A simple thing, I hope anyway. How are the trends doing? Perhaps you're going to address that?

Dr Anna Gavin:

I'll show you some of the trends actually later on, because that's a very good question—yes.

I want to just now… So, that's how we compare with Europe. So, that's been very interesting and exciting. And what I want to do now is come back now to patient delays, and if we think about it… and you're all aware of friends of yourselves or patients that you know where the delay has been.

The first thing is, the patient actually becomes aware that there's something wrong. Now, if a patient isn't aware about cancer, or has not the information or the know-how, then that can be a very difficult step for them to make. Then they have to somehow decide that they're going to see about it.

There's a bit of a… thinking, will it go away, or what will I do now? And it might be difficult for them to get their first appointment with the GP. Maybe the GP says, I'll give you an appointment for two weeks from now, and they may think, they mustn't think it's too serious—that's great.

And different countries have different ways of accessing GPs. Some places, you have to pay for it—like in the South you have to pay for it. So, that's a barrier—there are various barriers.

Then, the GP may or may not pick up on the symptoms; may have access to screening, to x-rays; may not have access to x-rays; may find that they have to join a queue then for a test.

Then the patient arrives at the Specialist for further diagnostics, and then there's a delay from referral to confirmation of diagnosis. And then once the cancer is confirmed, then the treatment begins, and there could be delays in that as well.

So, there are lots of cases where a week here and week there adds up to quite a lot of delay for the patient. I want to just keep that in mind while we explore some of these things.

But first before that, I want to just mention screening, because it wouldn't be right to do something about early diagnosis without talking about screening. And we have three screening programmes for cancer that are recognised here. The breast has been operational for quite a while, the cervix for slightly longer, and colorectal cancer screening has just recently be introduced.

And why does it make such good sense? Well, first of all, there is a survival improvement depending on the stage of colon cancer the patients have. So, the late Duke's D, this is time since diagnosis. So, this is almost another way of looking at your five years. This is again relative survival. The patients who have Duke's A are almost the same as if they never had cancer. So, if you can get it at that stage. Duke's B do a little bit less well. Duke's C, then there is this mixed bag of un-staged here, which are in the middle, and Duke's D after five years, there's not too many of them alive—there's about 12% or something alive. That's why you try and have a screening programme, to have earlier diagnosis of these cancers.

If we then look at trends. So, you were looking at, did we have trends here? And we'll come back to survival trends in a minute. This is actually the number of cases of breast cancer and the deaths. Over time, and this is age-standardised, the rate of deaths from breast cancer, it has actually fallen—not too much—but it has fallen. And the number of cases, the deaths, used to be just over 300 a year. And now it's under 300, despite the fact the population has aged, and you would have expected the ageing alone to push it up.

The number of cases of breast cancer diagnosis have increased since the introduction of the screening programme, and that's one of the issues to do with screening. This is age-standardized, so the ageing of the population is not a reason for this. Part of the investigation for breast screening shows that it does pick up earlier lesions, but it also picks up some lesions that might never have progressed to full breast cancer. And so, with any screening programme, there's a wee bit of a trade-off with that.

And before you introduce any screening programme, there are quite a number of criteria that have to be addressed which includes the harm-benefit ratio for patients which includes all the things about cost-effectiveness, and whether there will be an improvement in the outcome for patients.

If we look at cervical cancer, and this is from '71 to 2001—and these are deaths. When we screened for cervical cancer, we aimed to pick up a pre-cancerous lesion. So, the cancer's never actually developed, and so the people don't die from it. The triangles here are the South of Ireland. The South of Ireland started with a much lower level of deaths from cervical cancer than Northern Ireland, and this may be a treatment effect here, but their level has actually increased

over time. They don't have a screening programme, and the whole lifestyle change… there have been quite a lot of lifestyle changes in our society, and also in the South of Ireland, relating to sexual health.

This here, is Northern Ireland, here. So, we have a few more deaths, but our level has gone down, reflecting treatment and reflecting the screening that was organised, first of all on an opportunistic basis and since 1989 on a population basis.

In England, where they re-organised their screening programme, here, you can see the deaths as we go along here. This is England and Scotland, and then the introduction of screening programmes brought them right down.

And there are figures very like this from Scandinavia which shows that if you have a well-organised population-based screening programme for cervical cancer, it really pays off in terms of deaths.

Now, we have another one here that people are screened for, but there's no screening programme. And so, what we have here is prostate sampling. And here we see Northern Ireland has probably about 300 cases of prostate cancer per year in 1993, and now it's about 800, nearly 900. And that's because of the increased detection of cases with PSA screening. Mortality hasn't changed at all. We're just picking up early cases. We're still picking up the same number of advanced disease—people with bone metastases is exactly the same number and yet all these men will have had treatment, and some of the treatment may have led to serious side effects.

Just as an aside, the Cancer Registry received a grant from the Prostate Cancer charity to study this, and we could be contacting some of the GPs in the audience to help us out with information about patients. But I think it's a very important area to study because the long-term effects of this on men's health and well-being needs to be documented, because more and more men are having to make decisions about treatment, and the information really isn't out there.

Enough about prostate cancer—we could have a whole evening on that! Now, just back to see, what's the burden of cancer in Northern Ireland, and if we were to talk about earlier diagnosis, where would we want to work to make the best impact? If we look at, this is men, so the most common cancer in men and women is non-melanoma skin cancer, but lung is a big one, and then there's prostate there, colon, rectum, stomach—but the deaths are lung, colorectal, oesophagus and stomach. And the pattern is quite similar for females, except we have breast cancer in here as the big one. These are the cases of breast cancer, but the proportion who die is much smaller, and we also have lung cancer and colon and ovary and rectum. We need to be thinking, if we were to have an early diagnosis initiative, we would want to do it in something that… where it would make a difference.

If we look at lung cancer, this shows how poor the outlook is for lung cancer, but it has actually improved, so we were looking to see: what's the trend in survival? So, this is five-year relative survival. Women are slightly better than men in terms of a lot of cancer survival—and lung cancer's one of them. But here we see, for males diagnosed 1993-1996, compared with 1997-2000, there is an improvement. It's very small, but that's lifting up.

And if we look at the people who had surgery, there's been a marked improvement for them because they're picking the patients better, and they're having better post-op care and better surgery, and all that. So, there is something to be done for lung cancer patients that will actually improve their survival.

If we look though at lung cancer and early diagnosis, we have done some work in the Cancer Registry, and looking at 2006 diagnosed patients, there were almost 900 of those. Half of them presented as emergencies. So, they weren't diagnosed until they presented at A&E in some emergency condition, and almost half of them were late stage 4, and 90% of those… more than 90% of them had died after one year. 85% of patients went directly into palliative care. However, 12% of these patients had curative surgery, and their 1 year survival was 82%.

So, if we can get them in early, there is something that can be done for them. But we also asked patients about their delay, and this is what the patients did. All of these 900 patients, 10% of them had a cough, and 20% of that 10% had that cough for over 6 months. Weight loss—10% of patients had weight loss, and a quarter of them had that symptom for over 6 months before they were diagnosed. Breathlessness—80% had this symptom, and 17% had it for over six months. And pain—5% of patients had pain and 1% of those people—so, ten people had pain that they put up with for more than six months.

If we look at haemoptysis, which is a very visible sign. These are the changes over time, we monitored this over time, and we saw that in 1996, 19 patients had haemoptysis for over six months, but by 2006 this has gone down to two patients. So, I think there's an increased… we are getting people like this earlier, and I would suggest that that's evidence for it.

If we look now at observed survival for breast cancer… sorry for these lines coming in. This is observed survival. So, remember we were working on relative survival, well, the observed includes deaths from other causes. These are the 100 patients in the room, how many of them are left after a certain time period?

This is months since diagnosis, so we go up to two years here. But what we can see for breast cancer is a very marked improvement in survival over ten years, and these are Northern Ireland patients. So, you should all sit back and give yourselves a bit of a pat on the back for that, and it is continuously improving as well.

So, the next time that we are with Eurocare, we might be moving up or down. We would be better going down, because the survival's better at the bottom. Of course, breast cancer depends on the stage, and it's much better for stage one than for the later stage disease, and that's why there's the breast screening and why we need to have people come in earlier.

But what symptoms do women with breast cancer have? And what delays are with the patient? So, this is how many of them had a lump? If we look for 12 plus months, 5% of the women had… and this is 2006, 5% of the women had a lump for over 12 months. So, there's a bit of work needs to be done there. How many of them had pain? 4% had pain for over 12 months. If you look at over 6 months, 10% of women had a lump for over six months, 7% had pain for over 6 months. And these are of the people who had this symptom, it's not of all the women, because they would all have different symptoms. And nipple discharge or abnormality, 10% of that for over a year and 20% had it for 6 months.

If we look at oesophageal cancer, and again we see survival… this is all patients, 1996, 2001 and 2005. And there is an improvement here. In the top line there is 2005, but not very much. So, if we look by stage of disease, we see that the earlier stage disease had better survival. For all of these cancers, the earliest it's diagnosed, the better it is.

And what about patient delays for this. Well, if we look at difficulty swallowing, we see that 3%… there were 158 patients had this symptom, and 3% had it for over a year, 8% had it for over 6 months. Weight loss—18% had that symptom for over 6 months. Chest pain—7% had it for over 6 months, and loss of appetite as well.

People are sitting at home with symptoms. There has been some reduction in this over time, if we look at 1996 compared to 2006. So, people are coming that wee bit earlier.

If we think back to our overall delay. So, we've looked at this bit here and now we want to look at some of the system delays that we were able to pick up. It can't all be blamed on the patient. Now, those of you who are working in GP and all, will know that there are targets for waiting times in Northern Ireland since 2008, and there's a 52 day target from your referral until you start treatment. And there's a 31 day from decision-to-treat to treatment, and the GPs have a red flag facility. So, they can send in and say, I think this patient has cancer. Now, a lot of the patients that they send in, some of them do have cancer, but a lot of them don't have cancer.

How do we know what's going on? Well, some of you might be familiar with this new patient system. It's a new system that's used in hospitals, and it's one that actually the Cancer Registry developed the prototype of it, and it's about monitoring cancer targets. So, up here we have these numbers, and this is a countdown in terms of a waiting time.

At the multi-disciplinary team meeting when the surgeon's there, and the pathologist, and the radiologist, and everybody's there, all this is projected onto the wall, and then they're discussing the patient and various bits are entered, and meanwhile everybody's keeping an eye on these times, and it's monitored… you can see that that's the bit that they keep an eye on.

Now, the other thing is, is that this also gets rid… this system gets rid of the secretary having to dictate the letters, so that's a time delay. And so, what happens is that the letter goes off… will I show you that again? You see, the letter going off to the GP! So, the letter goes off, and it's signed at the meeting, so there's no need for somebody to sit there and think, oh I have to go and do my letters after my clinic. You know the way it used to be, two weeks later you'd be getting through your letters, and the GP may eventually get it, or whatever. This way it should be done, and it should actually become automated, so it will go by email. So, the GPs nearly know as soon as… before the patient's home is often happening.

These are all about improving the timeleness of the early diagnosis. And this is the tracking, and it just shows, in any Trust—what's going on. So, they have so many people who have cancer, there's so many if no cancer, there's so many with suspect cancer that they're monitoring, and there's somebody actually sitting there and monitoring all this, so that if a patient will get their PET scan, they'll get their MRI scan, they'll get their chest x-ray, they'll get whatever before the time runs out. So, it's all been speeded up within hospital, and it's individually directed care.

And so, there's all this monitoring. How many were under target? How many were over target? And the Trust are really hauled over the coals if a patient was over target, so there's big moves there to improve and… you know all about that because you haul them in!

Now, the red flags, there's time—we can look at cancer waiting times and how well people wait. So, these are red flag patients, and these are other patients. So, it looks like for most of the cancers that irrespective of whether you're red flagged or not, you are seen in the system quite well. There's a bit of a delay for other patients who have colorectal cancer, because of all this red flagging, and there's a big delay for the prostate cancer patients, because there's a lot of non-cancers in the red flag system, who are clogging up the system. And so, the challenge is to see how we can better red flag patients—how we can better differentiate that some of these are really likely to have cancer, as opposed to if they don't have cancer. So, there's quite a bit of work going on in that.

Now, with this here, I want to just show you some of these graphs, and I can explain this one to you. This is what's happening in the system. So, this is for all the patients who are diagnosed with different cancers. This is colorectal cancer. What we see here is we aim to have 100% patients diagnosed within either a month or two months, and three months of referral. We can see that for most of these here in all the three years, almost all of them were seen… they were first seen in hospital, so very few of them had to wait more than three months. And the majority of them were seen within a month—the majority of them in fact were seen within a week.

And here we have the 2006, 2001 and 1996. And what we see here is, actually it's falling, and we're not doing as well, we're doing slightly less well. So, what's happening with some of the other conditions, that's colorectal. Now, if we look then at more recent times,

that was from our report, and here's the 2008, 2009. Actually, 2008 was a brilliant year because we pulled it all up again, and that was the waiting time. But now the system's clogging up a bit again. So, maybe the red flags are doing that—we just need to keep an eye on that.

I'll show you similar ones for... and this is referral to first treatment. Here we see again, we were getting worse, but then we did do a little better once the cancer waiting times were introduced. This is for lung cancer, and you can see, if 50% of patients come in through A&E, well then, they're going to be diagnosed very rapidly. And we can see that there were very few patients who had to wait more than a month from referral to when they were first seen at hospital. So, the lung cancer patients were being seen very quickly. And this then was referral to first treatment, and you can see that was slower. But we can see that it has improved, and this is the more recent time here. It was going down a bit, and then the cancer waiting times were introduced and everybody's focused on that now. So, a bit of targeting doesn't do any harm.

Here we see breast cancer. And again, we see the very same pattern, where we're getting a bit slow and then it speeded up again. And then, the same for referral to first treatment. Prostate, the very same pattern. So, we're able to monitor these things for Northern Ireland and see how well everything's doing. And that's prostate again.

One of the other things that we have been looking at is, if we think of early diagnosis, if you look at deaths within 3 months of diagnosis, well, those are really very late diagnosed cases, and this is Northern Ireland data, where we see that 42% of male lung cancer patients, 38% of female, died within 3 months of diagnosis. And I'm sure that's your clinical experience. Breast cancer, only 3% died within 3 months of diagnosis. Colorectal, a bit more. But for colorectal about a third presented as an emergency. Ovary, 20% died within three months of diagnosis.

That means there's a huge pool of late diagnosis out there that we need to target. These ones are more likely if people are deprived, or if they're older. And 5% of all our cancer patients die during their last admission to hospital. They're diagnosed, and they died. So, these people come into hospital, not knowing what's wrong with them. They're diagnosed with lung cancer, and before they get home they die. 1 in 20, which is a big thing for us to target.

I want to just finish off really by telling you about a major project that we're involved with, which is called an International Cancer Benchmarking Project, which was established in 2009. So, we've seen that there's international variation in cancer survival. We've seen that it's quite marked in these cancers here—colorectal, lung, ovary and breast—we're not doing as well as we could.

We have joined up with 12 participating jurisdictions. In the UK, there's England and Wales, and ourselves. In Canada, there are four of the states... no, it's provinces in Canada, it's the states of Australia; Sweden; Denmark; and Norway.

And so, there's a major initiative going on, and we hope that in The Lancet before Christmas, there will be the first papers coming out from this, which show how the survival in these countries compare with one another. And just to tell you, we're very similar to the UK, but of course, slightly better! Since the UK are driving this we mightn't see that, but we're slightly better, but we're still not nearly as good as Sweden, or Denmark, or Norway.

There's various stages of this project. The first module is the one where we've given all our data and it's been analysed, and it looks at survival rates, and that's the one that's almost finished.

The next stage has been funded by the Public Health Agency, and there's going to be survey of population beliefs and awareness about cancer. So, we get maybe to the bottom of this, and then there may be initiatives to raise awareness about these cancers. It's about cancers in general maybe more than these ones here. So, that should be very informative. And it will also tell us how we compare with these other countries.

Module three then, is differences in primary care. So, if a GP gets a certain set of symptoms, what is he likely, or she likely, to think this could be cancer, or this maybe isn't cancer? Do the GPs have access to direct radiology, can they refer in, or do they have to go through something else? And there's differences in different countries. Do the patients have to pay? There are all those things which could affect that. That will be measured here in this module three, and we're linking with Nigel Hart in the Academic Department for General Practice who's working on that.

Module four, is what bits do the patients think delays them? The thing is, what we're going to do is we're going to ask patients themselves. How long did you have your symptoms? Why did you not think it was cancer then? Had you a long time to wait for your GP appointment then? To look through their pathway and do a survey of that backed up with a look at hospital notes.

And then module five is, we know that certain treatments work, but maybe they're not being applied the same in all the different countries. So, that's a high-resolution study. We hope to work our way through this over the next two or three years and have very good answers to some of the questions about why our survival's not so good, and what we can do about it.

These are some of the comparisons for these here, and this is from the data that we have done already. Here you can see, we are much lower than Canada. We're slightly better here, we're slightly better here and slightly better there—although we've nothing to be proud of, because we're bumping really along the bottom here, and so there's a major initiative to be worked out on that.

If we start to diagnose cancers early, will we see save a lot of money? And this is just something we've worked out on lung cancer. The hospital costs... for 70% of the patients, because we didn't have data on them all, unless it's just the hospital costs—not the GP

costs, not for anything else—we've calculated £4m for 1 year, with an average cost per patient of £6,000, and the main cost will be inpatient stay. But it's varied by stage, so earlier diagnosis actually costs more, because you do more with them—there's more that you can do. And more patients then will survive for longer, and they'll have increased needs and they have side effects or therapy. So, to diagnose people early, there's a bit of balance here, because it may not be cheaper for the Health Service per se.

Now, what's happening with cancer in Northern Ireland? These are numbers of cases, and when I started with the Registry, I would have said, of the serious cancers, there's 6,500 of them. I have to now say, there's 8,500 of the serious cancers. If we're counting on lung and then the skin cancer, every year is 10,500 cases. And this shows the increase now that we should have a squiggle here, but with the ageing population—that's what driving that, because our rates are pretty steady, and in fact the rates for some cancers are actually coming down. That's the pressure of an ageing population, but it's also the pressure of increased investigation of some of these older people, and actually recognising that [obscured] because of cancer, so they get counted.

So, early diagnosis is something that we need to be thinking about for these patients. Just to say, there are patient delays and there are system delays that we have. Screening has a role in detecting cancers earlier. There is this international study of cancer—of delays—ongoing, and we hope to see some results of that. And action on these fronts will reduce the cancer burden, but not necessarily the cause.

Thank you very much.

Professor Margaret Cupples:

Can I say, thank you very much indeed Anna, for a very interesting talk. I think you've opened a treasure trove for us.

Questions for Anna? I know some people have asked on the way through, but I'm sure she'll be happy to take some more.

Dr John Craig:

I don't know about the process that's involved, and how you run your Registry. In terms of how these people are identified, what information do you collect, in terms of comorbid conditions? And obviously, you have to have in whatever you're doing, your various adjustments and things. So, in terms of how these people are identified and how they get recruited or involved in the Registry, could you tell me something about it?

Dr Anna Gavin:

Okay. Well, the Registry aims to collect information on everybody who has cancer. It's a population-based one. You might hear of studies that are hospital-based, or that are just on the patients who had surgery, and those will not count the people who live a day after they are diagnosed, or whatever. We aim to collect information on everybody, and the way we do that is we get all the Pathology Reports and all the diagnoses that's a cancer diagnosis. And in fact, the Registry also collects pre-malignant conditions as well. So, that has been the basis of some of our research.

We then get information from the hospital discharge's, so from the PAS [Patient Administration System] system. We also get information from deaths. And now, increasingly, we're going to get information directly from this computer system that I showed you, the Capps system. We can also get some from Radiology and minor sources like that. What happens is, all those are put into the system, and patients are matched.

For some of the patients, everything fits. They have a pathology, they have a hospital discharge that says the same thing, and they may then have a death certificate. So, that's all great, and that's a registration. But sometimes all we get is a hospital discharge. For those patients we will go out and check the hospital records, because some of those are patients who maybe were diagnosed before the Registry was set-up. Some of them may have been diagnosed… they were maybe on holiday when they came over here and were admitted acutely, and they had a diagnosis, and they don't belong to our population. And some of them may not have cancer. There's a query cancer put on the thing, and it gets coded, and that's it. So, we claim that, and bring that back, and check the data.

For deaths we have a similar process, in that all the GP records for people who have died go down to, what used to be CSA [Central Services Agency]. And we pay to get those retrieved, and check that to see… if we only have a death record, we will check through the hospital records if need be, electronically. We try to get every case that we have in the population.

Now, for some of the other things that I showed you. I was going to show you for 1996, 2001 and 2006. For those years, we were funded by the audit groups, and we went out and looked out at every note that we could find on those patients. Occasionally, we don't find one, so it's not everybody. But we went and looked at all the breast cancer patients, all the lung cancer patients, all the prostate cancer patients, all the oesophageal, all the stomach—all of those patients—melanoma, in 1996, in 2001, and then in 2006. And from that, we were able to say what their symptoms were, how long they had the symptoms. We were able to measure their comorbidity. We were able to look very closely at the stage of their disease. So, a lot of the work that I showed you tonight is from those studies.

We spend a lot of time cleaning the data in the Registry. If you were to ask, what's the most up-to-date information that we have now, we could you give you a really good list of patients who were diagnosed in 2008; a pretty good list for 2009, but not complete; and quite a few of the patients who were diagnosed in 2010. There's about an 18-month delay in terms of cleaning the data, but we intend now, using some of these newer systems to have just a 6-month delay. So, we're going to work very hard now.

Our staging runs at about 50%, and we aim to put a big effort into improving staging, because if you think about it, over time, if we improve survival, we need to know what's been the factor in that. And the other thing that we're trying to work very hard to do, is to get information comorbidity. And we think actually primary care is the main source of that data. So, for the cancer patients, we would ideally like to link into some of the automated systems in primary care for just those patients, so that we would know if they had heart disease, we would know if they had diabetes, we would know if they had a serious condition that could impact on their survival, or their care, and that would really leave us ahead of a lot of places in terms of explaining our outcomes and survival.

Dr John Craig:

The reason that I ask, is I'm a neurologist, and brain tumours don't figure very highly in that. Would you still be picking those up, because most of the patients I see with brain tumours, they never even see a neurosurgeon. Most of them never have a biopsy taken or any pathology, just because of the nature of the condition and the damage you can do in trying to collect some. But will you be picking those cases up?

Dr Anna Gavin:

We pick up all malignant and benign brain tumours.

Dr John Craig:

So, meningiomas?

Dr Anna Gavin

All of those, yeah. We would have all of those.

Dr John Craig:

Developmental tumours.

Dr Anna Gavin:

Yeah, we would have all of those. Actually, say you wanted to see the list of patients that you have under your flag, or under your department, or whatever, all of your colleagues, with their agreement, the Registry would be able to give you that. You could say, look at their survival, you could do things like that. And the same thing goes for any GPs… and we did write out to the GPs when the new contract came in, and we offered, if you want the list of your patients to allow you to have a Disease Register for your payment, and almost all of them, I think everybody said, yes please. So, we sent them out the list. And it was a good check for us, because we asked them to check if they were complete, and we got a few minor changes, which was that this patient had died, or whatever, which we wouldn't yet have heard about. So, it was a very reassuring thing from the point of view of accuracy of the Registry, but also giving something back to the people who owned the data.

Professor Margaret Cupples:

Philip, I think you were first!

Professor Philip Reilly:

Thanks very much Anna, for all you've said. The primary care area is quite a challenging area, it's very noisy, if I could use that word—what goes on. Though it's equally important to distinguish or discriminate, and get the right diagnosis, or at least the right person. You talked about the red flags, how can we improve that area? I think you mentioned something about that, but maybe I didn't hear you properly, but how are we improving that?

Dr Anna Gavin:

Well, there's a whole lot of research actually going on in that about how you can better—using various symptoms—identify a cancer, and the Northern Ireland Cancer Network have been working with the Clinical Group. So, for example, all the urologists get together, or all the colorectal surgeons get together, or maybe all the brain surgeons get together, and also the clinicians as well, and they will look at NICE guidance and various other things, and they will come up with a list of symptoms. There's an age criteria, there's a criteria of rectal bleeding, or whatever, for a certain amount of time, plus maybe something else.

Those are the criteria that [NICANS?] have agreed for those symptoms, but the thing is, they have missed some cancers, and they will over pick the other ones. It's about refining the sensitivity of that. We had a very good study application that we put in, but we weren't successful in getting it funded. So, maybe we will put it in somewhere else, because we are one of the few places that can actually carefully monitor the red flags with this system, because we know whether they're are red flagged, we know what their outcome is.

Professor Philip Reilly:

Because it is very challenging. You're indicating there that it can gum up the system, and many GPs, I'm sure, have patients with lots of symptoms. So, it is really quite a challenging area, but obviously, you're on the case. Thank you very much.

Dr Anna Gavin:

Well, we would like to be on the case, and we have the data there, and we could do it, but you need to have a resource to do that—you need to have somebody to do it. We have access to all the things, we just need somebody to do it.

Professor Randel Hayes:

I'm interested that the evidence suggests that if you treat people earlier, that it makes a difference, because if you think about, let's say, two cancers, one where the doubling time is about four times greater than another. The one with the slower doubling time may not do you any harm at all. The other one, the more aggressive one, is the one that's going to do you harm, but you might not be able to pick that up.

Dr Anna Gavin:

And that's a real issue in breast cancer, and in

prostate cancer. And that's one of the areas that when you look at a screening programme, you have to be able to see, are you actually picking up indolent cases. So, your survival improves picking up these cases that are very slowly growing, or are you just picking cases up a bit earlier, so that the people live longer with the knowledge of their disease, but it hasn't improved survival. That's a very important point, and that's why you need to be very careful in looking at survival on its own, and that's why it's very important to look at deaths, because deaths are really what you're trying to reduce.

Audience member:

I was thinking of the new kid on the block, from a cancer point of view, we have buried two patients in the last 14 months with mesothelioma. One was a man of 72, a builder, and the other was a man of 54, an electrician since the age of 16. And it really sets you back on your heels, when you certainly see the younger man dying, really no treatment, and it was just hopeless.

Dr Anna Gavin:

Yes. Well, we didn't talk about prevention here at all. Prevention is a major issue, and I think increasingly... the deaths from mesothelioma almost match the cases. There is a bit of a lag, but not much. It used to be the ship workers, and there were a lot of cases around Belfast, and then they actually moved to live outside Belfast. So, there was a doughnut effect, you could see them outside Belfast. But increasingly, it's now in the construction workers, who would've been maybe dismantling asbestos, or who would have been working in houses with asbestos, and just working away like that electrician, or whatever. And the other group that have it are mechanics, because of the asbestos brake lining and things like that. Mesothelioma is a serious disease, but prevention really needs to have a thought given to it as well. And we're talking about lung cancer there, and you could get rid of 90% of them if we could tackle smoking.

Professor David Hadden:

We've all watched what you've achieved for the cancer screening, Cancer Registry, over the past 15 or 20 years since you started, and it's been wonderful what you've been able to do. And to produce data like this, and to be able to compare it with other countries is of course crucial. What I'm really asking is to look a little broader, and say, do you think that is it right that cancer should be the only diagnosis that is given this sort of top line treatment of having a really good Register, or would you feel, if you had access to the funds, that it could be done effectively for other diseases. I'm obviously interested in diabetes, but say epilepsy, or heart disease, or stroke. Would it be possible to get this sort of data that you've got?

Dr Anna Gavin:

The way cancer is slightly easier, and I wouldn't say it's easy at all, is because it's been done internationally already, and there's a gold standard there that you have a pathology diagnosis, and you can see what it is. In Northern Ireland there are some Diabetes Registers, there are Cerebral Palsy Registers, there was the MONICA Project, which did very good work on heart disease.

But I agree that if you want to know about these diseases, and about understanding them for your population, and monitoring the implications of them, and prevention, and improving treatment, it's very important to have the information on a population level, because if you have it on a particular proportion of the population... let's say the patients that come to you, you could be in the Centre of Excellence, you record them all, but that's the tip of the iceberg in terms of the total scope of the patients.

So, it is very important, and particularly if you think of diabetes and the way obesity is going to change things, and that. Now, GPs do have lists, and that's a very important source of that information. And I know, Miriam, you might have some input on that?

Miriam:

Yeah, there are lots of morbidity lists, certainly in General Practice. How complete they are, I'm not sure. People here are much more informed to comment on that, but I think that the point that you make about cancer does have a definitive point at which it is diagnosed, and then a diagnosis supported by pathology that helps to stage and is much more definitive than some other things like heart failure, for example, that would just be more difficult to quantify with the same accuracy. That's not to say we shouldn't be aiming to do it, because I think there is a wealth of information.

Dr Anna Gavin:

And I think just on that point, there's so much data collected in the Health Service that isn't used in this way, and we really need to have some sort of a legislative framework that allows that data to be used in a way that improves the whole care of patients, and yet, maintains the confidentiality of that data, and allows us to monitor the expenditure on the Health Service and where it's going, and make a case for new resources if they're needed, and be able to identify if there is waste in the system.

Professor David Hadden:

John Henry Biggart had a little quotation, which he always said, the study of things caused must precede the study of the causes of things.

Professor Sydney Lowry:

I want to congratulate you on putting a talk like that together so well, at short notice. One question, cancer of the pancreas, the incidences seem to be very low, considering how much we hear about it. It doesn't seem to me that early diagnosis offers much for the pancreas.

Dr Anna Gavin:

Pancreatic cancer, just from the top of my head I think is about 200 cases a year actually. And it does tend to occur more in older people, but there are some young cases. I know of somebody who had it and died before they were 30, before they were even 25, I think. So, it's a very, very poor prognosis. But there is a study going on about lifestyle factors that could possibly influence pancreatic cancer, and also looking for possible blood markers or history of something, that could maybe identify people who are more at risk that we could do something about. It's been a neglected area, and it's one where there is a European-wide study of that, and Northern Ireland is actually contributing…

Professor Sydney Lowry:

Is it increasing?

Dr Anna Gavin

I don't think it's increasing. Some of the risk factors are tobacco and alcohol, and chronic pancreatitis.

Professor Sydney Lowry:

We're hearing more about it.

Dr Anna Gavin:

It might be that we're hearing more about it—I don't know. I'd have to go back and look to see, but it's not one of the ones that we would have picked up an increase on. There are increases that we know in terms of melanoma, that we can see, renal cancers, uterine cancers, but pancreas is sitting there just not doing very much.

Professor Margaret Cupples:

One more question I think before the tea gets cold outside.

Audience member:

Anna, I really enjoyed your talk. Going back to Philip's point about the red flag system. I'm not sure whether you made the comment about red flags clogging up the system. That doesn't really surprise me, because the actual positive predictive value of symptoms is very low, and I remember reading an article about a year ago in the British Journal of General Practice, I can't remember who the authors were, but there were only about four symptoms that had a positive predictive value greater than 5%, and I think they were uterine bleeding in a woman over 50, iron-deficiency anaemia in a man over 50, dysphagia and haemoptysis. And I know that there are a very small percentage of cancers that have been red-flagged. Do you think the red flag system is a good system?

Dr Anna Gavin:

Without evidence, I couldn't possibly comment! Possibly for some patients it works very well, and it gives [a little?] power to the GPs to pick up things. Now, I know the Trusts will re-assign some of the patients depending on the criteria, so it probably has its good and its bad points, but it does, as you say, it needs to be refined because one of the risks is that with all these people who are red-flagged, first of all, they are very concerned that they are maybe going to be… that they have a cancer diagnosis, oh it must be serious, they're putting me in, but then the patients who have the cancer are then put back in the queue, say for a PET or an MRI or CT Scan, because there are other patients ahead of them, and they are being monitored on targets. The only thing I would say, is that once a patient then is diagnosed, irrespective of what way they've come in, they are then on this target for timeliness. So, I think the targets for timeliness have actually improved the service for patients. It's at a huge price in terms of the energy that the Trusts have put into it. But I think that it would be a shame to lose that, and undo that, from what we can see here.

Professor Margaret Cupples:

Can I say, thank you very much Anna.